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On the path to healing

A qualitative longitudinal study of colorectal cancer patients' accounts of trajectories to healing in Norway

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“What does that mean–– 'tame'?”

“It is an act too often neglected,” said the fox. “It means to establish ties.”

“'To establish ties'?”

“Just that,” said the fox. “To me, you are still nothing more than a little boy who is just like a hundred thousand other little boys. And I have no need of you. And you, on your part, have no need of me. To you, I am nothing more than a fox like a hundred thousand other foxes. But if you tame me, then we shall need each other. To me, you will be unique in all the world. To you, I shall be unique in all the world... Please–– tame me!” he said.

“I want to, very much,” the little prince replied. “But I have not much time. I have friends to discover, and a great many things to understand.”

“One only understands the things that one tames,” said the fox. “Men have no more time to understand anything.”

From The Little Prince by Antoine de Saint-Exupéry

“You have power over your mind- not outside events. Realize this, and you will find strength.”

Marcus Aurelius

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Acknowledgments

Firstly, I wish to thank the most important people in this project: the participants. They have shared their personal stories about their lived experiences of joy and suffering in contexts of cancer. They have externalized their inner worlds in order to help future patients. I have been very humble, grateful and honored to work with the participants' powerful stories. Through the texts, I have met very brave and wise human beings. I have read the data as a student, and the participants have been my teachers. Their life experiences have given them knowledge that cannot be learned at any school. I believe that their voices are fundamental to providing future patients with better care.

My supervisors, Gro Berntsen and Anita Salamonsen, have made substantial contributions to this dissertation. Since Gro is a medical doctor and Anita a medical sociologist, this study is a result of an interdisciplinary collaboration. I view this as a strength as the data were approached and discussed from various angles. My supervisors' experience and knowledge have provided professional growth and academic development. Their emotional and compassionate support through difficult periods has been invaluable. I am truly grateful for all their support, both professionally and personally. In fact, as in a pathway of illness, a PhD journey may affect many aspects of life. The way Gro and Anita have treated me with understanding, compassion and respect has touched me deeply. As one of the participants said about her doctor: "She was more than a surgeon". Gro and Anita have been more than supervisors. Thank you so much.

I would also like to thank the National Research Center in Complementary and Alternative Medicine (NAFKAM), The Norwegian Cancer Society (Kreftforeningen) and Northern Norway Regional Health Authority (Helse Nord RHF) for giving me this chance to explore patients' pathways. I also thank my wonderful colleagues for all the support and positive energy they have brought into my life during the period of my PhD. Special thanks go to Trine Stub, who helped me overcome some personal and professional obstacles. She read the thesis and suggested some final adjustments. Furthermore, I am grateful to my partner, Noom, who has been supportive even when I had to work late and when the tables were full of scientific literature. She has shown understanding for all the sacrifices I have made to complete this thesis. I also wish to thank my family, who have helped to ensure my progression and my well-being during this PhD journey. It is no secret that life can be somewhat unbalanced and challenging in the process of finishing a PhD thesis. The support of supervisors, colleagues, partner, family and friends has been the most important factor to complete this academic endeavor. Just as the Little Prince learned in the quote above, relationships are what really matters in life. It is through our bonds that we become special people and life becomes meaningful.

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Abbreviations

PCC - Person-centered care

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

CRC - Colorectal cancer

PTG - Post-traumatic growth

List of Papers

Paper 1

Frank Hansen, Gro K. Rosvold Berntsen & Anita Salamonsen (2018). "What matters to you?" A longitudinal qualitative study of Norwegian patients' perspectives on their pathways with colorectal cancer. *International Journal of Qualitative Studies on Health and Well-being*. 2018;13(1):1548240. doi:10.1080/17482631.2018.1548240

Paper 2

Frank Hansen, Gro K. Rosvold Berntsen & Anita Salamonsen (2019). Patient pathways as social drama: a qualitative study of cancer trajectories from the patient’s perspective. *International Journal of Qualitative Studies on Health and Well-being*, 14:1. doi: 10.1080/17482631.2019.1639461

Paper 3

Frank Hansen, Gro K. Rosvold Berntsen & Anita Salamonsen (2020). Medical pluralism in the aftermath of cancer: health seeking actions and cancer patients’ shaping of trajectories to healing. *Anthropology & Medicine.* doi: 10.1080/13648470.2019.1676637

Summary

Persons diagnosed with cancer often suffer from long-term illness and have complex needs. Survival rates for cancer are increasing, although survivors’ quality of life may be severely compromised following cancer treatment. The National Cancer Strategy (2018-2022) aims to enhance individual care and quality of life for Norwegian cancer patients. In the past decade, person-centered cancer care has increased in importance to become a principal goal for both patients and public healthcare services. To achieve this goal, greater knowledge of what actually matters to people living with cancer is needed.

As a contribution to such knowledge, the overall aim of this study is to learn more about long-term cancer pathways from the perspectives of the ill people concerned. What is a pathway from the participants´ perspectives? What matters to them during this period of illness? To the best of my knowledge, no qualitative studies have so far explored what matters to people over time during a cancer pathway. This approach not only includes people’s “journeys” in public healthcare, but also life events, experiences and health seeking actions. In this thesis, I seek to describe patients’ perspectives and develop theories and models that may provide researchers, healthcare professionals, health policy makers and others interested in cancer care with a conceptual framework to understand the complexity and dynamics that characterize patients’ cancer pathways.

This thesis is part of the PATH (Patients’ Accounts of Trajectories to Healing) project, a longitudinal qualitative study of colorectal cancer patients’ illness trajectories in Northern Norway. Ten persons diagnosed with colorectal cancer were followed closely over approximately one year. This thesis is empirically based on 46 in-depth interviews with the participants during this period. The data were analyzed using qualitative content analysis, involving a search for themes and patterns across the interviews.

In sub-study 1, I explore what matters for patients with colorectal cancer. Five themes were identified that the participants emphasized as crucially important:

1) “Biological goals” and biomedical cancer treatment mattered the most in the beginning of the pathways in order to survive

2) All pathways are unique and dynamic, and it mattered to be treated by healthcare professionals as “whole” people with different lives and needs

3) Family and friends heavily influenced participants’ quality of life

4) Access to care was strongly influenced by personal networks and individual navigation skills in the healthcare system

5) A variety of health seeking actions was important to meet patients' different needs.

In sub-study 2, I analyze the participants' pathways inspired by Victor Turner's "model of social drama" and related concepts such as "liminality" and "communitas". The analysis revealed that the participants' accounts of trajectories to healing share a similar underlying processual structure to Turner's four phases: 1) breach of norm, 2) crisis, 3) redressive actions, and 4) schism/reintegration. The recognition of symptoms escalates to a crisis when receiving the diagnosis, followed by the redressive actions, here understood as the health seeking actions the participants performed to solve their problems. These actions had certain outcomes, such as survival. However, many participants felt that they were neither ill nor well. They existed in a sustained or continuous liminality.

In sub-study 3, I draw on the findings from sub-study 1 and explore the phenomenon of medical pluralism in greater depth. According to the analysis,

1) medical pluralism is characterized by the implementation of contradictory models of reality and the making of pragmatic choices.

2) medical pluralism is a sociocultural phenomenon that sheds light on important aspects of cancer patients' health seeking actions, such as continuity and change in these actions.

3) medical pluralism can be perceived as a process, and

4) there was increased use of complementary and alternative medicine (CAM) and self-care to improve health and well-being among the participating cancer patients in situations where the conventional healthcare system has few available treatment options.

In addition to empirical descriptions of life with cancer, the three sub-studies present concepts and models that provide insights into the processes and experiences of severe illness. The understandings of experiences of illness from patients' perspectives, what matters to them over time, and the introduction in this thesis of a model that captures multiple dimensions of the pathway as a process may improve person- centered care and lead to less fragmented pathways in future cancer care.

Based on the findings and discussion in the three sub-studies, I suggest that person-centered care (PCC) may be a useful conceptual framework in an overarching discussion of the various aspects of patient-defined pathways among persons living with colorectal cancer (CRC). The main topics of the interviews were what mattered to the patients with cancer and how this changed during their pathways. Illness is dynamic, not static. The participants' goals, needs and values changed over time. PCC is here discussed in relation to the main points of the articles: medical pluralism, the model of social drama and what mattered to the participants. These three aspects of care may enhance our understanding of PCC in a cancer pathway, but from different perspectives. Therefore, this thesis is a contribution to the field of PCC in a Norwegian context.

The knowledge gained from this study could be used to understand and further develop person-centered, better integrated cancer care. Medical landscapes and the other models and concepts discussed in this study are analytical terms, but could also be used as tools for communicating and giving insights into patients' experiences in various contexts. This study may also be of interest to legislators, cancer organizations, educational institutions or others who wish to learn about cancer pathways from a patient perspective.

1. Introduction

This project forms part of the PATH (Patients' Accounts of Trajectories to Healing) project at the National Research Center in Complementary and Alternative Medicine (NAFKAM) in the Department of Community Medicine of UiT The Arctic University of Norway. PATH is a qualitative study with a longitudinal design conducted in co-operation with the University Hospital of North Norway. My supervisors are a medical doctor and a medical sociologist. I consider this project to be interdisciplinary, and its aim is to understand long-term, complex conditions from the perspectives of ill people. The project is targeted at PCC, here understood in terms of "'what matters' to the person drives decision making of the care plan" (Berntsen et al., 2019, p. 4). In order to provide PCC to cancer patients, we need more knowledge of their experiences of life with cancer and following cancer, their healing processes, what matters to them and how this may change during their illness, and which actions drive trajectories to healing. The PATH project explores colorectal cancer patients' pathways from their perspective. A qualitative longitudinal approach follows participants over a given period of time, exploring their experiences and dynamic processes as life unfolds (Neal, 2019). Qualitative longitudinal research (QLR) is therefore a suitable methodological approach for this study. The results of this research may be transferable to other types of cancer or even to chronic illnesses in general. In this thesis, I predominantly use anthropological theories as conceptual generalizations, but theories from other disciplines are also employed. In the following, I will visit some central concepts and topics of the thesis.

I will begin with a short introduction to CRC, its treatment and common late effects. An understanding of the condition is fundamental to attempts to understand the participants' experiences, actions and the pathway as a whole. I will then elaborate on common understandings of patient pathways and disease. By doing so, I introduce a central topic of this thesis: How should we understand pathways of chronic conditions? A further question is: Can we create an alternative understanding of pathways? After this, I examine patient experiences of cancer in a pathway context, particularly in a meta-study of patient experiences throughout treatment trajectories. I also introduce PCC and the call for more PCC in healthcare. Finally, I describe some previous studies of cancer in anthropology that may be useful in the discussion.

1.1 Colorectal cancer (CRC)

CRC is cancer in the colon or rectum. This means that the cells grow uncontrollably in these areas, but this may also spread to other parts of the body. CRC is one of the most frequently diagnosed forms of cancer, and its incidence rate is expected to increase (Arnold et al., 2017; Hildebrandt et al., 2019; Siegel et al., 2017). According to the World Health Organization (2020), more than 1.9 million new cases were recorded worldwide in 2020. The Norwegian Cancer Registry (Kreftregisteret) states that the number of people diagnosed with CRC has doubled in the last 50 years. In 2021, 4550 persons were diagnosed with CRC in Norway, distributed as 3204 with colon cancer and 1346 with rectal cancer (Kreftregisteret, 2022a). CRC is associated with high mortality rates and societal costs (Vrangbaek & Nielsen, 2010). However, the number of survivors has increased significantly. Survival rates for colon cancer are 71% for women and 69% for men, while for rectal cancer the figures are 73% for women and 71% for men. In 2021, 25 508 CRC patients and survivors lived in Norway. The majority of patients are 60-84 years old (Kreftregisteret, 2022b). Increased longevity is expected to result in an even greater social and economic burden of CRC in the future (Helse og omsorgsdepartementet, 2018). Cancer in general, but CRC in particular, is therefore prioritized in health policy agendas (Bordvik, 2019).

The type(s) of treatment recommended for CRC will depend on the individual situation. Surgery is a common form of treatment, but radiation therapy and chemotherapy may also be recommended. Improved clinical pathways with earlier and more accurate diagnoses as well as earlier treatment are important goals to improve positive outcomes at the individual and public levels (Helse og omsorgsdepartementet, 2018; Vrangbaek & Nielsen, 2010).

1.2 Cancer and late effects

Improvement of biomedical cancer treatment has clearly increased the survival rate (Harrington et al., 2010; Hildebrandt et al., 2019). However, solving one problem has led to another, or to use the title of Harrington and colleagues (2010): “It’s not over when it’s over”. More people live a life with illness or late effects of diseases, which is therefore a highly relevant topic in the contemporary world of health and illness. A worldwide survey shows that the rate of cancer survival is increasing greatly in Norway, and that Norway is one of the countries where patients have the best chances of survival of CRC and gynecological cancer (Allemani et al., 2018).

These facts imply that an increased number of people are struggling with late effects of cancer treatment. A late effect can be defined as “a side effect that occurs months or years after cancer treatment. Many people who have received treatment for cancer have a risk of developing long-term side effects. In fact, evaluating and treating late effects is an important part of survivorship care” (Cancer.net, 2018). A systematic review of the most commonly reported late effects revealed that "prolonged fatigue, cognitive limitations, depression/anxiety, sleep problems, pain, and sexual function are consistently present in heterogeneous cancer survivors following primary treatment" (Harrington et al., 2010, p. 174). Harrington and colleagues suggest that "quality care for cancer survivors does not only include surveillance of cancer over time, but better preventive health and better management of long-term and late-effects from cancer and its aggressive and often toxic treatments" (p. 174). We also know that patients report existential problems, and that some have religious/spiritual concerns that can be perceived as late effects of cancer. Such concerns are often taboo in secularized countries and may therefore represent an additional burden for patients (Hvidt et al., 2019). This existential suffering may at times be coherent with what Charmaz (1983) called "loss of self":

> A fundamental form of that suffering is the loss of self in chronical ill persons who observe their former self-images crumbling away without the simultaneous development of equally valued new ones. As a result of their illnesses, these individuals suffer from (1) leading restricted lives, (2) experiencing social isolation, (3) being discredited, and (4) burdening others. (p. 166)

Aspects such as self-efficacy and perceived body image may be concerns that affect the quality of life of patients with a stoma (Ayalon & Bachner, 2019). In a similar manner, women surviving breast cancer where they endure bodily changes can experience intense emotions. Their perception of their body, the vehicle of health and social expression, changes in a mostly negative way (Brunet et al., 2013). Moreover, even when people are diagnosed as fit, they may still have a fear of recurrence (Ozga et al., 2015; Rosmolen et al., 2017). Thus, people treated for cancer may experience a wide range of psychological, existential, and physical symptoms. These challenges may emerge during or after cancer treatment and persist as chronic and long-term illness (Stein et al., 2008). This brings us to the need for care providers to work with patients towards goals that respond to the unique challenges of individuals in their current context. In other words, there is a call for person-centered cancer care.

1.3 Patient pathways

A patient pathway for cancer in Norway, from a medical perspective, is often understood as a clinical pathway. Clinical pathways "are systematic ways to organize and display detailed, evidence-based treatment options and assist the practitioner with best practice. When selecting which treatment regimens to include on a clinical pathway, considerations must include the efficacy and safety, as well as costs, of the therapy" (Ersek et al., 2017, p. 597). Here patients are generalized according to diagnosis and the recommended evidence-based treatment. Where is the patient's voice and life in the understanding of clinical pathways?

In this thesis, I follow Salamonsen and colleagues' (2016) understanding of the "patient pathway" concept. Patient pathways, they argue, are commonly understood as clinical pathways, i.e., the routes patients embark on based on biomedical guidelines for the condition in question. Salamonsen and colleagues make a distinction between the patient's pathway and the clinical pathway. The former includes multimorbidity and patient experiences and preferences. They explore patient pathways as individual and cultural life courses with both "health events" and "life events":

> The concept of health events includes events involving the patient and a healthcare provider, experiences of symptoms and adverse events, and patient-initiated health events, such as dietary change and exercise. The concept of life events includes events that the patients themselves define as important in their life. Such life events may or may not be related to the cancer diagnosis and cancer treatment. (Salamonsen et al., 2016, p. 1592)

Patient-initiated health events are central to the later discussion. I have called these health seeking actions, a broad term to cover all kind of actions individuals undertake to improve their health, both within and outside public healthcare.

These concepts provide us with a conceptual framework to understand various perspectives of long-term conditions. They will be useful in the discussion, but also help me to create a meaningful positioning for the thesis. This thesis focuses on the personal, subjective experiences of the patient pathway in long-term conditions. It therefore places itself within the domain of illness and the healing journeys of persons with CRC.

1.4 Disease, illness and sickness

Disease, illness and sickness are concepts often used interchangeably. However, the different terms may covey different meanings and understandings of unhealth. Marinker (1975) suggested a distinction between "three modes of unhealth": disease, illness, and sickness. These are still widely used today. *Disease* represents the pathological process to which the clinical pathway responds. Cancer is often understood as a biomedical condition, characterized by its divergence from the biological norm. Disease is the objective, evidence-based, often measured aspect of the unhealthy and the perspective of professionals in the domain of biomedicine. *Illness* is subjective. It is an experience and a feeling of not being healthy. It is personal and cannot be measured. Illness often accompanies disease, meaning that a person may feel ill, but the disease may not be identified, as in the early stages of cancer. Alternatively, a person could have an illness, but no disease could be found.

> Traditional medical education has made the deafening silence of illness-in-the-absence-of-disease unbearable to the clinician. The patient can offer the doctor nothing to satisfy his senses - he can only bring messages of pain to the doctor, from an underworld of experience shut off for ever from the clinical gaze. (p. 82)

This particular problem will be relevant in my later discussions of the aftermath of cancer and liminality. Illness is here understood as a personal, internal mode of unhealth. *Sickness* is the external and public mode of unhealth. "Sickness is a social role, a status, a negotiated position in the world, a bargain struck between the person henceforward called 'sick', and a society which is prepared to recognize and sustain him" (p. 83). What is the relationship of illness to the other concepts? In Norway, sickness underpinned by a professionally verified disease entitles the person to healthcare and financial benefits. Sickness arising from illness, e.g., without a corresponding verified disease, is less likely to provide the same benefits. Sickness based on illness is, according to Marinker, an uncertain status. The uncertainty of the sick role depends on many factors. "Best is an acute physical disease in a young man quickly determined by recovery or death" (p. 83), Marinker argues.

Another pair of related concepts which may contribute to our understanding of a pathway is "cure" and "healing". According to Rankin (2011), "healing and curing are inherently different. Curing means 'eliminating all evidence of disease,' while healing means 'becoming whole'" (para. 5). Curing is related to disease and pathological processes. Healing is related to illness and the subjective experience of not being well. For Egnew (2005), the meaning of healing is about the personal experience of transcending suffering. A key to understand healing is suffering. "Suffering arises from perceptions of a threat to the integrity of person-hood, relates to the meaning patients ascribe to their illness experience, and is conveyed as an intensely personal narrative" (Egnew, 2009, p. 170). Mount et al. (2007) argue that "life-threatening illness is an assault on the whole person—physical, psychological, social, and spiritual. It frequently presents caregiver and sufferer with a paradox—suffering does not correlate with physical well-being” (p. 372). Cassel (1982) makes a distinction between suffering and physical distress. “Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity. Suffering can include physical pain but is by no means limited to it” (p. 639).

1.5 The experience of cancer

Patients’ experiences of CRC are complex and this complexity is underexplored to date (e.g., Salamonsen et al., 2016). A recent meta-ethnographical study explored CRC patients’ experiences from diagnosis through completion of treatment. Twenty-one papers were included, mainly on studies conducted in England and Sweden. The authors found the following:

> Throughout the course of treatment, patients are confronted with manifold acute or unexpected challenges that require diverse techniques and strategies to deal with emotional, mental, social, and physical aspects in the current situation. Widespread, numerous symptoms emerge from CRC itself, the complex treatment, and/or its side effects. Distressing symptoms such as diarrhea and nausea, physical limitations like lack of energy, or high levels of mood disturbances or psychological distress are experienced by individuals, from diagnosis until at least the completion of treatment. (Hildebrandt et al., 2019, p. 221)

Hildebrandt and colleagues concluded that persons dealing with CRC are “cycling between rather strengthening and rather weakening experiences…moving back and forth from mastery to disruptions” (pp. 221-222). They synthesized their interpretations of the results in the following figure:

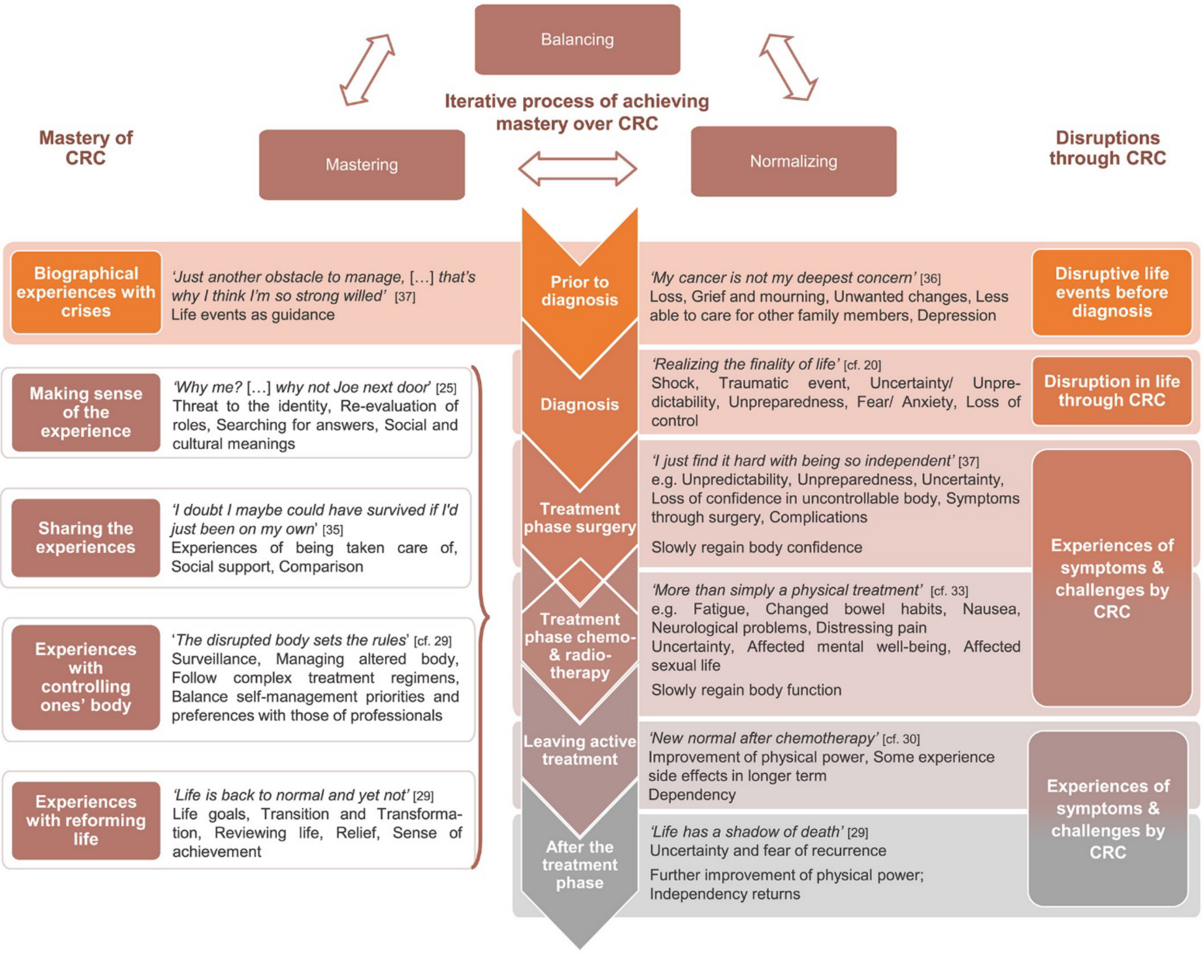

FIGURE 1: OVERALL FINDINGS OF CRC PATIENTS´ EXPERIENCES THROUGHOUT THE TREATMENT TRAJECTORY (HILDEBRANDT ET AL., 2019, P. 221)

This figure illustrates the process from prior to diagnosis to after treatment. On the right side, the authors show the disruptive experiences associated with a particular phase of the process, while the left side shows the strengthening experiences ("mastery"). The findings of this meta-ethnographical study will be further explored in the discussion.

A systematic review of the supportive care needs of persons living with and beyond CRC found the following:

> Just over half of the needs (51%) concerned information/education or health system/patient-clinician communication issues. Emotional support and reassurance when trying to deal with fear of cancer recurrence featured as the most prominent need regardless of clinical stage or phase of treatment. Information about diet/nutrition and about long-term self-management of symptoms and complications at home; tackling issues relating to the quality and mode of delivery of health-related information; help

> with controlling fatigue; and on-going contact with a trustworthy health professional also featured as salient needs. (Kotronoulas et al., 2017, p. 60)

Many CRC survivors have complex unmet needs, which can often not be addressed by the healthcare system. These unmet needs seem to be mainly psychosocial in nature and affect people's quality of life (Santin et al., 2015). It is therefore important to explore patient pathways from the ill persons' perspectives.

1.6 The call for improved person-centered care

Over the years, there have been many perspectives of PCC. Balint (1969) suggested that patient-centered medicine "should include everything that the doctor knows and understands about his patient; the patient, in fact, has to be understood as a unique human-being" (p. 269). In 1988, the Picker Institute suggested the term patient centered care as a way to shift the focus from disease and back to people (Gerteis et al., 1993). Laine and Davidoff (1996) defined PCC as acting according to patients' wants, needs, and preferences. The UK Royal College of Nursing sees PCC as follows:

> Put simply, being person-centered is about focusing care on the needs of the person rather than the needs of the service. Most people who need health care these days aren't happy just to sit back and let health care staff do what they think is best. They have their own views on what's best for them and their own priorities in life. So as health care workers, we have to be flexible to meet their needs – we have to make our system suit them, rather than the other way round. (Royal College of Nursing, 2018)

A greater focus on people's needs and active patients is also emphasized in the landmark report by the US Institute of Medicine, *Crossing the Quality Chasm.* Here, PCC was central in the Institute's "ten rules for redesigning and improving care". For instance, "care should be based on continuous healing relationships", "care should be customized based on the patient´s needs and values", "the patient should be in control" and "the system should encourage shared knowledge and the free flow of information" (Corrigan, 2005, pp. 96-97). In Norway, the aspect of empowerment is officially included in the healthcare system. This implies that service user participation in healthcare is not merely an ideal, but is embedded in Norwegian law (Helse og omsorgsdepartementet, 2001).

Peabody (1927) was an early spokesperson for greater focus on subjectivity in clinical practice, arguing that an interest in humanity was one of the most important qualities of a clinician. A common focus in the discourse of PCC is the patient-doctor relationship (Mead &

Bower, 2000). Furthermore, discourses of PCC involve improving the way healthcare is designed (e.g., Juhnke & Mühlbacher, 2013). For the World Health Organization (2015) this means "placing people and communities at the center of health services planning in a way that makes health services more comprehensive and responsive, more integrated and accessible, and offers us a coordinated method to address the diverse range of health needs facing humanity" (p. 5).

In this thesis, I have chosen to use the term "person-centered care" rather than "patient-centered care", which is also commonly found in the literature, as "person" gives connotations to all aspects of a cancer pathway. Further, "one uses the concept of person in order to give somebody responsibility vis-à-vis a situation which concerns him or her… Person-centered care highlights the importance of knowing the person behind the patient – as a human being with reason, will, feelings, and needs – in order to engage the person as an active partner in his/her care and treatment" (Ekman et al., 2011, p. 249). PCC is therefore closely related to shared decision making by engaging and educating patients to play an active role in the healing process, as well as encouraging clinicians to be more responsive to patients´ needs and values (Barry & Edgman-Levitan, 2012).

I understand PCC as a process of care which seeks in an empathic and sensitive way to understand "what matters" to the person. PCC implies making "what matters" drive decisions in care. In individual cases, PCC is about "what matters" to the ill person and the consequences this approach implies in practical care of the person. Health issues and life goals are often interconnected in a person's life.

> Most life goals lie outside the scope of healthcare's responsibility. However, when health issues are blocking the way forward towards a life goal, healthcare can be a vital enabler. The task at hand is to explore what the life goals may be, and then translate these into goals relevant for care. (Berntsen et al., 2018, p. 5)

As Berntsen and colleagues point out, even considering that healthcare's responsibility does not extend to life goals, there is still a clear connection between care and what really matters to patients. This is central to my understanding of PCC and in line with acting according to people's values and preferences in a shared decision making process. This interconnection between health issues and people's life goals clarifies further the importance of systematically including patients' perspectives in person-centered cancer care.

1.7 PCC and healthcare based on postmodern values

The concept of the postmodern experience of illness may be used to contextualize the call for improved PCC. Here I will outline some schools of thought that place this thesis in a broader context. Barry and Edgman-Levitan´s perspectives have had an impact by, for instance, inspiring the PCC movement “What matters to you (WMTY)”.

> Caring and compassion were once often the only “treatment” available to clinicians. Over time, advances in medical science have provided new options that, although often improving outcomes, have inadvertently distanced physicians from their patients. The result is a health care environment in which patients and their families are often excluded from important discussions and left feeling in the dark about how their problems are being managed and how to navigate the overwhelming array of diagnostic and treatment options available to them. (Barry & Edgman-Levitan, 2012, p. 780)

These thoughts are in line with Frank (2013), who suggested that the experience of illness has crossed three paradigms: Premodern, modern, and postmodern. In premodern times, people had descriptions of disease and remedies as well as practices for healing. The experience of illness crossed the modern divide “when popular experience [became] overtaken by technical expertise, including complex organization of treatments” (Frank, 2013, p. 5). In modern experience of illness, people went to paid professionals who interpreted their conditions as symptoms with a specialized language that was “unfamiliar and overwhelming” (p. 5). Furthermore, the patients were entered into “medical charts which in the most instances they [were] neither able nor allowed to read; the chart [became] the official story of illness” (p. 5). The modern experience of illness was characterized by “the sick role”, where the responsibility for patients’ health was in the hands of the doctors and the ill person played a passive role as compliant receiver of care (Parsons, 1991). According to Frank, crossing the postmodern divide began when “ill people recognize[d] that more is involved in their experience than the medical story [could] tell” and “…when the capacity of telling one’s own story [was] reclaimed” (Frank, 2013, p. 5). People’s self-awareness has shifted, which has brought us to a situation where “postmodern illness is an experience, a reflection on body, self, and the destination that life’s map leads to” (p. 7). It is about how ill people find meaning in their illness journeys (Borgmann, 1992). The traditionally asymmetrical relationship between patient and doctor is changing. In the postmodern picture, patients are equal partners to doctors, reclaiming their voices and uniqueness as people in the context of illness. Crossing the postmodern divide involves an emphasis on subjectivity and a shift where illness has a different feel. Patients expect care to fit into their lives, and work towards goals that are meaningful to them.

> To attend those who suffer, a physician must possess not only the scientific knowledge and technical abilities, but also an understanding of human nature. The patient is not just a group of symptoms, damaged organs and altered emotions. The patient is a human being, at the same time worried and hopeful, who is searching for relief, help and trust. The importance of an intimate relationship between patient and physician can never be overstated because in most cases an accurate diagnosis, as well as an effective treatment, relies directly on the quality of this relationship. (Hellin, 2002, p. 452)

Hellin´s ideas reflect the values of the postmodern experience of illness. To attend a human being in suffering, the clinician must manage to approach both the disease and the person in meaningful ways. According to Barry and Edgman-Levitan (2012), clinicians "need to relinquish their role as the single, paternalistic authority and train to become more effective coaches or partners — learning, in other words, how to ask, ´What matters to you?´ as well as ´What is the matter?´"

1.8 Benefits, implications and challenges of PCC

In the context of PCC, the importance of seeing the patient as an equal partner and as an expert is often emphasized. In this way, patients' knowledge and experiences become resources in their pathways and during consultations (Byrne & Long, 1976). However, another point that I find important is that the level of desired involvement in decision making during consultations will vary between patients (McKinstry, 2000).

One challenge with PCC studies is how to measure and explore the clinical outcomes of the approach (Edvardsson et al., 2008). However, according to the WHO, the benefits of PCC are documented as:

> Increased delivery efficiency, decreased costs, improved equity in uptake of service, better health literacy and self-care, increased satisfaction with care, improved relationships between patients and their care providers, and an improved ability to respond to health-care crises. (World Health Organization, 2015, p. 5)

In line with this statement by the WHO, it is generally assumed that four aims are the most relevant outcomes of PCC. The first three are 1) improving the experience of care, 2) improving the health of populations, and 3) reducing per capita costs of healthcare (Berwick et al., 2008). Bodenheimer and Sinsky (2014) found that physicians and other healthcare workers frequently reported burnout and dissatisfaction, which imperils these three aims. They therefore suggest a fourth aim: 4) improving the work situation of healthcare providers, including clinicians and other staff.

A systematic review showed promising results for improving physical and psychological health by using personal care planning. Personal care planning is cooperation between patient and doctor to solve the patient’s challenges in the context of chronic illness. It also improves patients’ ability to self-manage their condition (Coulter et al., 2015). Studies have also shown that a person-centered approach may improve medication adherence and some unmet needs of patients with lower urinary tract symptoms (De Nunzio et al., 2018). In combination with dementia care mapping, PCC seems to reduce agitation in persons with cognitive impairments in residential care (Chenoweth et al., 2009).

According to Ekman and colleagues (2011), most healthcare providers are aware of the benefits of PCC, but challenges should also be addressed:

> The challenge for the healthcare provider is to receive the person's self expression in such a way that confidence is strengthened and resources for healing identified. This can be understood from an ethical perspective as the health care provider's obligation to recognize and acknowledge the fragility of self and coherence in life…Studies have shown that despite the fact that care givers espouse person-centered values, care processes largely remain routinized, ritualistic and afford few opportunities for the formation of meaningful patient–provider relationships (Ekman et al., 2011, p. 249)

This study is not about PCC per se, because PCC is a healthcare approach to the individual, which is not the topic of our study. However, understanding what matters to patients is a precondition for providing PCC. This study may thus contribute knowledge of importance to public healthcare services in general.

1.9 Anthropological perspectives

Anthropological theoretical perspectives may be useful to understand and explain people’s actions, social processes, interaction, medical culture and subjective experiences. A longitudinal study such as PATH is particularly suitable for interpretation within an anthropological framework. Anthropology and its fieldwork are by nature longitudinal. Another reason why anthropology and qualitative longitudinal data is a useful combination is the importance of dynamics and theories of change in anthropology. In fact, Arnold van Gennep, who is a central figure in this thesis, is regarded as one of the earliest dynamic thinkers (Neal, 2019). With his work Les Rites de Passage ((1960), originally published in 1909), he has been an influential figure in social research. With his theory of rites of passage, Gennep suggested that rituals were actions that generated social and personal change, even transformation. Van Gennep's theories and his way of dynamic thinking inspired and dominated Victor Turner's work. The model of social drama, which is central in sub-study 2, is a model of crisis as a dynamic process in four stages: 1) breach of norm, 2) crisis, 3) redressive actions and 4) reintegration or schism. Neal (2019) describes qualitative longitudinal research as a panoramic scope of social dynamics. This is precisely what the model of social drama attempts to portray. The model follows the same structure as a rite of passage and similarly to Gennep, Turner is concerned with mechanisms of change (Neal, 2019). Liminality is another key concept in this thesis. Put simply, it is a phase between phases, where a person has left one stage but is not yet integrated into a new one. It can be compared to being in a tunnel; it is an ambiguous phase, a time for reflection on possibilities and changes, yet also a time of chaos, confusion and suffering.

Medical pluralism is another central concept borrowed from anthropology. Medical pluralism can be defined as "the employment of more than one medical system or the use of both conventional and complementary and alternative medicine (CAM) for health and illness" (Shih et al., 2010, p. 1). According to Hsu (2008), the concept was particularly appealing in the 1970s and 80s in anthropological discussions of cultural relativism and rationality. Anthropologists' notion of pluralism was in opposition to the medical profession's demand for a monopoly in healthcare, and implicitly the profession's aim to generate a general public belief in their superiority based on their medical qualifications (Freidson, 1988). The concept was first used by Leslie (1976) in his study of medical systems in South Asia. Leslie pointed out that Western, modern biomedicine did not have a monopoly, but was competing with other professionalized traditional systems of healthcare such as Ayurveda, traditional Chinese medicine, and Unani Tibb.

The concept of medical pluralism has been criticized for…

> …being grounded in an overly simplistic concept of culture; for conceptualizing health care from the professional's, rather than patient's, perspective; for engendering an overly behaviorist account of health; for generating a false consciousness of choice; for underplaying the importance of financial, structural, and other political economic considerations; for insufficiently attending to issues of power, authority, and policy, or working with naive notions of them; and for implicitly reproducing a monolithic concept of (bio-) medicine. (Hsu, 2008, pp. 316-317)

However, because of the contemporary extensive use of diverse therapies from various traditions, there is a need for a concept to describe and theorize the social phenomenon in question. There is currently an increased interest in medical pluralism, as seen in the journal Anthropology and Medicine's special issue on the topic (Penkala-Gawecka & Rajtar, 2016). Social scientists are attempting to construct new concepts to describe the phenomenon of medical pluralism.

The concept of medical landscapes has been constructed to improve understanding of medical pluralism. The notion of medical landscapes aims to solve the static character of medical pluralism that simply states the co-existence of several medical traditions.

1.10 Why this study? The rationale of this dissertation

Patients are the only people who are constantly present in their trajectories to healing. They are the reason why healthcare exists and the only ones who experience how this care is delivered. Patients' voices are therefore fundamental to improve future healthcare and create better solutions. Patients' experiences of what matters over time can teach us about the journey they embark on before and after diagnosis, during treatment and after treatment. There appears to be a gap in the literature on what matters to cancer patients with a qualitative longitudinal approach, which is surprising. What matters to the patient is what should matter to healthcare.

As I have already shown, cancer or other life-threatening diseases are an assault on the whole physical, psychological, social, and spiritual person (Little et al., 1998; Mount et al., 2007). Cancer may be removed from the physical body and the patient cured from a biomedical perspective. Yet from a subjective illness perspective, the patient may not be healed, which means not "being whole", when only the physical part is cured. By asking "what matters to you" over time, we may uncover different aspects of illness and people's accounts of trajectories to *healing*. A qualitative longitudinal study with a patient perspective may generate important and useful knowledge for areas such as PCC. To provide more person-centered care, we need knowledge about what matters to people over time in illness contexts.

Frank (2013) calls for more authority for patients and their voices: “Modernist medicine hardly goes away: the postmodern claim to one’s own voice is halting, self-doubting, and often inarticulate, but such claims have enough currency for illness to take a different feel” (p. 7). In Norway, service user participation is not only an ethical standpoint, but a statutory right (Helse og omsorgsdepartementet, 2001). The Norwegian health authorities’ health reform from 2002 aimed to put “the patient at the center of care”, a slogan which is also frequently used today to emphasize patient experiences. Patients’ perspectives become an indicator of quality in the evaluation of care (Veenstra, 2005). Overall, this study of cancer patients’ perspectives and accounts of trajectories to healing could be understood in this context.

Health authorities, ethicists, legislators, and patients aim to create better patient pathways and stronger PCC (Helse og omsorgsdepartementet, 2001; Pellegrino & Thomasma, 1987; Taylor, 1992). According to the Norwegian Ministry of Health and Care Services (2009) and the Coordination Reform (Samhandlingsreformen):

> - Patient participation should be maintained and further developed.
> - Involvement from patients and their organizations should be encouraged in efforts toward more cohesive patient pathways; they should also influence how this is to be accomplished.
> - More systematic efforts to analyze and describe good patient pathways, which can promote measures for improved coordination.
>
> (p. 6)

A pathway should take the patient’s perspective, and healthcare workers must be aware that people’s needs may change over time and be sensitive to the particularity of people’s situations. Patients’ voices must be heard and healthcare workers should focus on what matters to patients, which are naturally ideals that are coherent with PCC. The need for PCC is particularly important for people with long-term and complex illnesses (Helse og omsorgsdepartementet, 2017). Cancer could probably, in the majority of cases, be viewed as a complex illness. As Jain (2013) argued, cancer could be understood in terms of what Mauss (2002) called a “total social fact” in The Gift. Mauss’ understanding of the gift was that it had an implication for many sectors of society, including the economic, legal, political, and religious spheres. In a similar way, Jain (2013) understood cancer as a phenomenon affecting not only multiple aspects of the person, but the diagnosis also has implications for e.g., relationships, politics, and economic factors. It is not only a tumor, but a complex issue for the patient and society. In addition, the complexity of a life with cancer becomes even more intricate if the person has other challenges, such as sick family members, comorbidities, financial problems, or addiction. People with cancer often struggle with multimorbidity (Mazza & Mitchell, 2017). People with a complex chronic illness will have many needs, not only biomedical, but also in other facets of life. Moreover, the needs may change over time. Persons with CRC often have complex pathways, which become more intricate in cases when a combination of therapeutic modalities, such as surgery, radiotherapy, and chemotherapy, is needed (Hildebrandt et al., 2019; Labianca et al., 2010).

To provide better care based on PCC and the ideals above, we should acquire more knowledge about the "journeys" cancer patients embark on in the context of severe, complex, and long- term illness. In the PATH project, we therefore explore the patients' voices in their quest for healing. Using a longitudinal qualitative research design, we aim to gain insights into how these illness processes appear from the ill person's point of view and what really matters to the person over time. Improving our understanding of CRC patients' unmet needs is essential to providing them with better future healthcare (Kotronoulas et al., 2017). Healthcare workers may only receive segments of patients' experiences. Studies of the complexity of a lived life with cancer and how it may come to play out in different stages of the process are thus important, as they may provide useful knowledge for public healthcare, relevant organizations, and healthcare education. Knowledge about ill people's paths and what matters during their pathways should be of interest to healthcare workers. We should also remind ourselves that maybe the most important aspect of PCC is "transferring the patient's goals into realistic, rational and manageable professional goals" (Olsen et al., 2020, p. 12) . According to Olsen and colleagues, "What matters to you?" is a simple question, but integrating it into everyday practice is a complex process. We reflect on this issue in sub-study 2 and suggest some ways to use the model of social drama. Overall, I suggest that the PATH project may provide information to public healthcare that can be used to improve PCC for patients with complex long-term conditions.

To summarize: People with cancer in general, and maybe CRC in particular, tend to have complex and changing needs that extend over time. PCC focuses on what matters to patients, and is a goal for patients and health authorities alike. In the postmodern experience of illness, listening to and respecting patients' voices is an essential part of care. One way to improve care for persons with chronic disease is to gain insight into what really matters to them and analyze their accounts of trajectories to healing.

1.11 Aims of the dissertation and the main research problem

Based on the above rationale, the overall aim of this dissertation is to provide insights into cancer patients' trajectories to healing through a focus on what matters to them over time. What characterizes a cancer pathway from patients´ perspectives, and which concepts may be useful in order to understand their experiences and trajectories to healing?

This is explored through sub-research questions in the different articles. Paper 1 explores "What is important for persons diagnosed with colorectal cancer during their patient pathways? Further, based on these findings, "What significant features do the patient pathways share?". Paper 2 explores whether or not the model of social drama may be transferable to cancer patients' accounts of paths to healing and if the model has public health relevance. Paper 3 asks "Which health seeking choices do the participants make and what characterizes these choices?"

Presentation of papers:

Aims	Research question	Methodology	Publication
To gain more in-depth knowledge of what matters to patients, how "what matters" might change over time, and tentative descriptions of commonalities across patients' perspectives.	What is important for persons diagnosed with colorectal cancer during their patient pathways? Further, based on these findings: What significant features do the patient pathways share?	Longitudinal qualitative research with a series of interviews over one year with nine Norwegian patients who were recently diagnosed with rectal cancer tumor-node-metastasis stages I–III. The interviews were conducted by Salamonsen, Berntsen and a research assistant. Content analysis in NVivo was performed by Hansen and discussed with the research team.	1. Frank Hansen, Gro K. Rosvold Berntsen & Anita Salamonsen (2018). "What matters to you?" A longitudinal qualitative study of Norwegian patients' perspectives on their pathways with colorectal cancer. *International Journal of Qualitative Studies on Health and Well-being.*

To gain insights of lived experience of persons diagnosed with colorectal cancer and to create an understanding of cancer trajectories as a dynamic process.	Based on the subjective experiences of life with cancer, how can we understand the process and the changes in the pathway? Is the model of social drama potentially transferable to patients' accounts of pathways of long-term and severe conditions? Does the model have public health relevance?	The same data collection method as described for Paper 1. Hansen took notes, made mindmaps and temporary codes by hand when reading the interviews. Later, Hansen employed content analysis to explore the data collected. Went back and forth between the data and the theory.	**2.** Frank Hansen, Gro K. Rosvold Berntsen & Anita Salamonsen (2019). Patient pathways as social drama: a qualitative study of cancer trajectories from the patient's perspective. *International Journal of Qualitative Studies on Health and Well-being.*
To explore how persons with long-term conditions choose and make sense of their health seeking activities.	Which health seeking choices do the participants make and what characterizes these choices?	The same data collection method as described for Paper 1. Based on the findings in Papers 1 and 2, we were interested in exploring medical pluralism in greater depth. A combination of approaches was emphasized as important by the participants, and according to our analysis this phenomenon played a significant role in the redressive phase of the model of social drama. Hansen coded the interviews in NVivo and performed a content analysis. The findings were discussed by the research team.	3. Frank Hansen, Gro K. Rosvold Berntsen & Anita Salamonsen (2020). Medical pluralism in the aftermath of cancer: health seeking actions and cancer patients' shaping of trajectories to healing. *Anthropology & Medicine.*

Table 1: The aims, research questions and methodology of this research project

2. Materials and Methods

The three papers in this thesis are based on a qualitative longitudinal data set and analyzed using content analysis.

2.1 Epistemology, ontology, and generalization

What is the nature of being? And how can we know that we know anything about this world? Ontology and epistemology are extensive topics. I will introduce a theory which makes sense to my understanding of the world. Delmar (2010) argued that any situation is characterized by its quality of doubleness:

> It is unique and typical at the same time. People with each their unique story and life world constitute the uniqueness of the situation. And a situation is typical in the sense that fundamental experiences can be found in every situation. The typical is what we as people have in common. There will be typical traits and recognizable patterns in every situation. The findings show us that "generalizability" in qualitative research builds on recognizability and a challenge to practice as a practical reasoning. (p. 115)

Delmar's ontological view of what establishes a situation represents an epistemological foundation for qualitative research. This provides a useful methodological perspective for this qualitative study, with its focus on ill people's trajectories to healing.

The doubleness of the situation is evident across all the papers in this study. All pathways represent unique individual stories. This aspect of the doubleness is important to recognize with regard to the respect and integrity of people with long-term, severe conditions. The uniqueness of the paths is naturally also highly relevant to PCC, with its focus on placing the person in the center of care and understanding the patient as a unique human being (Balint, 1969).

"Qualitative studies give emphasis to the perspective of individuals and their experiences, meanings, situations and actions through the eyes of those who are familiar with these experiences" (Jormfeldt, 2019, p. 1). This thesis is built on the fundamental objective of qualitative studies, here expressed by Jormfeldt. At the same time, all paths share some common features, and all the papers have highlighted patterns we have identified. A key goal in analyzing the interviews was to develop concepts, typologies, metaphors or theories that could have relevance for other cases than those in the PATH study. Tjora calls this kind of generalization “conceptual generalization” (Tjora, 2013, 2017). In my interpretation, this corresponds to the “typical” quality of a situation. Both the typical and the unique are important aspects of qualitative research.

An individual experience may simultaneously be unique and typical of others in a similar situation. Being diagnosed with cancer, for instance, is a unique situation for every individual. However, a pattern can be observed during the interviews and in the participants’ descriptions of their experiences. News of the diagnosis was often described as a “shock” and “unreal”. This is a plausible ontological understanding of what constitutes a pathway and it was also expressed by the participants when they stated that it was easy to talk with other patients as they understood what the participants were going through on a deeper level. Not only does this dualistic understanding of a situation provide an ontological and epistemological foundation for qualitative research, but also an important worldview that we need to remember when taking care of people. Delmar (2010) quoted the philosophy or slogan of the University Hospital of Aarhus: “The individual is like no others, like some others and like all others” (p. 121). We cannot be inside people´s heads, but I do believe that we can get under their skin. We can listen to people´s stories and grasp both their typical and unique aspects.

2.2 Philosophy of science and research position

My position regarding the philosophy of science generally lies within hermeneutics. Hermeneutics refers to the art of interpretation (Grondin et al., 1994), and consists of a broad field containing a variety of philosophical discussions and approaches. In general, as I understand the concept, it involves the process of gaining knowledge about the social world through interpretation. In social sciences such as anthropology, this knowledge is dependent on historical, social, and cultural contexts. The interpretation of meaning in human (inter)action must be contextualized to gain knowledge. Social life always takes place in a particular setting; it does not exist in a vacuum (Agar, 1980; McCaffrey et al., 2012). The concept of “thick description” is widely used in anthropology to describe the interpretive methodology in the field.

2. 3 Material

Participants were identified in the electronic patient records of the University Hospital of North Norway (UNN). One criterion for participation was an age range of 18 to 70. Further, they had to have been diagnosed with rectal cancer, tumor-node-metastasis stages I–III (Dukes A–C), within the last six months. Their primary surgical treatment had been completed, and they lived no farther 500 km from UNN. Out of 20 patients who fulfilled the recruitment criteria based on the electronic health register of UNN, and who were sent a written invitation during the fall of 2010, ten gave written consent. One of the participants withdrew after the initial baseline interview. The nine remaining participants were from 54 to 68 years old at baseline, and all provided data at the one-year data collection.

Table 1: Demographics

Characteristics		**Number of participants (n=10)**
Gender		
	Female	5
	Male	5
Age		
	Unknown	1
	25-44 years	0
	45-65 years	6
	>65 years	3
Education		
	Compulsory education	3
	High school or equivalent	2
	Trade/vocational diploma	3
	Bachelor’s degree	0
	Master’s/professional degree	2
Marital Status		
	Married or living with a partner	7
	Not married	3
Living Situation		
	Alone	3
	With children	
	With spouse/partner	5
	With spouse/partner and children	2
Work		
	Unknown	1
	Employed part time	1
	Employed full time	2
	Self-employed	2
	Unemployed	0
	Retired	1
	Disability benefits	1
	Sick leave (full or part time)	2
Colorectal cancer stage, TNM		
	Stage 1	3
	Stage 2a-b	3
	Stage 3a-c	4
Treatment		
	Preoperative radiotherapy	5
	Surgical treatment:	
	Biopsy only	1
	Bowel resection and re-anastomosis	7

Bowel resection with permanent stoma	2
Postoperative chemotherapy	7

(Hansen et al., 2018)

2.4 Data collection method

Here I provide further details of the data collection method. First, I will elaborate on qualitative longitudinal research and qualitative interviews. This will be followed by the data collection process and various aspects of the data analysis.

2.4.1 Qualitative longitudinal research (QLR)

Contemporary QLR aims to understand change in particular socio-cultural contexts (Carduff et al., 2015). The method is "a rich and evolving methodology for exploring the dynamic nature of people's lives" (Neal, 2019, p. 1). As the name suggests, the methodology combines both qualitative and longitudinal traditions. By following same people or group over time with a qualitative in-depth approach, QLR is a methodology that…

> …gives insights into how people narrate, understand and shape their unfolding lives and the evolving world of which they are a part. QL research is conducted through time; but it also engages with the temporal dimensions of experience, opening up the potential to 'think dynamically' in creative, flexible and innovative ways. These features of QL research suggest it is a part of a developing theoretical orientation, an emerging paradigm for social research that offers new and exciting ways to know and understand the social world. (Neal 2019, 1-2)

QLR has over the past decade appeared as an emerging methodology in social research (Calman et al., 2013). "Longitudinal qualitative research is distinguished from other qualitative approaches by the way in which time is designed into the research process, making change a key focus for analysis" (Calman et al., 2013, p. 1). The researcher is better able to grasp change during chronic illness, and thereby uncover changing needs and experiences. Following patients over time by applying a QLR methodological approach "can add depth and understanding to health care research, especially on topics such as chronic conditions, adherence and changing health policies" (Grossoehme & Lipstein, 2016, p. 1). Murray and colleagues (2009) argue that qualitative interviews of persons during the course of illness give the researcher a better picture of their experiences than single "snapshot" techniques.

Frequent interviews may enhance the development of the relationship between researcher and participant, which again may provide access to "backstage" information such as sensitive and personal issues. With regard to the PATH project, I found that the QLR methodology used there enabled me to learn more about the processes participants went through in their everyday lives with CRC. Using Neal’s concepts, the approach in the PATH study could be categorized as retrospective intensive QLR. In the quarterly interviews, the participants were asked to narrate what had mattered most to them in the previous three months. The explorative nature of the repeated qualitative interviews not only provided new understandings of health events, but also of life events and how these events evolved and influenced each other over time. The QLR approach elicited in-depth information and suitable material to understand how patients’ ideas about what mattered changed over time, how needs fluctuated and how participants’ coping strategies mattered in the context of dynamic processes.

2.4.2 Qualitative interviews

In the PATH project, the overall aim is to learn more about pathways with cancer from patients´ perspectives. In addition to the emphasis on people’s subjectivity, we also believe that illness experiences and health seeking actions must be understood in their sociocultural context. Therefore, we need methods that grasp the subjective experience of lived life with severe and long-term conditions.

The data used in this thesis consist of 46 qualitative semi-structured interviews, which are “in-depth interviews where the respondents have to answer preset open-ended questions and thus are widely employed by different healthcare professionals in their research” (Jamshed, 2014, p. 87). The project had three different interview guides. The baseline interviews focused on topics such as the participants’ experience of diagnosis and treatment choices, and their health issues. The purpose of the subsequent quarterly interviews was to explore the health events and life events that participants found most important in the three-month period prior to each interview. Some of the participants also wrote diaries that they shared with the researchers before the quarterly interviews. In those cases we used the diaries to structure the interviews, and thus the main themes in the diaries became the starting point of the interviews. For those who preferred not to document their lives through diaries, we used an interview guide that invited the participants to tell us about the most important health and life events since the last time we spoke. The interview guide for the closing interviews also focused on health and life events, but contained a section for a summary of the past year and the participant’s experience of participating in the project.

We aimed to conduct the interviews as a form of dialog (Crapanzano, 1992), allowing for reflection (Middelthon, 2001). We used open-ended questions such as "Would you like to tell us about what you felt were the most important events since the last time we met?" If the participant touched on topics that required further elaboration, the interviewer asked follow-up questions to clarify ("Did I understand you correctly…?") or to delve deeper into the issue. This is in line with the approach outlined by Grossoehme and Lipstein:

> The in-depth approaches used in qualitative research allow for a better understanding of the lived experience of disease, including the ways in which individuals interacted with the health care system and why they made specific health care choices. This research then helps generate hypotheses for future study and ultimately leads to improvements in health and health systems. (Grossoehme & Lipstein, 2016, p. 1)

By using in-depth qualitative interviews in a longitudinal study design, I argue that it is possible to come close to certain aspects of human life, making this method a suitable approach for our aim.

2.4.3 Data collection process

We interviewed the participants five times over a period of approximately 12 months. We began with a baseline interview, followed up with three quarterly interviews where the participants reflected on what had been most important for them in the previous three months. As mentioned, between interviews we encouraged participants to write diaries and complete monthly symptom questionnaires which they sent back to us ahead of interviews. After 12 months, a closing interview was conducted.

I wish to emphasize that all interviews were conducted by a sociologist, a physician, or a research assistant trained in qualitative interviewing. Each interview was audio recorded and later transcribed. I did not conduct any of the interviews, but worked on the transcriptions in close co-operation with the physician and the sociologist, who were my supervisors for this thesis.

The baseline interviews were conducted face-to-face at NAFKAM in Tromsø, while the remainder were telephone interviews. A professional transcriber was hired to perform the transcriptions. Some interviews were long and complex and others were short with less complexity.

2.5 Analysis

We performed a content analysis as described in sub-studies 1, 2, and 3 (Hansen et al., 2018, 2019; Hansen et al., 2020), but with different theoretical lenses applied to the data in the three papers. I will here elaborate further on certain aspects of the analyses:

2.5.1 The NVivo tool

After the first reading I had developed a set of codes that I categorized in NVivo 11 Pro during the second round. This process resulted in codes based on a relatively large amount of textual material (Weber, 1990). The NVivo 11 Pro software was a useful tool to organize and code my thematic findings (Richards, 1999). The categorization was motivated by relevant research questions in a thematic analysis of patterns of meanings, which I explain in further detail below. In addition to the categorization in NVivo 11 Pro, I used mind maps, drawings, and infographics. I also made summaries of interviews to obtain a general idea of each case.

Using NVivo 11 Pro helped to clarify differences and similarities across the different cases. For instance, I developed categories for sub-study 2 that represented Victor Turner’s model of social drama. This not only applied to the main phases, but also relevant sub-categories such as rituals, communitas, and liminality. I had also identified other categories such as “What matters to the participants”, coding passages where the participants were asked about this or explicitly stated that something mattered to them. Moreover, I had a category called “metaphors” where I coded passages where the participants explained their experiences by using metaphorical language. This systematic approach connecting theory, themes and empirical data provided me with confidence that my analysis made sense in understanding the material. My findings were presented and discussed with the research team and were frequently evaluated during the writing process, where NVivo 11 Pro was also a useful tool.

2.5.2 Conceptual generalization

I applied conventional content analysis to interpret meanings of the transcribed data. Content analysis is a suitable method to find meanings and what matters in people´s lives (Erlingsson & Brysiewicz, 2017; Krippendorff, 2018).

> The objective in qualitative content analysis is to systematically transform a large amount of text into a highly organised and concise summary of key results. Analysis of the raw data from verbatim transcribed interviews to form categories or themes is a process of further abstraction of data at each step of the analysis; from the manifest and literal content to latent meanings. (Erlingsson & Brysiewicz, 2017, p. 94)

The coded categories were thus directly extracted from the transcribed interviews (Hsieh & Shannon, 2005). In the first phase of the analysis, I chose an inductive approach to explore the data. "In its idealized form, inductive research involves the search for pattern from observation and the development of explanations" (Bernard, 2011, p. 7). After the categorization of codes and development of theoretical frameworks, I also worked deductively by checking my theories against the interview data. My research process therefore had similarities to Tjora's stepwise-deductive induction (Tjora, 2013, 2017, 2019) which has conceptual generalization as an aim, and starts the analysis with an inductive approach and checks from theory to empirical data deductively during the process. For example, Victor Turner's model of social drama, which is the main focus of sub-study 2, emerged from inquisitive reading and coding of the interviews. I observed that many of the interviews had the same form. Categorizing the codes revealed that it would be a fruitful approach to explore Turner's model based on the PATH data. I then created the structure of the social drama model in NVivo 11 Pro and worked more from the theory to empirical data. I could not find that the model had been applied previously to explain pathways of illness. Therefore, the theory helped to explain the empirical data, but the data also helped to develop the theory.

Since what mattered to the participants was a vital issue in the interviews and articles, I decided on a framework of person-centered care for the thesis.

3. Results

3.1 Sub-study 1: “What matters to you?” A longitudinal qualitative study of Norwegian patients’ perspectives on their pathways with colorectal cancer

In the first sub-study, we focused on what the participants emphasized as important during their pathway and over time. To the best of our knowledge, no qualitative studies had actually explored what matters to patients with cancer over time. What matters to patients during a pathway could be an important contribution to more person-centered care.

We found that:

1) Patients have an initial focus on “biological goals” and conventional treatment: In the first period following diagnosis, the patients had biological goals. It was important to initiate cancer treatment according to the medical professionals’ advice using methods such as radiation, surgery, and chemotherapy in order to survive.

2) Pathways are unique and dynamic: The participants emphasized various aspects that mattered to them, where what mattered changed during the pathway. Each lived life with illness is a unique and dynamic journey with individual health and life events forming a personal biography.

3) Family and friends had a positive effect on patient pathways in terms of meaningfulness and quality of life, but for some participants also a negative effect because of heavy burdens of receiving care. Family and friends were frequently highlighted as important during the pathways. In the context of a potentially fatal disease, many participants found that what matters most in life is relationships, and spending time with family and friends gave meaning and emotional support. However, some also preferred to be alone at times. Having others pity them and needing care at times became an extra burden on the participants.

4) Receiving help in the healthcare system depended on the patients’ navigation skills: Whereas some found that they could not get the help they needed because they did not know where to access it, others made use of professional networks to choose their preferred surgeon. Others had to use the “backdoor” of the healthcare system to obtain help when they needed it.

5) Plurality in health seeking behavior was important in all patient pathways: The participants made use of different methods to cope with their various challenges. These ranged from being

in nature, hiking, and physical exercise to visits to healers, herbal practitioners, and Christian priests.

What matters to patients is characterized by dynamic, transient, and individual qualities. A pathway includes both life and health events as well as a variety of health seeking actions. The clinical understanding of a standard patient pathway normally includes only biomedical care for a patient. In this paper, we therefore suggested that "person-centered pathway" could be a useful concept for a holistic understanding of pathways that also cover the aspects mentioned above.

3.2 Sub-study 2: Patient pathways as social drama: A qualitative study of cancer trajectories from the patient's perspective

In sub-study 2, we aimed to understand long-term illness as a process by applying Victor Turner's model of social drama. Turner suggested a four-phase model of social dynamics in the context of conflicts and crises: 1) breach of norm, 2) crisis, 3) redressive actions, and 4) reintegration or schism. We found that this model could provide us with a plausible understanding of the processes patients go through in the context of cancer. *Breach of norm* represents the stage when patients realize that something is wrong with their bodies and consider seeing a doctor for a check-up. *Crisis* fits in with the participants' experience of being diagnosed with cancer. After receiving the diagnosis, *redressive actions* are taken, with the aim to address the problem. The actions have an outcome; the problem is either solved or not solved. However, the interpretation of this stage may be overly simplistic and it has implications. Turner also made use of the concept of "liminality", which is the phenomenon of being in between stages. The stage of normality is left behind and the stage of reintegration has not been reached. Some patients find themselves in a situation where they are neither ill nor well for a long time after they have been diagnosed as cancer-free by clinicians. We discussed this phenomenon by integrating the concept of "sustained liminality" proposed by Little et al. (1998). Some patients find that it takes a long time to reach normality, while for others liminality may even last for the rest of their life. The outcome of a pathway of cancer shows individual variations. For some, biomedical cancer treatment is a "quick fix" and life returns to normal after the intervention(s). For others, the end of treatment is the start of a new journey with late effects and other complications.

3.3 Sub-study 3: Medical pluralism in the aftermath of cancer: Health seeking actions and cancer patients' constructions of trajectories to healing

Sub-study 3 is a further exploration of the sustained liminality found in sub-study 2, in addition to the findings in Paper 1 where medical pluralism was emphasized as important during a pathway, particularly in the post-treatment phase. In this third paper, we were particularly interested in how the participants' shaped their trajectories to healing through complex health seeking actions in the context of sustained liminality. We also aimed to suggest what characterizes medical pluralism. We categorized medical pluralism or medical landscapes as conventional, CAM, self-care, religious coping, and traditional healing. We found that 1) medical pluralism is characterized by the implementation of contradictory models of reality and the making of pragmatic choices, 2) medical pluralism is a sociocultural phenomenon leading to continuity and change in health seeking actions, 3) medical pluralism can be seen as a process, and 4) there is increased use of CAM and self-care to improve health and well-being in situations where the conventional healthcare system has few available treatment options. We argue that trajectories to healing are constructed by people making choices and that this process could be understood in greater depth by applying the concepts of medical pluralism and medical landscapes.

4. Discussion

Just to remind the reader, the overall aim of this dissertation has been to learn about patients' trajectories to healing from their perspectives and what matters to them over time. The findings in the papers may generate a number of interesting discussions in the field. In this thesis, I suggest several concepts which can help us understand pathways and the experience of living with cancer.

4.1 Similarities and differences

All three sub-studies explore patients´ accounts of trajectories to healing from different perspectives. The phenomena that the participants emphasized as important in their lives were the main focus of the interviews and central to the data analyzed in all sub-studies. A central feature of the PATH project is that we followed the participants over a period of time. The gathering of longitudinal qualitative data related to participants' perspectives over time facilitated analysis of the processes and features of pathways of severe, long-term illness. All papers are empirically based on the participants' accounts of living with cancer in Norway.

The aim is to generate a greater understanding of patients´ cancer pathways. Through these three sub-studies, the aim was approached through 1) What matters to you? 2) Pathways as a dynamic process, and 3) Health seeking actions and medical pluralism. In general, we may say that the main focus of sub-study 1 is experiences, while in sub-study 2 it is processes and in sub-study 3 the focus is on actions. These are three different but complementary ways of approaching this overall aim: to enrich our understanding of patient pathways. Since all sub-studies are based on what matters to patients, they are all relevant knowledge for the field of PCC.

4.2 "Boundary walkers" in medical landscapes

In sub-study 1, we found that medical pluralism was one of several important aspects of a pathway of cancer from participants' point of view. In Paper 2, we viewed health seeking actions as part of a process, as "redressive actions" in Turner's model of social drama. Sub-study 3 seeks to understand medical pluralism on a deeper level, and especially in the context of the post-cancer period. Actions both within and outside conventional healthcare were of great importance for the participants' trajectories to healing. Per, for example, told us: "…the most important things were those I did myself… I walked for five or six hours every day. When I came back, I felt much better than when I left" (Hansen et al., 2019, p. 7). We categorized this health seeking behavior as a form of medical pluralism as the actions were performed in areas such as conventional healthcare, self-care, CAM, traditional healing and religious coping. We also suggested the concept of medical landscape to be suitable for our empirical data. Salamonsen (2013) provides us with "insights into cancer and MS patients' use of CAM within a Scandinavian healthcare context" (p. 37). Similarly to sub-study 3, Salamonsen found that patients' decisions were active, explorative and pragmatic. Inspired by Kushner and colleagues (2001), Salamonsen argued that the patients in her study were "boundary walkers" between CAM and the conventional healthcare system. Kushner and colleagues characterize boundary walkers as persons inhabiting margins, borders, limitations, and edges. Salamonsen has already shown us the usefulness of the concept in a Scandinavian healthcare context. Based on the findings in our study, I suggest that an elaboration of the concept of boundary walker could provide us with a deeper understanding of patients' accounts of trajectories to healing.

4.3 Neither ill nor well: The liminality of cancer

Health seeking actions become meaningful in light of the particular context in which patients find themselves. When a person is first diagnosed with cancer, that person wants to take actions to remove the tumor in order to survive. Maybe less obvious, but important to understand, is the connection between health seeking actions and liminality. In sub-study 2, we analyzed the data using Victor Turner's model of social drama and pointed out the significance of liminality as a central feature of a cancer pathway. Here are some examples of participants' accounts:

> When receiving the diagnosis, Jacob said, "I immediately felt that I was outside the rest of the world". Mari told us that her world became "total chaos". Elias said that it was like sitting on the outside and looking into a mirror: "It is almost like it isn't you. Very strange". Eva said that the pathway had been like "being in a bubble". (Hansen et al., 2019, p. 9)

It is interesting to note Elias´ experience of "looking into a mirror", but also that of Jacob who felt outside of the world, because Stephenson (2015) actually describes liminality as like looking into a mirror: "If we tell someone, 'take a good look in the mirror', we are suggesting (actually, imploring) that person to think about who they are, their behavior and actions, their lifestyle, their past actions, and their hopes and plans for the future. The mirror is a liminal and reflexive place" (p. 50). Liminality is an abstract and complex term, often described as an experience of disorientation, ambiguity and chaos when a person is between two states. It is being "neither here nor there", it is like being in a dark tunnel, betwixt and between states (Gennep, 1960; Turner, 1974). Sontag (1978) stated that "everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick" (p. 3). However, many patients with cancer find themselves in a state being neither ill nor well (Solem AG, 2018), not in the kingdom of the well nor in the kingdom of the sick, but inhabiting borders and margins. In addition to Salamonsen´s use of the concept, boundary walkers could therefore also refer to the experience of being neither in the kingdom of the sick nor in the kingdom of the well, but walking on the boundary between the two worlds. However, a boundary walker will long to cross the border into the kingdom of the well. I would argue that crossing boundaries to different medical systems through pragmatic health seeking actions and rituals are attempts to enter the kingdom of the well.

Some, but not all, will find themselves in a state of being neither ill nor well. A state of extended liminality in the context of severe illness may potentially last the rest of a person's life (Little et al., 1998). A similar argument is found in Hedlund's (2008) study of chronically ill patients with neurological illnesses. She found that the patients lived their lives in a state of never getting well, but continuously being more or less sick. In the following, I will visit more literature that shows the significance of "being neither ill nor well", and later discuss the possible relevance of this for patients' pathways to better health.

A qualitative study of CRC patients showed that many found that their life was normal, but still not normal. The author elicited the following themes to characterize why life was not as before: "Life has a shadow of death", "The treated body sets the rules" and "To share or not share the illness" (Ohlsson-Nevo et al., 2012, p. 555). Not everyone manages to find meaning in suffering. Despite being "successfully" treated for their cancer, many suffer from physical and psychological late effects after treatment, they may be unable to work, and they may have social and financial challenges. "Paradoxically, and put in crude terms, the treatments they go through also make them sick" (Hansen & Tjørnhøj-Thomsen, 2008, p. 375). The anthropologist and former cancer patient Stoller (2013) interpreted his cancer experience as liminality.

> For me, the experience of cancer has unfolded much like a rite of passage. As is portrayed in the film *50/50*, cancer forces you, like any neophyte, into a liminal state. The side effects of cancer treatments result in noticeable physical changes—a pale pallor, a slow unsteady gait, hair loss, and a frail body—that set the patient apart from "normal" people. The physical manifestations of cancer and its treatment regimens are markers of impeding death, which, given the intense fear we have of death in Euro-American societies, makes most of us uncomfortable. What do you say to someone who has cancer? (Stoller, 2013, para. 26)

Since people do not know how to interact with a person with cancer, Stoller experienced the social isolation often associated with liminality. Even though Stoller realized that his cancer experience unfolded like a rite of passage, he argued that the liminal phase was not as finite as we find in Turner's studies of rituals. "To borrow from Maurice Merleau-Ponty, you are in a space that is '*everywhere and nowhere'*. Once cancer has touched your being, there is no going back to a life in the *'village of the healthy'*, in which health is taken for granted" (Stoller, 2013, para. 29). The liminal phase, as he experienced it, never ends. Stoller called it "continuous liminality". Little et al. (1998) described the same phenomenon as "suspended liminality":

> We believe that all cancer patients enter and experience liminality as a process which begins with the first manifestations of their malignancy. An initial acute phase of liminality is marked by disorientation, a sense of loss and of loss of control, and a

> sense of uncertainty. An adaptive, enduring phase of suspended liminality supervenes, in which each patient constructs and reconstructs meaning of their experience by means of narrative. (p. 1485)

Frank (2013), like Stoller also a former cancer patient, argues that this group of individuals could be considered "remission society": "all those people who like me, were effectively well but could never be considered cured" (p. 8). The technological advances in biomedical cancer treatment save more lives now than before, which means that the "remission society" is a growing group of people struggling with various late effects of treatment (Kreftregisteret.no, 2018; Solem AG, 2018). Hedlund (2008) argues that chronic conditions represent a paradox in healthcare. Modern medicine's technological innovations and developments in treatments save more lives than before, but at the same time, patients with chronic conditions demonstrate the limitations of modern medicine. Its innovations cannot heal the lives of people with chronic conditions. The result is a world with more ill people.

Interestingly, when Stoller (2013) wrote about continuous liminality, he actually pointed out immigrants as another example of people that "continuously inhabit spaces somewhere between a home and a host country" (para. 32). Frank (2013) suggests: "The remission society is left to be either a demilitarized zone in between them, or else it is a secret society within the realm of the healthy" (p. 9). Frank explores the remission society further using Sontag's metaphor and stating that people in the remission society do not use any of their passports, but "are on permanent visa status, that visa requiring periodic renewal" (p. 9).

Frank compares modernist medicine to colonialism. "Just as political and economic colonialism took over geographical areas, modernist medicine claimed the body of its patient as its territory, at least for the duration of the treatment" (p. 10). Is this colonialization inevitable? Frank's critique is constructive. The problem is the status as patient and the loss of status as person in clinical settings. Therefore, Frank draws a line to the postmodernist school of thought, emphasizing a more predominant view of the particularity of the ill person versus having individual suffering reduced to the generality of modernist medicine. This is in line with my understanding of PCC, which also emphasizes subjectivity and actions according to patients´ goals, preferences, and values. In sub-study 1, when we asked Jacob how he felt public healthcare could improve in his experience, he answered that they could be better at seeing the person behind the diagnosis. Frank's argument is therefore still relevant, and the experience of being reduced to a patient may be a problematic experience in contemporary healthcare from the ill person's point of view. If PCC is about "what matters" for ill people, the concept belongs within the postmodern school of thought and the reclaiming of the voices of ill people. When healthcare services do not manage to be person-centered, is the tension between illness (healing, subjective) and disease (curing, objective), or modernist medicine and the postmodernist school of thought still at play? We will continue discussing this aspect of liminality in the following section "Better quality of life in the aftermath of cancer".

In discussing what characterizes people's trajectories to healing, liminality is an important and highly relevant phenomenon to illuminate. First, it is possible that the "remission society" is a large group of people experiencing suffering in their daily lives. As I showed in the introduction, in Norway alone there were 25 508 survivors of cancer in 2021. Second, when analyzing the pathways by using the model of social drama, the concept of continuous liminality provided us with an analytical framework that enabled us to gain insights into pathways in later phases. Some pathways seemed to have a somewhat clear ending with participants explaining that life was back to normal, they were back to work and had no symptoms. At the same time, as Ohlsson-Nevo and colleagues (2012) found in the study above, life could be as normal, but still not quite normal. Other participants did not reintegrate into "normality", highlighting challenges such as a permanent stoma, pain, anxiety of recurrence, stomach problems, and being permanently disabled for work. Check-ups and waiting for test results were associated with fear and anxiety for the participants. According to Frank (2013), and to continue with Sontag's metaphor, the check-ups are like getting one's visa stamped, which reaffirms the lack of permanent citizenship. Check-ups are not just monitoring, he argues, but "the background of illness shading back into the foreground" (p. 10).

4.4 Better quality of life in the aftermath of cancer

Sometimes CAM is used with the aim of curing diseases such as cancer, as we showed with Julie's case. However, often CAM is used to feel better, to reduce symptoms of late effects, to feel in control, to stay positive, to boost the immune system, and/or because people want to use natural methods or remedies rather than medication (Cancer Research UK, 2018). According to Salamonsen and Ahlzén (2017), CAM use is "often found in persons living with chronic conditions who seek relaxation and well-being when full cure is not possible" (p. 359), and "…increasing expectations among Western populations for well-being and quality of life create an increasing demand for therapies in addition to what the predominant healthcare systems are able to offer" (pp. 359-360). Siahpush (1998) suggested that people turn to CAM because of 1) dissatisfaction with the health outcomes of treatments within social healthcare, 2) dissatisfaction with interactions between patient and doctor or healthcare system, or 3) postmodern values that are congruent with philosophies often found in CAM modalities. The reasons for seeking access to pluralistic medical landscapes are complex. However, I believe that Salamonsen and Ahlzen's (2017) assumption that people with chronic conditions seek a better quality of life applies in particular to the post-cancer period. In sub-study 3, we mapped the participants' health seeking actions. CAM practices and self-care were often associated with "feeling better". Moreover, many of the participants' needs could not be met by current biomedicine. Hansen and Tjørnhøj-Thomsen (2008) explored the rehabilitation of cancer patients in a Danish context, arguing that key goals are normalization and stigma avoidance, but many find that their efforts are in vain.

> They struggle with side and after effects and the fear of recurrence, and they cannot escape their strong doubts about recovery. They are forced to acknowledge the physical, psychological, social, and existential changes that affect their everyday life as a result of their encounter with cancer and their treatment. (p. 375)

The authors argued that the increased focus on rehabilitation has changed the dominant restitution narrative of "sick-helped-cured" to a rehabilitation narrative of "sick-helped-as if cured". The rehabilitation narrative is in line with the continuous liminality and the story of the remission society, and was observed in this study in the pathways with a more complex treatment regime.

The continuous liminality following cancer may be understood through some basic concepts. In the introduction we visited the pairs of concepts illness and disease, healing and curing, suffering and pain. In sub-study 2, I showed how the participants had biological goals in the beginning of the pathway. In this phase, they trusted the experts' knowledge of disease (objective) and the goal was to remove the cancer, i.e. to cure. Later, medical pluralism flourished. We have argued that cancer is more than the tumor, it is an attack on the whole person. We also know that biomedical treatment may have serious late effects. In this context participants need to heal (become whole again). The majority of CRC patients in Norway will be cured. However, I would argue that the inability to heal is the reason why those in the "remission society" feel that they are in continuous liminality.

> The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick. Physicians' failure to

> understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself. (Cassel, 1982)

In the post-operative phase and the phase of continuous liminality, both physical pain and suffering may be present, and both should be obligations of physicians, as Cassel argues. There are aspects of suffering, as a subjective psychological and existential concept, that may be better dealt with through self-management such as social support, building physical strength and adapting to the situation by using self-care techniques that suit the individual´s situation and values (Lo et al., 2021)

4.5 A pragmatic attitude to medical pluralism

In order to improve understanding of the participants' pluralistic health seeking actions during the course of an illness, I will compare Kristiansen`s (1995) theory of religious pluralism in northern Norway with our data. Kristiansen’s theory is based on a story about the fisherman Isak. In order to best master life, Isak must relate to the forces that prevail. Isak must take his precautions. When he is out at sea, he has to deal with the "unofficial" religiosity. He must relate to the figures who rule over safety and a good catch. These forces may be ancestors, mythical figures and other forces that he does not understand. Furthermore, he must relate to the popular knowledge and wisdom that has been passed on through generations in order to survive. To ensure a good life after death, Isak also needs to be allied with the God of Christianity. It is also through the doctrine of the official religion that Isak learns and practices compassion towards his fellow men.

For ordinary people, it is therefore best to live with a “cosmological duality”. Following both the official and unofficial traditions may be the most pragmatic approach to life. For the Church, Christianity is the way, the truth and the life. Its relation to folk traditions is therefore problematic. For ordinary people such as Isak, this duality is unproblematic. It is a pragmatic attitude for this life and the life beyond, for the life in heaven and on earth. Being pious and far-sighted is simply the only sensible way to live.

In sub-study 3, we found that one characteristic of medical pluralism was how people implemented contradictory models of reality and made pragmatic choices. I suggest that the story of Isak and Kristiansen’s reflections on religious pluralism could be a useful addition to this discussion. Medical pluralism and religious pluralism may share some common features.

All participants related to the official, biomedical treatment. That was the best way to survive cancer. At the same time, patients often have many everyday needs and these may change quickly, especially in the post-operative period when the hospital has less to offer (Salamonsen et al., 2016). Some needs, maybe particularly existential needs, cannot be solved with biomedicine. In the same way that Isak relates to the forces that prevail and can benefit him, patients relate to methods of coping that can help them with the complexity of challenges of their cancer trajectory, even if their health seeking actions conflict with the cosmology of the official healthcare system. In sub-study 3, we categorize the various actions as CAM, religious coping, self-care and traditional healing in addition to conventional healthcare. If the methods corresponded with the patients' cosmology, the patients viewed them as complementary to the official medical system. In sub-study 3, we referred to participants who said, "There is more between heaven and earth", and who emphasized "trying all possibilities". This illustrates pragmatism and an epistemological individualistic approach that may lead to the exploration of several types of health seeking actions.

To sum up, I have now elaborated on and discussed two aspects of patients as boundary walkers. First, through Salamonsen's insights, in terms of active and pragmatic patients choosing both CAM and conventional healthcare to achieve best possible results. Secondly, I used the concept to suggest that a boundary walker may also be understood as a liminal patient, in between states. I argue that there is a connection between these understandings, as medical pluralism may represent the attempt of a person in liminality to become well, or at least feel well temporarily. The experience of liminality in a part of the pathway, or as we have seen as a state for the rest of a patient's life, has received the most attention. Continuous liminality is a central feature of a pathway of cancer and other chronic conditions. I have argued that even if a person is cured from cancer, he or she may continue to suffer in a liminal state. Cancer may attack the whole person and affect all parts of a person´s life. To heal may therefore require more than removal of the tumor.

4.6 Medical landscapes and patients' accounts of trajectories to healing

Norwegian: Døden er ikke så skremmende som før. Folk jeg var glad i har gått foran og kvistet løype. De var skogskarer og fjellvante. Jeg finner nok frem.

English: Death is not as frightening as it was. People I loved have walked before me and made a path. They were forest people and accustomed to walking in the mountains. I will find my way. (My translation)

~ Kolbein Falkeid (Helse og omsorgsdepartementet, 2017)

This quote by the poet Kolbein Falkeid was used by Norwegian health authorities in a document outlining and evaluating current ideals of patient pathways and care. It shows how important metaphors are - not only in general, to communicate and understand the world, but also in the particular way the health authorities' use of this poem shows that landscape metaphors work when describing pathways.

We have already drawn on Sontag (1978) in a discussion of liminality and boundary walkers. Sontag stated that all people are born with dual citizenship, in the kingdom of the well and in the kingdom of the sick (p. 3). Like the Norwegian health authorities' use of Falkeid, Sontag could also be understood as using landscape metaphors in order to convey an understanding of medical phenomena. I understand Sontag's notion in relation to Hirsch's concepts of "foreground" and "background":

> There is a relationship here between an ordinary, workaday life and an ideal, imagined existence, vaguely connected to, but still separate from, that of the everyday. We can consider the first as 'foregrounded' in order to suggest the concrete actuality of everyday social life ('the way we now are'). The second we can consider as a 'background', in order to suggest the perceived potentiality thrown into relief by our foregrounded existence ('the way we might be'). (Hirsch, 1995, p. 3)

Those who reside in the kingdom of the sick (foreground actuality) will most likely wish to move to the kingdom of the well (background potentiality). In fact, this is the function of a healthcare system. When a human life crosses the boundary into the landscapes of illness, the human would probably try to find its way back to the landscapes of the healthy. That is the ideal state. DelVecchio (2007) notes that in American clinical culture, particularly that of oncology, one often meets rhetoric suggesting a dichotomy of humanism and biotechnology. However, DelVecchio finds that there is a relationship between technological developments in medicine and patients' subjective experience of hope, since technological advances represent possibilities. I believe that hope of crossing the border into the healthy land is the underlying power of all redressive actions, within and outside conventional healthcare. When patients choose to expose their bodies to radiation or chemotherapy, the power of hope is at play, a hope to return to the kingdom of the well.

A cancer diagnosis is often associated with death. In receiving the message "you have got cancer", the participants found that they came face-to-face with the temporality of life itself. This experience not only involved a feeling of losing life, but the end of relationships with loved ones. Furthermore, it evoked thoughts about all the things one wanted to do before life's journey was over. In other words, a cancer diagnosis immediately brings people to the kingdom of the sick and a new viewpoint where life itself can be observed from a different perspective. By inhabiting the kingdom of the sick, the kingdom of the well can be reflected upon in a way unknown to those who have not experienced cancer. When travelling to another country, people see their own society with new eyes. Everyday life is unreflexive (Bourdieu, 1984), but a cancer diagnosis causes a breach with normality, and the state that we took for granted is no longer a matter of course. The diagnosis taught the participants learned that life was fragile, and that we never know which way life's journey will take us or when it is over. There is a strong desire to continue one's relationships, especially those with close family members such as one's children. This is a very important factor for wanting to live and strongly affects the subjective experience of hope when undertaking potentially harmful treatments.

Living a life with cancer can be described as having the foreground and background reversed. The participant David said, "Like other people look forward to going on holiday, I've been looking forward to getting back to work". The Norwegian celebrity, Anne Christine Koht, is currently struggling with cancer and severe side effects. In her podcast, *Koht vil leve* (*Koht wants to live*, my translation), Koht shares similar thoughts as David:

> My dream, my only dream is to experience a day that other people don't even remember. Just an ordinary Tuesday or Wednesday. I just dream of an ordinary day where I can put on some clothes, just sit down not being dizzy. To just be and do nothing. There are so many joys during a day that we forget. Not just watching the birds and things like that. But simply to have a cup of coffee or tea. There is so much beauty in a normal day. (Koht, 2019, min. 11:06-12:00`, my translation)

Illness brought a new perspective. Both Koht and David dreamt of the state of everyday life. Their experiences of dwelling in the kingdom of the sick were their actuality (foreground). The previous foreground, the everyday "normal" healthy life, has become the state they dream of attaining, the potential ideal state (background). The foreground has become background. I suggest that understanding people's actualities (foreground) and perceived potentialities (background) may provide central insights into their paths and the underlying dynamics.

Many of the participants in our study emphasized the importance of coping strategies that I interpret as practices associated with a healthy lifestyle in Norwegian culture. For instance, in the context of cancer they talked about the perceived benefits and importance of going for walks, working out, being at their cabin, and spending time in nature. My interpretation of this is that the background potentiality of being healthy is foregrounded as an everyday experience. Being in nature, for instance, evoked a feeling of wellbeing, according to the participants. Even though life was challenging, being in the outdoors represented a temporary transition into the kingdom of the well and a feeling of normality.

As we showed in sub-studies 1 and 2, people's journeys are unique, complex, and dynamic. In the initial phase, the biological goals and survival based on biomedical treatment were important. Later, in the post-cancer phase, medical pluralism was prominent. As the journeys progressed, new spots in the landscape were discovered and the participants' needs, values, and preferences fluctuated. Each pathway was unique, but we also found some phases common to the processes. One was the first experience of symptoms. The second phase was the cancer diagnosis followed by treatment. In the post-treatment phase, some said that they were well and functioned normally, while others felt that they were neither well nor sick. In the second article, we therefore suggested that the patient pathways theoretically fit Victor Turner's model of social drama. In the landscape metaphor, the social drama model represents the common paths that are trodden into the landscape. In sub-study 3, we focused on health seeking actions and found that the participants chose many paths and directions to attempt to return to the kingdom of the well. Movements in various medical landscapes were emphasized. I found mainly five different types of health seeking actions: conventional, CAM, self-care, religious coping, and traditional healing. These categories can be understood as different paths taken through the medical landscapes which the participants chose to visit to various degrees and according to their preferences, needs and beliefs. Kolodziejska-Degorska (2016) conducted fieldwork amongst village dwellers in Central Ukraine. The author explored the villagers' various therapeutic choices, interpreted as medical landscapes.

> Medical landscapes are not fixed, but vary and dynamically change for each person, depending on their fluid and interchanging, hierarchical webs of mutual relations with

> other people, personal bodies, institutions, discourses, political powers, other non-human organisms, or objects such as medicines. (p. 155)

In a similar way as I do, Kolodziejska-Degorska highlighted the pathways as dynamic and unique journeys. The author further argued that movement within the medical landscapes in Ukraine is possible because of people's webs of relationships, which can be an interesting comparison to the Norwegian context.

Kolodziejska-Degorska pointed out that an important feature of Central Ukrainian villagers' medical landscapes is the dysfunction of official healthcare. Accessing official healthcare is challenging, the cost is high, and people distrust the system and, to various degrees, particular doctors. Therefore, the villagers often explore the possibility of plant medicine as their first treatment option. In comparison, the participants in our study expressed trust in biomedical doctors' knowledge, official healthcare was accessible, and the financial cost was low. All participants chose biomedicine as their first treatment option and this was expressed as an obvious choice. However, I find similarities to Kolodziejska-Degorska's finding regarding the web of relationships as a significant factor for movement within medical landscapes. I argued in the first paper that navigation within the landscape of public healthcare depended on people's knowledge and networks. By making use of networks in official healthcare, some participants accessed better treatment by, for instance, choosing the best surgeons. Others expressed frustration at not knowing where to get help. Furthermore, Arne Berg, a specialist in oncology, argues that conventional healthcare in Norway is two-sided, consisting of public and private healthcare, and that better healthcare may be more easily accessible for well-informed and affluent people (Johansen & Huuse, 2017). I would add that this is mostly relevant for people living in large cities such as the Oslo region, and perhaps Trondheim and Bergen. Elsewhere, private care enterprises only offer limited types of healthcare. I will not discuss this in greater detail; the welfare state of Norway is built on egalitarian principles (Rothstein, 1998), but as shown access to care may depend on patients' ability to navigate in the medical landscapes.

Access to traditional healing (*lesing*) is another example of how movement within medical landscapes is made possible through relationships. To access a traditional healer (*leser*), one needs to know certain people, but the healing itself is free and there are thus no financial barriers to receiving this treatment. Networks and webs of relationships as a resource, or "social capital" to use Bourdieu's (1984) term, seem to be important for movement in medical landscapes that leads to treatment in both Norway and Central Ukraine (Kolodziejska-Degorska, 2016). However, the difference in sociocultural context in these two locations creates different patterns in terms of treatment choices between these two groups.

Both "access" and "trust" could be seen as features of journeys in medical landscapes. Access is a matter of organization of care and in a landscape there will be "low threshold" areas that are easy to reach, and "high threshold" areas, which must be scaled with mountain climbing gear and various additional skills and resources. Trust concerns how well the people we interact with in healthcare services are able to help us navigate the landscape. Some helpers will help us climb mountains, while others will deceive us in our weakest moments. For many cancer patients, the pathway is a long and challenging journey. It is like climbing a mountain in a weak condition, and a navigator could be very useful on the way to the top.

Understanding movement within medical landscapes is a complex undertaking. Webs of relationships, economics, politics, cultural repertoires, emotions, values, and changing needs are some factors regulating people's choices of paths. Cultural flows and globalization represent movements of ideas, people, and things (Appadurai, 2002) that generate a constantly changing medical landscape of possibilities for the ill person. The following section is an expansion of the idea I presented above.

4.7 Liminality, transformation and reclaiming life

Cancer patients often experience change: physical, mental or spiritual. In sub-study 2 we demonstrated this by interpreting the data using the model of social drama. The concept of liminality was central in sub-studies 2 and 3; it is central in terms of explaining change or transformation during a time of crisis, and a key concept in transformation during a rite of passage. I have already shown the relevance of the concept as a state of being neither ill nor well, caught between the lands of illness and health, potentially for the rest of one's life. Here I will discuss liminality in the light of movement in medical landscapes. Liminality is often explained in terms that give associations to being in a certain space. Furthermore, it is a term often used in the context of processes, transitions, change and movement. Above, I showed that Jacob's feeling when he heard the diagnosis was "I immediately felt that I was outside the rest of the world" (Hansen et al., 2019, p. 9). I interpret this as the transition from the kingdom of the well to the kingdom of the sick. Life is turned on its head. This corresponds to the model of social drama and liminality as a state, an experience and a potentiality of transformation (as we see in a rite of passage, for example). Transformation or change does not happen by itself, but is a result of redressive actions in order to meet different needs.

On another level, foreground and background could be seen in the perspective of the participants' philosophy of life itself. Late in the pathway, participants pointed out the importance to live life as it is, not as it should be. Acceptance of one's current state was a liberating mindset to help to control a world that cannot be controlled. In sub-study 2, the participant Jacob talked about this topic. He viewed his time with cancer as a process and used the word "reorientation" to describe the last phase, which represented a new perspective on what really matters in life as one never knows what is waiting around the corner. Being with family and friends had become especially important to him. I have interpreted this realization or acceptance as a key for some of the participants in order to reclaim "life" in the context of cancer. This concurs with the findings of Sherman et al. (2012). With their title *Reclaiming Life on One's Own Terms* they found that breast cancer patients viewed the diagnosis as a turning point in their lives, and that the recognition of cancer as a part of life was important.

> Participants revealed that breast cancer survivorship is a process marked and shaped by time, the perception of support, and coming to terms with the trauma of a cancer diagnosis and the aftermath of treatment. The process of survivorship continues by assuming an active role in self-healing, gaining a new perspective and reconciling paradoxes, creating a new mindset and moving to a new normal, developing a new way of being in the world on one's own terms, and experiencing growth through adversity beyond survivorship. (Sherman et al., 2012, p. 258)

Acceptance may sound like a contradiction to performing any health seeking actions. However, accepting one's life situation does not mean that one should not try to improve, to change, and to heal. It is rather the acceptance of the nature of life, which the participants had learned through experience can be fragile, rapidly changing, uncontrollable, full of suffering, and temporary. It also means trying to live life more in the present moment, and as Sherman et al. found, reclaiming life on one's own terms. Diagnosis, treatment, and results are all interconnected events related to past and future. There may therefore be two levels interplaying, a level of time and a level of timelessness, or a level of striving and a level of acceptance of how life is, which both affect lived life. The striving (such as health seeking actions) may be the aspect that we associate most with change, but the acceptance of life as it is provided the participants with significant change in terms of inner peace. When a person accepts what is, that person lets go of the existential suffering related to "this was not how life was supposed to be".

The acceptance of life as it is and not how it should be can bring joy and a better perspective toward life, even in unfortunate situations. Frankl advocates for the importance of finding meaning in suffering, where meaning could be found in every moment of lived life. "Everything can be taken from a man but one thing; the last of the human freedoms—to choose one's attitude in any given set of circumstances, to choose one's own way" (Frankl, 1992, p. 86). The wellbeing of humans not only depends on the conditions they find themselves in, but the freedom of choice, as in choosing one's attitude in suffering.

Another phenomenon often reported by cancer patients, including in the PATH data, is called post-traumatic growth (PTG), which…

> …describes the positive life changes that develop through a stressful, frightening experience. For some, this growth happens during the cancer experience. Researchers note that post-traumatic growth is not the same as resilience. Resilience describes people returning to their previous levels of functioning. Meanwhile, post-traumatic growth refers to positive personal change. (Cancer.net, 2019)

Examples of PTG are improved relations with others, new life experiences, a greater appreciation of life, a sense of personal strength, and spiritual development (Cancer.net). A quantitative study found that HSCT (hematopoietic stem-cell transplantation) "survivors reported poorer physical, psychological, and social functioning but, conversely, more psychological and interpersonal growth, differences that appeared to persist many years after HSCT" (Andrykowski et al., 2005, p. 599).

PTG is a phenomenon or outcome of going through the hardships associated with lived life with cancer and its treatment. Several of the participants in our study reported PTG, but Jacob is probably the best illustration. Here from sub-study 2:

> I got a new understanding of what really matters in life, what one should care for and to carefully select which wars to fight. Therefore, I would say that I am standing on a different platform or level than before. Something different than I had before, and that is in a positive sense. It has been experiences that have been very valuable, and that have led to a perspective on life that is very good. I enjoy life even more now than before. (Hansen et al., 2019, p. 8)

I therefore argue that cancer as a process has similarities to the underlying structure of rites of passage, which was also Turner´s inspiration for the social drama model. “Standing on a different platform or level than before” in a positive sense is typical for both rites of passage and the model of social drama. Liminality is namely a potentiality for personal growth. Let me revisit my citation of Turner in sub-study 2, where he describes liminality as “a fructile chaos, a fertile nothingness, a storehouse of possibilities, not by any means a random assemblage but a driving after new forms and structure…” (Turner & Turner, 1985, p. 295). Whether we are referring to a rite of passage or a cancer pathway, a liminal phase has the potentiality of bringing about personal transformation. Therefore, my hypothesis is that there may be coherence between the phenomenon of liminality and PTG. I underline that PTG is a phenomenon some people experience, but not all. Others experience continuous liminality, as I have already argued, or just normality. I will explore PTG further and relate the phenomenon more specifically to cancer as well as involving the perspective of “hitting bottom”.

4.8 “Hitting bottom” and personal growth in the context of cancer

The focus on quality of life for cancer survivors is common in the research literature. However, according to Jansen et al. (2011), we are missing an important aspect if we overlook PTG, which is a phenomenon that many cancer patients experience. With their book *Trauma and Transformation: Growing in the Aftermath of Suffering*, Tedeschi et al. (1995) became known for the concept, which until then had been an under-researched phenomenon. In a later article they defined PTG as…

> …the experience of positive change that occurs as a result of the struggle with highly challenging life crises. It is manifested in a variety of ways, including an increased appreciation for life in general, more meaningful interpersonal relationships, an increased sense of personal strength, changed priorities, and a richer existential and spiritual life. Although the term is new, the idea that great good can come from great suffering is ancient. (Tedeschi & Calhoun, 2004, p. 1)

PTG is widely used as an analytical concept in cancer research. It has been employed in several of the academic traditions as well as within different perspectives and various types of cancer (e.g., Cormio et al., 2017; Holtmaat et al., 2017). Gianinazzi et al. (2016) called it cancer’s positive flip side. A study from Korea found that PTG had correlations with social support, resilience, coping, and the importance of religion (Ju Lee & Sook Jun, 2016). This more or less corresponds with a meta-analysis that found that…

> …religious coping and positive reappraisal coping produced the largest effect sizes. Social support, seeking social support coping, spirituality, and optimism were moderately related to posttraumatic growth. Acceptance coping yielded the smallest effect sizes. (Prati & Pietrantoni, 2009)

This is in line with Mattingly (1998) who suggested that "therapeutic plots are secular rituals that help patients make the transition from illness reality to new reality and, even, a new self. This passage occurs along many different dimensions all at once. A healing process involves not only the body but social and cultural shifts as well" (p. 64).

It is interesting to see Prati and Pietrantoni's finding in relation to anthropological theory. In his analysis of alcoholics' mentality, Bateson (1976) explored the phenomenon of "hitting bottom".

> The panic of the alcoholic who has hit bottom is the panic of the man who thought he had control over a vehicle but suddenly finds that the vehicle can run away with him. Suddenly, pressure on what he knows is the brake seems to make the vehicle go faster. It is the panic of discovering that it (the system, self plus vehicle) is bigger than he is. (p. 330)

The epistemology of self-control is bankrupt when a person experiences hitting bottom, Bateson continued. It is a realization of one's self being a part of a larger system and that the self is not in control, i.e., the realization of being part of a whole. "A favorable relationship with this Power is discovered through 'hitting bottom' and 'surrender'" (p. 332), Bateson argued. For instance, drug addicts commonly experience PTG: "A successful recovery from addiction is associated with positive changes, particularly regarding spirituality and meaning-making, and the construct of addiction-related growth may explain why" (Haroosh & Freedman, 2017, p. 1).

"Our life course is changing fast and it is unpredictable," Julie told us in an interview. Cancer patients often have a feeling of loss of control (Wicks & MitchellL, 2010). By drawing on Bateson's somewhat complex ideas of cybernetics, my point is to argue that the feeling of losing control, which often accompanies cancer, leads to the realization that the body and the self are not in charge, but there are other factors contributing to this journey. Some, but not all, people in a crisis may therefore come to realize that we are a part of a larger system.

Jacob described his experience of being diagnosed with cancer as “going down in the darkest basement”, which I interpret as hitting bottom. In addition to a previous accident, the cancer diagnosis was the second time he had felt he was at the border of life and death. He especially emphasized his relationships with family and friends as helping him get up from the dark place where he found himself. After overcoming the obstacles of cancer, Jacob had gained a new and better perspective of being alive in the world. The bonds to his family had grown stronger, and he realized that these relationships represented what really mattered in his life. The emphasis on family relations as the most important aspect of life was a common realization among the participants in the PATH study.

I believe that hitting bottom, such as receiving a message of potential death and severe illness, creates a very strong contrast to the “normal” healthy life. It is a common understanding that one cannot miss something that one already has. When something is taken away from a person, that person learns to appreciate it more. We do not have a reflexive attitude to everyday life and states of health. They are too close, but when there is distance, we can examine these conditions and appreciate them more. This simple, yet significant knowledge may play a role in the generation of PTG.

Furthermore, as a contribution to the understanding of PTG, I suggest that we consider liminality as a precursor. As we have shown above, the liminality phase is a phase of possible transformation and potentiality. It is a process where change is happening before integration into a new phase and identity. I therefore argue that liminality precedes PTG, and by studying liminality we may learn more about how some people’s lives improve following cancer. Understanding how PTG is generated in people after a crisis may provide valuable information for all those involved in recovery in the context of cancer or other severe conditions. For instance, as I discuss below, such knowledge may be of benefit to the “remission society”, those who struggle with late effects and/or feel that life is not back on track after cancer or other illnesses. Linking Bateson’s ideas with existing research on the phenomenon of PTG may reveal a useful connection to PTG.

A central aspect of the liminal phase of social drama, which is often given credit for change and problem solving, is meaningful and effective actions in the form of rituals.

4.9 Rituals in medical landscapes

It is in a phase of transition toward preferred states that pragmatic techniques reach their fullest expression (Turner, 1974).

Rituals come in diverse forms, types, and expressions (Bell, 1997), and scholars in various fields have "turned to ritual as a *window* on the cultural dynamics by which people make and remake their worlds" (Bell, 2009, p. 3). To remake one's world can in this thesis be understood as "rebuilding the person" after cancer treatment. Hargraves and colleagues recognized a change of perspective within medicine from combating disease to rebuilding human life (Hargraves et al., 2018). This makes very much sense regarding rituals in this context, but also with regard to the concepts we have already introduced, such as postmodern experience of illness, PCC, the liminal "remission society" and the dichotomy of cure and healing. Rebuilding human life is a prominent topic in the PATH material, when we ask "what matters to you". The methods of rebuilding come in many different forms, address many different needs and are often ritualized.

In sub-study 2, we argued that rituals could play an important role in the healing process, in particular in the liminal, redressive stage of Turner's model of social drama. I will here elaborate on this idea and also relate it to health seeking actions in sub-study 3. But first, what is a ritual?

This question is not easy to answer and definitions often have limitations. For instance, Victor Turner (Turner, 1967), who is central in sub-study 2 with his model of social drama, defined ritual as "…formal behavior prescribed for occasions not given over to technological routine that have reference to beliefs in mystical beings or powers" (p. 19). Turner's definition makes ritual a religious act, tied to beliefs and non-instrumental actions. This definition probably made sense at the time and in the sociocultural context Turner studied. In my opinion, Turner's definition is too narrow and it limits the analytical use of the concept in today's healthcare context. However, I support his dynamic thinking, which is still highly regarded in methods such as QLR. Turner, inspired by van Gennep's rites of passage theory (Gennep, 1960), represented a step away from social functionalists such as Durkheim (1915), and their understanding of ritual. Van Gennep and Turner emphasized rituals' efficacy and dynamics, but Turner does not only shed light on rituals in terms of social dynamics. Following van Gennep's theory of rites of passage, rituals make people transition from one state to another, e.g., from an unhealthy to a healthy state. In other words, the focus is on what rituals *do* and generation of change at both the individual and social levels (Gennep, 1960; Turner, 1974, 1977). Redressive rituals are similar to rites of passage as they are intended to bring persons or groups from one state to another. I could also have used the concept "rituals of affliction", which is used to approach individual health problems (Turner, 1974). Rituals of affliction are therapeutic in nature and include healing rites performed to restore health and social stability. Since this term is often used to describe spiritual healing rituals in Turner´s work and my understanding is broader, “redressive rituals” is more suitable for this project.

Another discussion is whether a ritual is a non-ordinary action separate from ordinary life or it could also be applied to everyday situations. Døving (2001) interprets the serving of coffee in a household in Norway as ritual. The practice has a special meaning and function - to create social bonds. In addition, the serving of coffee has a special style and structure performed by the “ritual specialists” (in this case the women in the household). Goffman (1956) argues that an everyday, face-to-face action could be understood as a ritual, especially when deference and demeanor are a convention of the interaction. Therefore, everyday actions must be performed in a particular way. The ritual act has deep value and is symbolic communication that conveys meaning. Also in the context of healthcare, researchers find ritual to be a useful analytical term. For example, Mattingly (1998) views occupational therapy as a healing ritual. Davis-Floyd (1992) analyzes the medical procedures of childbirth in an American hospital as a rite of passage. Wright et al. (2016) understand past and current medical practices as rituals and instruments to bestow values, attitudes and meaning on institutions, while ritual is also a useful term to evaluate medical practice such as the patient-caregiver relationship. My view of ritual as a concept is that it could describe an everyday, ordinary action.

For the purpose of this study, I will limit my analysis to redressive rituals. For me, redressive rituals in the context of illness are actions which aim to improve health or cure disease, which could also be expressed as establishing order where there is disorder. This is in line with Turner’s model of social drama and the liminal phase, which is often characterized as chaos and disorder. The function of the redressive actions is to reestablish order. Redressive rituals, therefore, overlap with both rites of passage and healing rituals. I understand ritual as an standardized action that may belong to secular or sacred spheres (Feuchtwang, 2010).

Rituals must be understood in the sociocultural context and situation in which they are performed. An action can be ritualized by giving it particular meaning and significance (Gennep, 1960). The health seeking actions listed in sub-study 3 are participants’ responses to what matters to them in their cancer pathway. They are actions intending to improve health and have a special significance in this particular context. I suggest that ordinary routines can be ritualized, meaning that they could take on a different significance in the context of illness. For instance, going for walks, physical exercise and being in nature are actions rooted in the cultural repertoire of many Norwegians. In the context of cancer, these actions seemed to have acquired a greater significance for the participants. They were associated with building oneself up after being broken down by cancer treatments. The actions therefore became imbued with meaning. Inspired by Durkheim's idea of ritual, going for walks became a metaphorical and literal story the participants told to themselves and others. An everyday action may be a story about reaching a state of health and normality. Taking a walk tells a story about standing on one's feet (versus being down). Step by step one moves forward (versus moving backwards or suffering setbacks). As seen in the quote above, what mattered most for Per was the things he did for himself such as having long walks. Before and after walking were two different states. The Norwegian meaning and style of taking a walk is not an activity to get from A to B. It is an activity for physical improvement and mental clarity, for self-reflection and/or a good conversation if undertaken in company with friends or family. The goal is often to become exhausted, which in this context is a good thing. According to Long (1992), taking a walk or hiking in Norway is like a cleansing ritual. Negativity leaves the body through the sweat and it feels good for body and soul, she argues. Similar to the findings of Appleton et al. (2013), sub-study 3 found that the process to healing often involved a broad range of techniques, and personal strategies and interests. Some activities, such as walking and being at one's cabin, were rooted in Norwegian culture. Ordinary actions became actions for healing, to manage different aspects of illness and to adjust to normality. Frequently in the interviews, such actions were those that mattered most from the participants' perspectives. The health seeking actions in the table in sub-study 3 are all activities to improve health. The table is an expression of how Norwegians, with their particular society and culture, respond to severe, long-term illness. The health seeking actions are often repetitive and standardized, yet they are meaningful actions designed for creating change and even transformation. I interpret these actions as redressive rituals.

Even though some people find themselves in a state of continuous liminality, their actions may still improve their health and well-being. In general, "health improvements are fragile and easily disturbed" (Hildebrandt et al., 2019, p. 222). Repetitions of actions are required to keep physically, psychologically and spiritually healthy. Repetitive actions, which are often typical of rituals, are therefore an inevitable means to gain or maintain health. A meta-ethnographical study of CRC patients' experiences, as presented in the introduction, found "experiences with controlling one's body" to be a pattern in the literature of strengthening constructs (Hildebrandt et al., 2019, p. 222). As we showed in all our sub-studies, maybe particularly in sub-study 3, participants emphasized the benefit of physical activity in the context of cancer. Whether the activity is walking, running, skiing or cycling, it must be undertaken frequently to achieve results. In other words, although participants moved between different medical landscapes, these actions were often repeated in one particular landscape. In my interpretation, activities such as a daily walk or exercising could be seen as a secular ritual, and take on new meaning in context of cancer.

4.9.1 The ritual context

Rituals are often performed in contexts associated with greater risk and uncertainty. Malinowski observed that rituals were not performed when the Trobriand Islanders went fishing in the lagoons close to land. However, when they went to the open sea, rituals were commonly used. Not only was fishing in open sea very dangerous, the catch was by no means guaranteed. In the lagoon, the fishermen were not in danger and they could rely on their knowledge to catch fish. However, in the open sea, they coped with risk and uncertain outcomes by performing rituals (Malinowski, 1954). People living with or beyond cancer often find themselves in "deep water". Their lives may be perceived as uncertain, with fear of recurrence and fear of death. With the potential fatal outcome of the disease and a potentially hazardous treatment regime, cancer is also associated with risks and serious late effects (Linda et al., 2001).

4.9.2 The power of rituals: Change and communitas

When the participants in our study were asked what had been most important to them during their pathways, many highlighted repeated, standard coping strategies associated with rebuilding human life such as going for walks, doing exercises, and being in nature and at their cabin. Some also emphasized reading and painting. When they felt tired, many adjusted their activities and performed those they had the energy to do.

The center of a ritual is the body; the body is of course also the vessel that contains illness, emotions, hope, the self, and more. The point here is that the performance of rituals does something to the body (Stoller, 2013). For Stoller, rituals played a significant role during his cancer pathway. He considered the most powerful aspect of a ritual to be "communitas", which Edith Turner (2012) described as spontaneous collective joy. It takes place between people in a liminal phase, when they find themselves in the same situation. It is an experience where life takes on full meaning and bonds are formed on an almost mystical level. Closely related to this phenomenon is the concept of anti-structure, which is the absence of social structure such as positions and hierarchies and may take place in the middle phase of the ritual process. It is characterized by equality, which may also be expressed by people wearing the same clothes (Turner, 2012; Turner, 1977), often observed in a hospital setting. Stoller argued that…

> …communitas reaffirms the social foundation of the human condition. It reintroduces us to a spiritual dimension of life that lies beyond the domains of organized religion. That's why moments of communitas are so special for anyone, including those of us who have participated in cancer rites. Whenever I have casual encounters with cancer patients, I feel a sense of communitas. (Stoller, 2013, para. 48)

In sub-study 2, I wrote about Eva's experience of the chemotherapy ritual and interpreted this in terms of communitas. Eva told us that the patients receiving chemotherapy together became very close. They joked about what kinds of wigs they were going to buy. One of them suggested calling her husband to ask him to make dinner and then all of them could go and eat together when the food was ready. The bond between patients seems to be a very important strength in the healing process, not only in terms of mutual sharing of knowledge and experience, but also when expressed as collective joy.

4.9.3 Religious and spiritual coping

Religious and spiritual actions are understood as rituals. To cope with illness and other stressful life changes, both medical and psychiatric patients commonly use religion/spiritual beliefs and practices, according to Koenig (2012). Koenig points out that studies of religion/spirituality and health have increased significantly since the 1990s. Based on a systematic review, Koenig summarized hundreds of quantitative research studies examining the relationship between religion/spirituality and health. Twenty-nine focused on religious and spiritual practices in relation to cancer. The 20 most methodically rigorous studies showed an association between religion/spirituality, lower risk, and better outcomes. Koeing's systematic review showed that people who are engaged in religion and spirituality have better mental health and manage their health problems better than those for whom religion and spirituality are less important.

The participants told us about various religious and spiritual rituals, ranging from healing rituals, prayers and the use of religious objects. In sub-study 3, we showed how Mari derived strength from using religious objects such as a wooden cross, an angel, and a prayer cloth. The power of objects is an old topic in anthropology. One example is Mauss' classic from 1925, where he explored the "hau" or spirit of objects given as gifts (Mauss, 2002). A more recent theorist, Gell (1998), suggested that objects may have agency, meaning that they influence people's thoughts and actions. Gell used Mark Rothko's paintings as an example, because they are known for affecting the observer's emotions, which was his intention with his art.

Mari's case suggests that objects may be used as cognitive or emotional tools in the context of crisis. I suggest that Mari's case can teach us something about how people may navigate in medical landscapes. Mari said that she did not care what other people thought about her perception of the effect of the objects; what really mattered was that she felt good and stronger when holding them in her hand. She did not need any scientific or logical assessment of the effect, because she held the truth, her truth. Movement within medical landscapes is sometimes based on scientifically informed choices, but often choices are a matter of epistemological individualism. Mari knew from her own experience how the objects made her feel. She acknowledged how they gave her meaning and affected her being in the world in a positive way. It was especially in situations of uncertainty that she held them in her hand, such as before an appointment at the hospital, which also corresponds to Malinowski's theory of ritual magic. Furthermore, inspired by Frankl (1992), the use of objects in times of suffering could be an example of a strategy to find meaning in affliction.

4.10 Therapeutic landscapes: Everyday and extraordinary places of healing

Being in nature as a healing practice fits the concept of therapeutic landscapes, which must not be confused with medical landscapes in this thesis. Therapeutic landscapes are understood in a more literal way as the contribution of one's environment to well-being and/or healing (Gesler, 1992; Williams, 2007). In view of the participants´ emphasis on being in nature, we could say that in Norway therapeutic landscapes exist within the geography of medical landscapes. English et al. (2008) explored the significance of everyday and extraordinary places in breast cancer patients' trajectories to healing. Various landscapes were found to be important for their participants' health and healing. "The body, being the smallest and most personal landscape, represents the embodiment of illness for women living with breast cancer. In other words, the body is both an everyday site of illness but also an everyday landscape of healing" (p. 76). However, the women's bodies and fear of recurrence made the body into a site with extraordinary characteristics, and their daily coping strategies to regain health could be understood as attempts to restore the everyday characteristics of the body. The notion of English et al. is interesting to review in light of my argument above. When a person embarks on a journey into the land of the sick, he or she will probably perform certain kinds of actions to move back to a normal life in the kingdom of the well. This is also our argument when applying the model of social drama. Hope for normality and resolution motivate people´s actions and drive the process. Inspired by Turner, we have argued that ritual actions in a pathway are performed in order to exit the liminal stage and regain health. The argument of English et al. concerning the extraordinary and everyday characteristics of the body is also in line with Hirch's background and foreground; these dimensions or poles generate dynamics. This is how I understand landscapes as a process, or in this text, illness as a dynamic process. In the context of illness, the desired ideal is everyday "normal" life. Continuing with the exploration of healing places of English et al., the authors argued that the home is an everyday site of healing and is also where people spend most time; it is a place with minimal exposure, an individual space of comfort, and a place to get support from one's family. I would add that home is not always a safe place or a place with a supportive family, but in many cases it may be a healing place. Natural sites are also important healing places, they argue, both everyday sites like a walk in the forest and extraordinary sites such as cottages and holiday destinations. Such extraordinary landscapes were important to our participants. Being in nature and going to the cabin to escape from urban life mattered, but traveling was also emphasized as important in their healing process. For Julie, a trip with her family was the most important event during one of the periods when we interviewed her. English et al. demonstrated the connection between places and feelings, such as feeling better at a certain place. They argued that "the emotional geographies embedded within places are integral in the creation and maintenance of therapeutic landscapes among breast cancer survivors. In this way, physical landscapes of healing become emotional spaces of healing" (English et al., 2008, p. 76). This recalls the Norwegian bodybuilder and cancer patient who felt that hospital was a "paradise" because of its association with healing caused by the staff there (Brandvol & Solstad, 2017).

We have argued in sub-study 2 that many of the participants' activities in the liminal phase were kinds of ritual. Being at the cabin and in nature were frequently emphasized as activities that mattered to the participants. Being in the outdoors, in a Norwegian cultural context, is associated with inner peace and is a suitable place for contemplation (Eriksen, 1996). An equivalent to Norwegians' relationship to nature in the context of illness can be found in Japan where forest bathing, or shinrin-yoku, is a popular health seeking action. In Japanese, the term means bathing in the atmosphere of the forest. In practice, shirin-yoku involves stimulating the senses through mindful in nature, listening to sounds such as birds twittering and water gurgling, smelling the scent of the trees, and feeling the textures one encounters.

There has been an increasing interest in the therapeutic effect of the forest amongst researchers and people in general. Shinrin-yoku has shown promising results for stress relief and relaxation, but more research is needed (Hansen et al., 2017; Tsunetsugu et al., 2010).

Therapeutic landscapes provide us with another concept to understand health seeking actions in a context of severe illness. I have introduced several concepts and themes that matter to patients with cancer. All are relevant for creating an understanding of patient pathways. Liminality, medical landscapes, medical pluralism, rituals, model of social drama, PTG (post traumatic growth), rituals and therapeutic landscapes are all concepts that fit within the framework of the model of social drama.

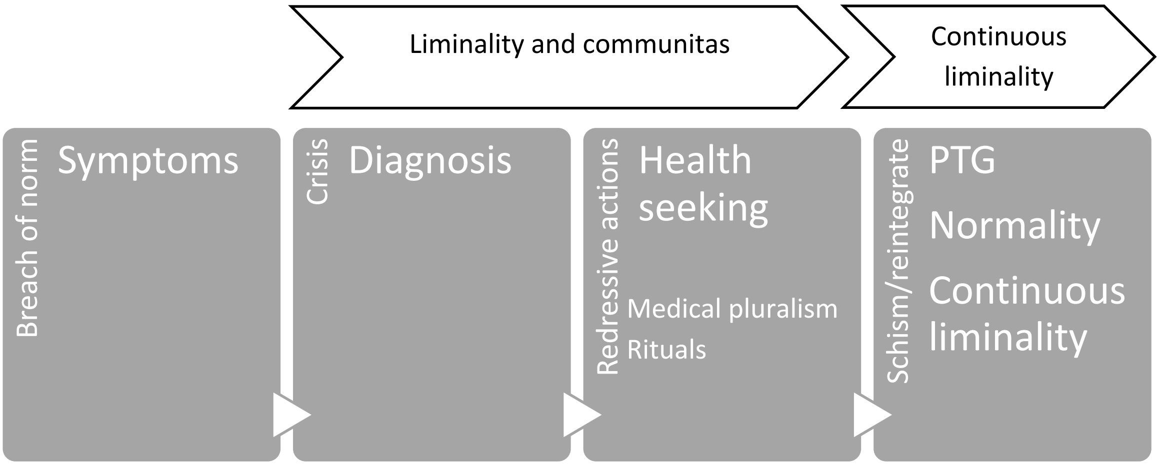

FIGURE 2: CANCER AS A DYNAMIC PROCESS ANALYZED WITH VICTOR TURNER´S MODEL OF SOCIAL DRAMA. TO THE LEFT (VERTCAL) IN EACH BOX IS TURNER´S PHASE. HORIZONTAL IN EACH BOX SHOW MY INTERPRATION OF TURNER´S PHASE IN CONTEXT OF A CANCER PATHWAY. THE MODEL IS MODIFIED BY ADDING "CONTINUOUS LIMINALITY" TO SHOW THAT SOME CANCER SURVIVORS LIVE IN A LIMINAL STATE POTENTIALLY FOR THE REST OF THEIR LIVES.

The stories began with the participants, their peers or medical doctors recognizing symptoms. These were usually not associated with cancer by the participants. They then had an examination which resulted in a cancer diagnosis. This was often a shocking experience, giving a feeling of being "outside of the world". They entered a state of liminality, where they had left the kingdom of the well and were trying to re-integrate to a healthy state. This stage began with the participants having biological goals by removing the tumor. Later they try to rebuild their life. In other words, the first phase is seeking cure of the disease following diagnosis. The later phase is seeking healing of the illness and suffering, after biomedical treatment and late effects. The redressive phase is often characterized by medical pluralism and rituals. A special bond to peers and other patients, here interpreted as communitas, can also be observed. Some feel neither ill nor well for a long time, potentially for the rest of their lives. By contrast, others experience PTG with a new and greater perspective on life itself and an emphasis on what really matters in life such as family, but also other goals that they associate with a good life. Others reported that life was their normal healthy state, with neither PTG nor continuous liminality. The stages, inspired by Turner´s model of social drama, are therefore: 1) Breach of norm (symptoms), 2) Crisis (diagnosis), 3) Redressive actions (health seeking actions) and 4) Schism/reintegration (continuous liminality, normality, PTG).

4.11 Implications for practice and future research

"The physician must generalize the disease, and individualize the patient." German physician Christoph Wilheim Hufeland (1762–1836) (Taylor, 2010, p. 48).

Hufeland´s quote fits well with the model of social drama presented in sub-study 2 and Delmar´s (2010) notion of the doubleness of the situation. A cancer pathway is both unique and typical at the same time. Within the underlying structure of the model of social drama, there is an individual unique human life. While the disease and treatment may be generalizable, the human being containing the disease must be individualized according to the person's goals and life situation.

> Profound understanding of individual experiences of health and well-being is a crucial prerequisite for health professionals to sufficiently be able to support human health and well-being in a numerous of care and support contexts in our society. (Jormfeldt 2019, p. 1)

According to Jormfeldt, understanding of individual experiences and meanings of health and illness is one of the important contributions of qualitative studies. In sub-study 1, I showed that it was important for the participants that they were understood as unique persons. Healthcare could be better at seeing the person behind the diagnosis, as Jacob said. Mari was an example of a success story. She said that her doctor "was more than a surgeon", meaning that the surgeon managed to generalize disease and individualize the patient. What I called "person-centered pathways" in sub-study 1 was an attempt to create a concept that captured the clinical pathway and the individual story. Both are important and are intertwined. The person-centered pathway was a suggestion to include the temporal aspect in the principles of PCC. PCC in itself may appear to be static, but illness is dynamic and what matters to patients changes. The model of social drama, as presented in sub-study 2, captures both biomedical and biographical aspects of being unhealthy and may function as a model for person-centered pathways. Berntsen and colleagues argue that there is a need to re-design care systems towards PCC (Berntsen G & Yaron S, 2022). The QLR approach…

> …is increasingly used to evaluate health, social care and welfare interventions. Since the approach is flexible and grounded in real time developments, the longitudinal frame gives space to develop productive collaborations with policy and/or practice partners and with participants themselves (Neal, 2019, p. 123).

This thesis contributes models and theories based on patients´ perspectives, as well as empirical descriptions of what matters to them over time. The thesis could provide knowledge and inspiration for re-designing and collaboration at the system level in the direction of PCC.

Trails are made when many people walk the same path. The standard pathway in conventional healthcare represents such a route. Many patients have entered this landscape with the hope of surviving cancer. My interpretation of Kolbein Falkeid's poem in the section above is that since many people have walked before us, they have created a path that shows the way to the destination. Further, the people who went before us have trodden down the vegetation to make it easier to walk along the path. In other words, since we know the way and since the journey is easier, the odds of reaching the goal are better. The participants in this study are no exception and because of them we gain insights into what mattered to them during a cancer pathway. It is important to note that the participants' intentions behind sharing their stories in this project were to improve future healthcare and the lives of future patients. Mari emphasized that her experience and knowledge could perhaps support other patients who were feeling down. A focus on strengthening people could be relevant in every phase of the illness process, but I particularly saw the relevance and need in the post-cancer phase, when many suffered from the side effects of biomedical cancer treatments and a lower quality of life. Some of the participants felt alone following cancer treatment and did not receive the help they felt they needed from public healthcare or privately. For instance, Per found it difficult to get help with his stoma and Ken had problems in getting a professional diet plan. These needs mattered a great deal for the participants. Per's stoma problem was very frustrating as it leaked, making him insecure and sometimes embarrassed in social settings.

Ken loved to fish, but could not go fishing due to stomach pain and diarrhea. As Berntsen and colleagues suggested, care for patients should be centered on patients' life goals or "what matters", because health issues may obstruct the path to achieve a person's goals in life (Berntsen et al., 2018). Per's and Ken's cases illustrate areas where health issues block the way for doing what matters and how this in reality affects lived experience. Quality of life following cancer is currently of high priority for the Norwegian health authorities (Helse og omsorgsdepartementet, 2018).

As already stated, more and more people now survive cancer, which means an increase in the numbers of people who are neither ill nor well and are struggling with late effects in continuous liminality. I related this to the model of social drama. In addition, I found that medical pluralism was most prominent in the post-operative period, and one hypothesis may be the lack of available paths in conventional healthcare in this phase or the experience of not receiving needed help.

However, a central question to ask is whether or not the conventional healthcare system should be used for all health related problems. How active should conventional healthcare be in the phase of continuous liminality? This will depend on the person and the need, which underlines the importance of shared decision making, understanding the individual and asking, "What matters to you?". Many needs are better met in other medical landscapes than conventional healthcare. Mari felt that the priest was more useful than the psychologist for certain needs during her pathway. Spiritual and religious coping has several health benefits in the context of severe illness (Koenig, 2012), and the alternative and religious landscapes may be a better choice for some people to meet some of their needs, especially existential needs, in their particular situation. I also found that people solved many of their challenges and created a better life for themselves by drawing on their cultural repertoires. Taking walks, being at their cabin, being in nature, and exercising are examples of activities associated with health in Norway, and they became particularly meaningful in the participants' struggle with late effects. I assume that the alternative ways sought by participants following cancer are both because of the lack of options in conventional healthcare and because the needs could best be solved in other medical landscapes. At the same time, as Per and Ken's cases showed, I believe that patients may benefit from a greater focus on the post-cancer period and continuous liminality in conventional healthcare. From a patient perspective, the pathway may not be over even if they are diagnosed as fit by conventional healthcare. They may experience suffering in between states, and I hope this thesis will create greater awareness of this phenomenon.

Continuous liminality shows that a pathway may extend beyond the clinical pathway. However, the lived experience of this extended pathway may not only be longer, but also broader than the clinical one. This implies that lived experience of cancer has many dimensions. The series of contacts with conventional healthcare is but one dimension of people´s trajectories to healing. Exploration of the breadth or depth of pathways from a patient perspective is one of the advantages of a qualitative longitudinal study such as this. In Paper 1, we found that biomedical treatment mattered to the patients in the beginning of the pathway in order to meet biological goals. Later, medical pluralism became more prominent. In Paper 3, we categorized this pluralism into five categories: Conventional, religious coping, traditional medicine, self-care, and CAM. For the participants, coping strategies both within and outside conventional healthcare were important during their trajectories to healing. Furthermore, in Paper 1 we found that each pathway was dynamic and unique. Some participants explicitly stated that conventional healthcare workers should be more concerned about the person behind the diagnosis. Referring again to the German physician Christoph Wilheim Hufeland, who stated, "The physician must generalize the disease, and individualize the patient", there is a duality between standardized and individualized care. The terms standardized and individualized may seem to represent a contradiction. In view of Hufeland's words, maybe these complementary concepts could be viewed as the yin and yang of treatment?

Mari was highly impressed by the person-centered care she received from a particular physician at the hospital. "She was more than a surgeon," Mari said, emphasizing how the surgeon showed empathy and took time to understand Mari's life situation as a whole. Mari's satisfaction was due to the surgeon's ability to be "more than a surgeon", i.e., not only providing evidence-based biomedical treatment, but also understanding Mari as a person in a clinical context. Cancer is manifested in a human body and the illness is thus entangled in a complex web of relationships and events not specifically related to cancer.

I suggested in Paper 1 that "person-centered pathways" could be a useful term to integrate the biomedical and biographical aspects of a pathway. As Hufeland pointed out, both the disease in general and the particular individuality of the patient matter. This clearly calls for the integration of both aspects in the understanding of a pathway. Salamonsen and colleagues found that patients in Norwegian conventional healthcare experienced that the focus was on standard cancer care and they therefore had unmet emotional and practical needs, which supports Frank’s (2013) concern about modernist medicine discussed above. I view “being more than a surgeon” as a postmodern ideal in conventional healthcare, and person-centered pathways aim to integrate the individual and the general in a single concept. A greater focus on the person may help to meet the practical and emotional needs of people with long-term, severe conditions.

The National Cancer Strategy in Norway 2013-2017 aimed for increased PCC, and this goal was continued in the Cancer Strategy 2018-2022 (Helse og omsorgsdepartementet, 2018; Norwegian Ministry of Health and Care Services, 2013). This is also in line with Norwegian health authorities’ assertion that PCC is important, particularly in long-term complex pathways (Helse og omsorgsdepartementet, 2017). Here, the health authorities explicitly state that care should include patients’ perspectives, voices, and needs. We may add that conventional healthcare should always ask what matters to patients at any given time. Since the number of cancer survivors is increasing in Norway, the new cancer strategy focuses particularly on lived experience with cancer and those who struggle following cancer treatment. For instance, closer attention to patients’ needs and psychosocial care are among interventions intended to improve quality of life for these patients (Helse og omsorgsdepartementet, 2018). The Minister of Health, Bent Høie, acknowledged that there is pressure in conventional healthcare and digital tools are planned that will provide more individualized care, and be used for shared decision making (Bordvik, 2018). The current National Cancer Strategy in Norway is within the scope of the PATH project. Papers 2 and 3 focused strongly on the post-cancer period and patients´ accounts of trajectories to healing in this phase. I explored topics such as pathways from patients’ perspectives, the processes they go through, the needs they have and how they cope, what they emphasize as important and how people navigate in medical landscapes. I therefore consider that this knowledge will be of interest to health policy makers as well as clinicians in conventional healthcare.

People’s journeys in conventional healthcare are only one of many paths in lived life with cancer. A clinical pathway or care pathway has a specific goal and a predefined path to its destination. It might be preferable to view lived experience with cancer as an open landscape. The people involved may have many goals, choose many paths and directions, but may not have any clear destinations. “Life goes on”, as one of our participants said. Being flexible, maneuvering in multiple medical landscapes, and being able to choose various paths are important factors during this journey, according to the participants. I think it is important to understand that having cancer, based on lived experience, is not a cancer journey per se, but more or less a dramatic *part* of one's ongoing life journey. Cancer is an episode amongst many others taking place simultaneously, but is also attached to a past and a future.

The Cancer Strategy's increased focus on survivors' quality of life is in line with the understanding of cancer as part of an individual, dynamic life. This is especially important as the strategy emphasizes that a pathway is not over when the tumor is treated, and for some this implies a wide range of healthcare needs. If these are not systematically addressed in conventional healthcare, because technically the patient is well, this may make the patient feel all alone with complex needs.

I argue that the most important contribution of this project is in the spirit of Arthur Frank and his notion of the postmodern experience of illness (Frank, 2013). Patients' voices are important in the design of future healthcare, but as Frank noted, the voices are still whispering. "If we can view the health care experience through the patient's eyes, we will become more responsive to patients' needs and, thereby, better clinicians" (Barry & Edgman-Levitan, 2012). To the best of my knowledge, there is a lack of models that explain people's journeys within and outside conventional healthcare, which are empirically based on patients' perspectives and what matters to them over time. The ideological perspective is that patients' experiences are an invaluable resource for the shaping of care, because they are the only ones experiencing unhealth and care, and who are present in their pathway at all times.

The findings may also contribute to discussions and practice in the field of health and illness studies. For example, Kvåle et al. (2020) have used our sub-study 2 and the suggested new way of thinking pathways in their work on patient-doctor communication:

> This model emphasizes people´s perspectives, values, needs, and experiences contextualized in an illness process. The model pay close attention to people´s journey and how these may dynamically change over time. By taking biographical and clinical aspects of people´s journeys into account, this model could be an alternative to clinical pathway models (p. 1).

When the theories are applied to other studies, it builds knowledge and establishes new ways of thinking about patient pathways.

One of the patterns in the data was that the participants emphasized being in nature in different contexts such as going for walks, being at their cabin and picking berries. These are low-threshold activities that mattered to the participants in coping with mental, physical and existential stress during life with cancer. Outdoor activities may be beneficial to offer cancer patients in Norway, where this is culturally understood and experienced as a form of healing. The participants´ positive experiences of being in nature may also provide inspiration for further exploration of this topic in qualitative and quantitative research.

The findings also suggest that the focus on rituals should be better acknowledged as an effective, meaningful and repetitive form of action. This may include both secular and sacred rituals. Some of the participants found meaning in activities such as prayers, healing rituals and keeping religious objects. Others found meaning in a daily walk, creating art and frequent exercise. All are repetitive actions aimed to create a certain order. What we interpret as ritual actions was important in the healing process, according to the participants themselves. Repetitive meaningful actions may create order when the world is chaotic, as the participants felt when they received the cancer diagnosis and went into a liminal state. This knowledge may be useful for patients, families and all those who work with patients in a phase of rebuilding the person living with and beyond cancer.

Our use of Turner´s model of social drama would be interesting to apply to other cultural contexts or to immigrants in Norway. What is their experience of being diagnosed with cancer? What matters to them in such a situation? How do they maneuver in the medical landscapes to get well? Will the model fit in other cultural environments? The use of the social drama model and the findings in our study enable comparison in future research. It would also be interesting to discuss, develop and implement person-centered pathways and the model of social drama in a framework to enhance practice.

5 Methodological considerations

5.1 A multidisciplinary project

The PATH project has been a multidisciplinary collaborative effort. I was the first author in the three articles and I am an anthropologist. While most of the theoretical perspectives in this thesis belong to the anthropological tradition, the multidisciplinary aspect should also be emphasized as it has influenced the final product. This thesis is naturally colored by anthropological and social sciences, but I consider it as a qualitative health science project and not an anthropological study. A typical anthropological study would have fieldwork as its main method and the PATH project was designed as a multidisciplinary project. I did not design the project nor conduct the interviews but worked on the transcribed written material. The interviews were discussed and viewed from different perspectives by the team of a medical doctor, a sociologist and an anthropologist. The theme of the discussions was often the anthropological perspectives of the material and its usefulness in a healthcare context. Using my anthropological background in addition to perspectives from other fields was useful to view the data through a new lens and use a variety of resources to answer the research question.

5.2 Strength and weaknesses of qualitative research

A qualitative approach provides in-depth information of life in a particular socio-cultural context (Mwita, 2022). It is useful for exploring research questions where the researcher needs to come close to lived human life, tell people´s stories and learn about particular phenomena from their perspectives and experiences (Frank, 2010; Van Manen, 2016; Weiss, 1994). I will elaborate later on my experience of working on transcripts and my reflections on qualitative interviews. In this project, where the aim was to learn about trajectories to healing from patients´ perspectives, the qualitative approach provided us with data about what mattered to them, and their stories and experiences in the context of having a CRC diagnosis and treatment.

Weaknesses of qualitative studies are the researcher´s bias and subjectivity, limited generalizability, replication of findings, while data analysis is complex and time consuming (Mwita, 2022). I will elaborate on these topics later.

Other choices of theoretical lenses and types of participants might have yielded other types of insights, which might have been equally valid. We have not studied how professionals or care systems might use or not use PCC. Our proposition is that we are exploring a phenomenon about which we believe healthcare needs more knowledge based on people´s own perspectives. The perspective of healthcare is not gleaned from our data, but from secondary sources. This may be a weakness, but at the same time, the participants were chosen to fit the research problem and to describe their trajectories to healing in depth.

5.3 Impression management

According to Goffman (1969), impression management is controlling which impressions the actor gives the audience. Impression management is relevant "…when an individual appears in the presence of others, there will usually be some reason for him to mobilize his activity so that it will convey an impression to others which it is in his interests to convey" (p. 3). Berreman put it this way:

> Impression management is a feature of all social interaction. It is apparently a necessary condition for continued social interaction. An understanding of its nature and of the resultant performances is essential to competent ethnography. Methodological procedures must be employed which will reveal not only the performance staged for the observer, but the nature of the efforts which go into producing it and the backstage situation it conceals. (Berreman, 1962, p. 24)

In his fieldwork in a village in Northern India, Berreman experienced that his switch from a high caste Brahmin (Hindu) to a Muslim (low in the hierarchical system) assistant, changed how people interacted with him and which kind of information he received. Not only did the position of the anthropologist change, but the actors in the social system had good reasons for deciding which information they shared and which information they kept backstage. The participants or informants are the portal into other people's worlds. Interaction with them, including the aspect of impression management, is key to how our data will appear and is therefore an important methodological reflection in qualitative studies.

Whether the researcher uses interviews or has interactions with people in a fieldwork study, methodological reflections on the reliability of participants' words are important. People's words are the background for the researchers' analyses and conclusions. We should be aware that the interview situation may foster a performance where the participants may over-communicate some aspects and under-communicate others (Goffman, 1969, p. 87). Participants may have an idea of what the researcher expects them to say and overemphasize those aspects. On several occasions during the PATH interviews, participants stated "there is nothing to tell" and thereby under-communicated the small everyday aspects of life with cancer that actually could have been interesting. They may have had an expectation to give the researcher a particular kind of story. In such situations, the interviewer re-defined the situation by informing them of his expectations of what should be communicated.

We may assume that the data (like all social interactions) are colored by impression management. Cancer and stigma is a well-known challenge. However, stigmatization of cancer is changing, but it is still a relevant problem (Ahmad et al., 2018; Knapp et al., 2014; Oystacher et al., 2018). This could clearly affect a person's impression management. There may be some intimate details and stories that the participants for some reason chose to keep backstage. Here I would like to emphasize that the participants had every right to do so. However, I believe that the interviews were successful in capturing a rich picture of lived experience with cancer and I feel that the interviewers managed to gain backstage information from the participants. We received information about unsatisfactory sexual life such as impotence and the embarrassment of having intercourse with a stoma. We were told about tragedies in families, conflicts with doctors, public stoma bag leakage, and in general very private information that is not normally told to everybody.

The reason may be the longitudinal approach and the trust that may therefore develop. Another reason may be relational. Impression management is related to statuses, here understood in an anthropological way as an aspect of one person in relation to another, and not as rank. Due to different statuses, the actor plays different "social roles" defined "as the enactment of rights and duties attached to a given status" (Goffman, 1969, p. 9), and each society may have different expectations of how these statuses and roles are performed in the presence of the "audience". It is about "the presentation of self in everyday life", which is the title of Goffman's book (Goffman, 1969).

> Let us now turn from the others to the point of view of the individual who presents himself before them. He may wish them to think highly of him, or to think that he thinks highly of them, or to perceive how in fact he feels toward them, or to obtain no clear-cut impression; he may wish to ensure sufficient harmony so that the interaction can be sustained, or to defraud, get rid of, confuse, mislead, antagonize, or insult them. Regardless of the particular objective which the individual has in mind and of his motive for having this objective, it will be in his interests to control the conduct of the others, especially their responsive treatment of him. This control is achieved largely by influencing the definition of the situation which the others come to formulate, and he can influence this definition by expressing himself in such a way as to give them the kind of impression that will lead them to act voluntarily in accordance with his own plan. Thus, when an individual appears in the presence of others, there will usually be some reason for him to mobilize his activity so that it will convey an impression to others which it is in his interests to convey. (pp. 2-3)

Participants in the PATH project explicitly stated that they participated because they wanted to improve the lives of future patients in the context of cancer. After studying the interviews, I am convinced that the participants’ interest was to share information, not to withhold it. The success of one’s role as an interviewer depends on the interaction with the participant in a way that conveys trust and a safe environment, which can then result in an in-depth exploration of lived experience with severe illness.

5.4 The interviewer-participant relationship

The statuses of the participant and interviewer are more or less “neutral”. The interviewer is bound by professional confidentiality and privacy regulations and the relationship is not of a private nature. There is “nothing” to hide, so to speak. “I have told you things that nobody else knows,” one of the participants said. In fact, some used the interviews as a way to “release” all their deepest concerns. Even when going to the doctor, as a patient you may hold back information as the doctor has the power to act contrary to the patient’s wishes. That relationship is of a different kind. In interaction between mother and daughter or son, the mother may have reason to keep some aspects of her illness backstage and play the role of a strong and caring mother instead. Several of the participants explicitly stated that it had been challenging not to succeed in playing previous roles such as mother, father, wife, or husband, in the way that they wished and that their family expected of them. The interviewers were there just to listen to their accounts of how life with cancer had been and to learn. Whatever they had told us, it would not affect our relationship. After twelve months, we asked Elias what had been most important to him during the last year. “It has to be talking with you,” he answered. In my interpretation, this statement articulated an interview process where both interviewer and participant benefitted from the communication, resulting in an equitable process of give and take. This also suggests that the interviews may to some extent have been experienced as therapeutic by the participants.

5.5 Qualitative longitudinal research

The QLR approach and the material generated through this method have played a central role in this thesis. I will now give some examples of the benefits of QLR in the three papers, followed by some general benefits and implications of the methodology.

One of the biggest advantages of QLR is its ability to grasp change and dynamics in socio-cultural contexts (Neal, 2019). In the first paper, my co-authors and I analyzed what mattered most to the participants. One of the findings was that what mattered for the participants changed over time. In the second paper, we analyzed trajectories to healing through Victor Turner’s model of social drama. In this article, the data generated by the QLR method were essential for the analysis of the paths as dynamic processes. In comparison, the longitudinal, dynamic approach of Arnold van Gennep (1960), “enabled him to develop insights into life course transitions that were in tune with local meanings and mechanisms of change” (Neal 2019, p. 8). The analysis of patients´ accounts of trajectories to healing in the second paper is in line with the tradition of QLR and a dynamic perspective of social life. In the third paper, we wrote about medical pluralism following cancer. The temporal aspect was crucial for analyzing which health seeking actions were taken and when they were taken. In this article we presented Julie’s case chronologically and the timeline showed us how Julie’s aims, challenges, and health seeking actions changed over time from biological goals in the beginning to more medical pluralism in the later phases.

An important aspect of QLR is that it is time consuming, both for researcher and participants. This also means that a QLR project may be costly. In our project with ill participants and long distances, traveling could have represented an additional burden. We solved this by conducting telephone interviews. The analysis of the data took a long time, and required a more systematic approach than other projects as the data were extensive and had a temporal aspect. A relevant question in this context is therefore whether QLR is worth the extra effort. In a qualitative study of patients´ pathways, I think the method is invaluable. We gained knowledge of how choices, what mattered, actions and ideas changed over time. QLR gave us data to understand processes, dynamics and stories that unfolded. We came close to human life and the method reduces the risk of recall bias. We developed trusting relationships with the participants over time, which may have given us backstage information. A further relevant question is the length of a QLR study. When should we stop? This question has implications for the method, which is based on the notion of an ever-changing life in an impermanent context. An extension of our study would provide us with new findings. QLR “…alerts us to an ever-changing kaleidoscope of lives ‘in the making’, perpetually unfolding through a complex and unpredictable web of events and influences” (Neal, 2019, p. 123). The temporal aspect of QLR has implications for generalization, saturation and definitive conclusions. Research in a changing world also makes replicability of studies problematic. Even though the world and people’s lives are constantly in flux and flow, I still argue that analysis of the complex web of events may result in more or less universal theories. For example, Turner´s (1974) model of social drama and Goffman´s (1969) impression management have proven to have relevance even today. It would have been interesting to follow up the participants with further interviews in our study, which could have provided us with more data on continuous liminality, PTG and the last phase of the model of social drama. However, the participants had already given us a considerable amount of their time and energy during a difficult time of their life. It was a question of ethics as well as resources. As a conclusion, I am convinced that the QLR approach was suitable for the research question.

5.6 Telephone interviews

In-depth interviews are often expected to be face-to-face interviews, but for some projects it may be beneficial to conduct some or all interviews by telephone for various reasons. In PATH, the baseline interviews were conducted face-to-face, while most other interviews were conducted by phone. The reason for this choice was to balance the strengths and weaknesses of the telephone interview against the feasibility of face-to-face interviews with participants in Troms, Nordland and Finnmark, a region with vast distances and sometimes transport and communications difficulties. Several of those who could have been interviewed would need accommodation in addition to traveling to Tromsø for the interview. Some would need flights. The project budget did not cover travel and accommodation five times for each participant. It would also place a huge burden on the participants who were living with cancer, with the associated risk of drop-out. We also did not have the capacity to travel to the patients' homes for all the planned interviews. Furthermore, we reasoned that there are indications that one can achieve just as good and possible even better contact in a telephone interview, especially since we started the data collection with a face-to-face interview and also worked with diaries. Participants who lived in Tromsø could choose whether to meet us face-to-face or be interviewed by phone.

According to Tjora (2013), we lose central aspects of the conversation such as body language by conducting interviews by telephone. Skilbrei (2019) similarly argues that telephone interviews can represent challenges in the contact between participant and researcher. However, Tjora (2013) adds that telephone interviews can also have their benefits. If sensitive topics are discussed, it may feel safer for participants to express themselves on the phone than face to face, perhaps especially with regard to privacy. In fact, studies have shown that telephone interviews may be an effective method for disclosing information of sensitive topics (Pridemore et al., 2005; Reddy, 2006).

In the PATH project, pragmatic choices had to be made to make the study feasible within the constraints of the resources available. The researchers found they achieved a close connection and good communication with the participants during the phone interviews. Finally, I feel that the answer to whether this was an acceptable way of collecting data lies in the depth of the material, the “backstage” information and the topics revealed, in addition to the strength of the relationships that some participants developed with the researchers.

5.7 Analyzing transcripts

In this context, it is important to emphasize that my co-authors and supervisors conducted interviews, while I analyzed the interview data in the form of transcripts and was not involved in the interviewing myself. The data were already collected when I started as a PhD student. This was a different situation from previous projects where I had conducted long-term fieldwork. When I read the PATH interviews, I was surprised at how well the participants’ characters came across through their words. I felt that the textual data were very close to human life and full of insight into these people’s lives. Transcripts have a distinct oral style which drew me into the stories. The length and complexity of the interviews varied considerably. Sometimes there was not much to tell, while other participants had complex pathways with dramatic life and health events, and had a great deal to share. As pointed out in the section on telephone interviews, studying transcripts will lack the face-to-face interaction that can be valuable. Analyzing transcripts at a distance enabled me to focus on what the participants had to say, and I could go back and forth to delve deeper into their accounts. Transcripts were also ideal when analyzing the data in NVivo as well as when studying the text in a team. The fact that I never met any of the participants may have been both a strength and weakness. It may have enabled me to be more open and less prejudiced in my reading of the material. From a pragmatic point of view, studying transcripts rather than conducting interviews gave me more time in a tight PhD project to spend on analysis and writing. However, I might have missed valuable knowledge conveyed through body language and tone of voice. It may also be more difficult to gain ownership of the material without participating in the interview process.

5.8 Credibility of research: Validity, reliability and transferability

According to Noble and Smith (2015), “evaluating the quality of research is essential if findings are to be utilized in practice and incorporated into care delivery” (p. 34). In this section I will demonstrate efforts in the PATH project to establish research credibility. The QLR method, as I have described above, is ideal to learn about cancer pathways from a patient perspective. In our study, QLR was able to capture what mattered to the participants over time. Forty-six interviews were conducted by a physician, sociologist and a trained research assistant. By meeting the participants quarterly for one year, we established a trusting relationship with them, which may have positively influenced the kind of information we received. We were given intimate details, “backstage” information and overall very rich data on life with cancer. In the epistemology section, I cited Jormfeldt (2019) who wrote that “qualitative studies give emphasis to the perspective of individuals and their experiences, meanings, situations and actions through the eyes of those who are familiar with these experiences” (p.1). Our data reflect this aim of qualitative research.

Since I had no previous experience with cancer, neither professionally nor personally, I could interpret the data with a lesser degree of pre-understanding. At the same time, my supervisors were experienced cancer researchers and valuable contributors to discussions of my ideas. My background as an anthropologist shaped the way I interpreted the meaning of the data. As this project was in my own culture, one implication, if we follow Bourdieu (1984), is that culture may be unreflexive. We may become blind to our own values and practices. This is an argument for why anthropologists have researched exotic cultures. That said, my encounter with the data was like entering an exotic, unknown world.

If this study had been based on fieldwork, it would have been less replicable than an interview study. By asking the same questions and following the same design, one can replicate the PATH study to a degree. People´s stories will of course be unique, but the underlying patterns and meanings could be found by other researchers. One of the advantages of using models in qualitative research, such as our use of the model of social drama, is the transferability of the model to other contexts or studies. Our modified version of the model of social drama may be applied to other projects for comparison or theoretical development. The drama of the pathways may have the same underlying structure, but I would expect cultural differences, particularly with regard to redressive actions, if applied to patients from other cultures.

When we read the interviews, similar comments and types of stories unfolded repeatedly. At a certain point, no new categories emerged from the material and I was confident that we had reached saturation in this study (Saunders et al., 2018).

6 Ethical considerations

6.1 Procedures and approvals

The PATH project was approved by the Regional Committee for Medical and Health Research Ethics (REK) and by the Norwegian Data Protection Authority. The study was conducted according to the Declaration of Helsinki (World Medical Association, 2000). All participants were sent letters of invitation. They also received ethical information such as that participation was voluntary and that they could withdraw from the study at any time. All participants signed informed consent forms. In addition, they received general information about the project, such as the procedures and aims of the study.

6.2 Qualitative interviews of vulnerable groups

Cancer patients are a vulnerable group. There are thus ethical considerations regarding qualitative interviews. McIlfatrick et al. (2006) suggested an ethical framework consisting of three principles: Non-maleficence, respect for human dignity, and justice. Non-maleficence refers to the principle of not harming the participant in any way. This naturally includes both physical and psychological harm. Respect for human dignity is a principle that "incorporates the right to self-determination and the right to informed consent" (p. 44). The principle of justice "involves the right to fair treatment and the right to privacy" (p. 45). Polit (2004) emphasized that the principle of doing no harm embraces several of the dimensions of research ethics. Since harm is understood as both physical and psychological, I would agree that the principle of doing no harm would also apply to respect for human dignity and justice. The written material was stored in a locked closet and on a memory stick with a six-digit password.

6.3 Anonymization

Qualitative cancer research generates sensitive information and protecting participants' identity is thus important, unless any of them wish to be known in the articles or other presentations of the project. One way to protect the identity of the participants is to anonymize the persons in the text. Anonymization while also maintaining the integrity of the data can sometimes be challenging (Saunders et al., 2015). I did not conduct any of the interviews personally and the transcript did not contain the participants' names. I do not know their names, nor where they are from. In the papers, I used pseudonyms and I have chosen names that are common in Norway but would also be easy to use in an English text. Even though it could make it easier to identify a person, I chose to reveal the participants' gender in the articles as I considered this aspect to play a role in the stories. For instance, intimate challenges caused by cancer treatment, such as potency problems, are directly associated with gender. I still consider this choice to be "safe" for the participants. In some cases I also revealed the professions of some of the participants as this was essential to the discussion. There were some parts of the participants' stories that I considered writing about, but chose not to due to the concern that it might compromise the identity of the participants. "Qualitative research focuses on how people live and act in very particular, situated contexts.

Removing identifying information also, inevitably, removes contextual information that has potential value to the researcher” (Thomson et al., 2005, p. 1). The process of removing or adding information, according to Thomson and colleagues, is therefore a compromising process, and the researcher has to make many decisions in this respect. With regard to qualitative interviews, I would argue that the most important ethical principle in writing health research is to do no harm.

7. Concluding remarks

What characterizes a cancer pathway from patients´ perspectives, and which concepts may be useful in order to understand their experiences and paths to healing? What matters to people during a cancer pathway?

Trajectories to healing following a cancer diagnosis are dynamic journeys in medical landscapes. This was an impression common to all the qualitative interviews in the PATH project. It is a change process: a journey with ups and downs, hope and fear, goals and actions, and navigation to find the land of the healthy. There is a doubleness in all these journeys: they are similar and unique at the same time. Person-centered care is a goal for healthcare, legislators and patients, but it is challenging in practice. Knowledge about what matters to patients over time and the different aspects of cancer as a dynamic process may improve person-centered care.

Firstly, many patients find that they have been cured, but not healed. Arthur Frank calls this group the “remission society”, i.e., people who are neither ill nor well, but live in continuous liminality. The liminal and continuous liminal phases are a burden for a growing number of survivors, potentially for the rest of their lives. There is a need for a greater focus on suffering, not only pain, and on healing, not only cure.

Secondly, illness is dynamic. By using and modifying Victor Turner´s model of social drama, I have suggested that individual pathways have the following structure: 1) breach of norm (symptoms), 2) crisis (diagnosis), 3) redressive actions (health seeking actions) and 4) reintegration or schism (PTG/normality/continuous liminality). The redressive phase often starts with biological goals to cure the cancer, followed by a plurality of health seeking actions to approach multiple challenges (psychological, physical, existential, and social). I argue that medical pluralism can be understood as a movement in various medical landscapes, here categorized as conventional healthcare, traditional healing, self-care, religious coping and CAM. Since cancer may strongly affect various aspects of a person, the participants found medical pluralism to be an important part of their trajectories to healing. In the redressive phase, actions were often ritualized and adjusted to the participants' needs, interests, energy and available resources. Rituals are an effective and meaningful kind of action. In social dramas, rituals help the transition from one state to another. In the context of illness, this relates to trajectories to healing. The ritual actions are meaningful in the context of illness and simply make people feel better. I found that coping strategies were resources integrated in the participants´ cultural repertoires such as being at one's cabin or walking in the forest. These previously "normal" actions got new meaning in context of cancer and became not only a coping strategi, but also a story about a new normal. Some problems may be better solved in other landscapes than the conventional healthcare. Health seeking rituals play an important part in patients´ healing journeys and can lead to better health and less support from conventional care. Health seeking rituals are often powerful low threshold actions, easily available for all, and a greater focus on these rituals may make a difference. Many patients experience profound, meaningful relationships of joy (communitas) with each other during cancer. This phenomenon also matters in patients' trajectories to healing. I argue that health professionals should have an overview of individual patients' medical pluralism. Healthcare that involves both clinical and biographical aspects will provide us with a more complete and integrated model in line with the values of PCC.

Thirdly, conventional healthcare has been profession centered. It has often been good at treating disease, but it could be better at treating people or seeing "the person behind the diagnosis", as Jacob said in sub-study 1. This implies asking not only "What´s the matter?" but also "What matters to you?". Healthcare should be responsive to what matters to patients and should practice shared decision making.

To the best of my knowledge, this thesis introduces a new perspective on cancer pathways. Concepts such as liminality, medical pluralism, rituals, continuous liminality, post-traumatic growth, medical landscapes, communitas and healing are all terms that give insights into various aspects and experiences of cancer from patients´ point of view. In this thesis, all these concepts are also woven together as part of the dynamic and multi-faceted model of trajectories to healing. I am convinced that this new approach is of value to legislators, educators, cancer organizations, conventional healthcare and others involved with patients, as a useful theory to be discussed in relation to practice. PCC is about what matters to patients, but why is it so difficult to implement and how can this be solved? First, an analysis of what matters to patients over time in the context of cancer is fundamental to improving person-centered care services. Second, I suggest that the main challenge is at the system level. How to improve PCC at the system level is beyond the scope of this thesis, but I hope it can provide inspiration and knowledge to systematically redesign structures that facilitate PCC in everyday practice. Improved PCC should be felt in patients´ hearts because they have interacted with empathic healthcare professionals who work for what really matters to patients in a system that facilitates this goal. Finally, I argue that the aspect of time should be implemented in the PCC concept. I therefore suggest "person-centered pathways" as a dynamic concept driven by what matters to patients, including both biomedical and biographical aspects of trajectories to healing.

To learn from people with experience of being patients with cancer has been invaluable and a privilege. They are the only ones who truly know the experience of getting cancer, how healthcare contributes to their journey, how treatments are experienced in their body and particularly what matters to them over time. I think and hope that their voices shine through in this study and that our teamwork contributes to the aim of Norwegian Ministry of Health and Care Services cited in the introduction: further development of patient participation and better understandings of patient pathways from patients´ perspectives.

What is the overall meaning of a healthcare system? The system has been created for the health and care of the people. What matters to patients is what matters to healthcare.

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Paper 1

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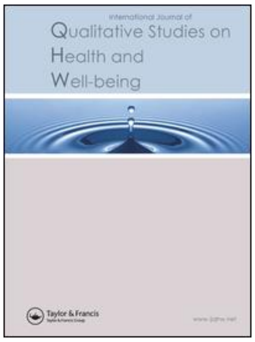

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"What matters to you?" A longitudinal qualitative study of Norwegian patients' perspectives on their pathways with colorectal cancer

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ABSTRACT

Purpose: Person-centred care (PCC) is a well-acknowledged goal throughout the western world both within the health care services sector and for the patients themselves. To be able to create a future health care system that includes improved PCC, we need more in-depth knowledge of what matters to patients, how "what matters" might change over time, and tentative descriptions of commonalities across patients' perspectives. The aim of this study is to contribute to this knowledge base. **Methods**: We conducted a qualitative interview series over one year with nine Norwegian patients who were recently diagnosed with rectal cancer tumor-node-metastasis stage I–III. **Results**: We found that: (1) patients have an initial focus on "biological goals" and conventional treatment; (2) pathways are unique and dynamic; (3) family and friends affected patient pathways positively with respect to meaningfulness and quality of life, but for some participants also negatively because there were heavy burdens of caretaking; (4) receiving help in the health care system depended on the patients' navigation skills; (5) pluralism in health-seeking behaviour was important in all patient pathways. **Conclusion**: Long lasting illness may be a dynamic and complex journey. These results represent some features of a pathway with cancer and are important because they contribute with knowledge about what matters most seen from the cancer patients' point of view.

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Colorectal cancer; longitudinal study; patient-centredness; person-centred care; supportive cancer care; illness trajectories; patient pathways

Introduction

Studies have revealed that person-centred care (PCC) leads to better health (Coulter & Ellins, 2007; Coulter et al., 2015). It is therefore not only an ethical standpoint, but also pragmatically oriented towards best outcomes. This has led to PCC being called for by health authorities, ethicists, legislators, and patients alike (Helse og omsorgsdepartementet, 2001; Pellegrino & Thomasma, 1987; Taylor, 1992). The practice of person-centred treatment is here defined as acting according to patients' values, preferences, and personal needs (Mead & Bower, 2000). Health care professionals should relate not only to medical knowledge, but also to people's individual understandings of what is important to them as patients. Despite the importance placed on PCC, there are no qualitative longitudinal studies that have explored what matter most to patients who are in a long-term illness, and how this may change over the course of long-term diseases progression. This article is a part of the PATH study (Patients' Accounts of Trajectories to Healing) with the overall aim to get insight into long-term illness from a patient perspective. Demographics, cancer stage and biomedical treatment of the participants are presented in Table 1.

PCC and criticism of health care practices

The quality of treatment and care of patients depends on both clinical knowledge and knowledge about the patient's character and personal life. Along with conventional treatment, these are important aspects of patients' pathways to healing. Despite this acknowledgement,

> from the late twentieth century there have been increasing critiques of the dehumanising aspect of contemporary medical practice. Criticism has focused on the displacement of the person of the patient by technologies, the redefinition of the patient in biomedical terms, and the distress suffered by the patients navigating a highly impersonal, overpressured health care system. (Parsons & Hooker, 2010, p. 345)

One of the earliest critics was Peabody. In his article "The Care of the Patients" published in 1927, Peabody was approaching some of the same challenges that we are trying to solve today:

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Table I. Demographics, cancer stage and biomedical treatment of the participants in the PATH study.

Characteristics	Number of participants (n = 10)
Gender	
Female	5
Male	5
Age	
Unknown	1
25–44 years	0
45–65 years	6
> 65 years	3
Education	
Secondary education	3
High school or equivalent	2
Trade/Vocational diploma	3
Bachelor degree	0
Master's/Professional degree	2
Marital status	
Married or living with a partner	7
Not married	3
Living	
Alone	3
With children	
With spouse/partner	5
With spouse/partner and children	2
Work	
Unknown	1
Employed part time	1
Self-employed	2
Unemployed	0
Retired	1
Disability/income	3
Colorectal cancer stage, TNM	
Stage 1	3
Stage 2a-b	3
Stage 3a-c	4
Treatment	
Preoperative radiotherapy	5
Surgical treatment:	
Biopsy only	1
Bowel resection and re-anastomosis	7
Bowel resection with permanent stomy	2
Post-operative chemotherapy	7

*One of the participants withdrew from participation in the project after the baseline interview.

> The most common criticism made at present by older practitioners is that young graduates have been taught a great deal about the mechanism of disease, but very little about the practice of medicine—or, to put it more bluntly, they are too "scientific" and do not know how to take care of patients. (Peabody, 2015, p. 877)

Thus, a barrier to achieving the aim of care that is more person-centred in the professional sector is when the doctors do not see the person behind the diagnosis. Stange (2009) highlighted this issue when he quoted Osler, writing "it is more important to know what sort of person has a disease than to know what sort of disease a person has" (p. 102). It is therefore clear that the ideology of providing PCC is old, but the challenge of embedding it in everyday clinical practice still persists (Naldemirci et al., 2017; Riding, Glendening, & Heaslip, 2017). For example, a study found that doctors who were courteous often still systematically avoided dealing with the personal topics that patients brought up, even when they could be relevant to diagnosis and treatment (Agledahl, Gulbrandsen, Førde, & Wifstad, 2011).

The problem of a fragmented health care system

Norwegian health authorities acknowledge that the present uncoordinated health care service is a challenge. For example, there are few elements in the current system that incentivize holistic needs. Fragmented health care systems such as this are especially a burden for patients with long-term illnesses and complex needs, and in Norway the number of such patients is growing (Regjeringen.no, 2008–2009).

Depersonalization and despair are some of the unintended consequences of well-intentioned actions, Stange (2009) argued in his critique of fragmented, disintegrated health care systems. He saw a holistic approach as key:

> Viewing health care as an evolving whole instead of only as fragmented parts can help us to feel hope where now there is cynicism. Personalization and relationship where now there is detachment and isolation. Professional and corporate shared responsibility where now there is narrow self-interest. High value health care where now there is waste and inequality. Maximizing the opportunities for health and healing, and abiding when healing and health are not possible. (p. 102)

The best possible pathways depend on a system that supports health and healing. To reach the goal of PCC, we need a system that combines the pieces of a multidimensional life with illness into a purposeful whole.

Patient pathways

Norwegian health authorities understand patient pathways as being "a holistic, coherent description of one or several patients' contacts with different parts of the health care system during a period with disease" (Helsedirektoratet.no, 2017). This definition of a patient pathway focuses on the series of evidence-based interventions *within* conventional health care services. While this may be a useful template for treating single diseases, it does not meet the holistic needs of patients, as the biomedically motivated pathways of clinical care are only a subplot of the pathways experienced by the patients. We therefore propose that in order to provide care that is truly person centred, health practitioners need to adjust their understanding of what constitutes patient pathways to include a wider set of dimensions beyond just health care related events; that is to say, they must include "life events" as well:

> The concept of health events includes events involving the patient and a health care provider, experiences of symptoms and adverse events, and patient-initiated health events, such as dietary change and exercise. The concept of life events includes events that the patients themselves define as important in their life. Such life events may or may not be related to the cancer

> diagnosis and cancer treatment. (Salamonsen, Kiil, Kristoffersen, Stub, & Berntsen, 2016, p. 1592)

By including both health events and life events in the understanding of a pathway, one manages to grasp both the episodes of treatment and other important aspects of the life lived with illness from a patient's perspective (Salamonsen et al., 2016). Compared to the clinically based understanding, this definition not only includes the patient's perspective, but also gives a richer longitudinal picture over time of what patients are going through.

Contribution

Though there is one quantitative, longitudinal study that has measured changes in the quality of life of patients with long illness pathways (Chambers et al., 2012), we are not aware of any qualitative longitudinal studies that have focused on determining what is important to such patients over time. By following patients over time and listening to their accounts, we can generate knowledge about what is important to them, which in turn can lead to care that is more person centred. The findings of this study may be transferrable to a larger group of patients, namely severe, long-term illnesses with relatively acute starting points.

Aims and research questions

This article aims to uncover knowledge that will support the transformation of care services to become person centred. We aim to offer rich descriptions of the participants' lives lived with colorectal cancer and what they themselves emphasize as important. The research questions analysed in this article are:

> *What is important for persons diagnosed with colorectal cancer during their patient pathways?*
>
> *And, based on these findings, which significant features do the patient pathways share?*

The exploration of these questions leads us into a discussion of the implications of current understanding of the patient pathway with regard to PCC.

Sample

To be included in the study, patients had to fulfil the following criteria: they had to be between 18 and 70 years old, have been diagnosed with rectal cancer tumor-node-metastasis stage I–III (Dukes A–C) within the last 6 months, and have completed their primary surgical treatment. Our sample was a small sample of a diagnostically relatively homogenous group of patients, although the clinical cancer stages and prognoses varied across the group. Due to potential recall bias, it could have been interesting to meet the participants before primary surgical treatment as well. However, this was not our intention when designing the project because (1) we did not want to include the terminal patients. We therefore had to wait until after primary surgical treatment to know the patients' prognosis; (2) our main intention was to learn more about how patients shape their own pathways, and not so much the acute phase; and (3) ethically we did not want to be an extra burden for newly diagnosed patients. Furthermore, their residence had to be a maximum of 500 km from the University Hospital of Northern Norway (UNN). All potential participants were identified based on UNN's electronic patient records in the autumn of 2011. Patients who fulfilled the criteria for inclusion received an invitation letter (N = 20). All participants were informed that participation was voluntary and that they could withdraw from the study whenever they wanted. While 10 patients signed a written informed consent form, 1 withdrew from the project after the baseline interview, leaving 9 participants aged between 54 and 68 years old who participated in the study.

Method

Choice of data-collection methodology

This research is based on a longitudinal qualitative approach, a method that "can add depth and understanding to health care research, especially on topics such as chronic conditions, adherence and changing health policies" (Grossoehme & Lipstein, 2016, p. 1).

All the participants were Norwegians situated in northern Norway. Two of the authors and a research assistant conducted baseline and quarterly qualitative interviews in 2011–2012. The participants were followed over a period of 1 year every 3 months. Altogether, 46 interviews were conducted. Five of the nine the participants wrote diaries that were the starting point for the quarterly interviews. For the remaining four patients, we employed a semi-structured interview guide to gather information regarding their health and life events since we last talked. The baseline interviews were conducted face to face, while the rest of the interviews were mainly conducted over the phone. The interviews were between 45 and 150 mins long. As a part of the PATH study, five of the participants took part in a workshop where, among other things, they were asked to make a drawing of their patient pathway.

We chose colorectal cancer patients as the focus of our study as cancer is a diagnosis with a somewhat obvious starting point and that stretches over time. Furthermore, cancer patients' needs are often complex and the patients frequently initiate treatments outside conventional health care (Horneber et al., 2012). Cancer patients therefore make up a suitable group for the study of variation in patient pathways over time in complex and long-term contexts. We have used pseudonyms instead of the real names to represent participants in this study to protect their anonymity and confidentiality. Because cancer is a sensitive topic, this was both an ethical and practical choice in this study.

Analysis

All the interviews were transcribed verbatim by a professional transcriptionist. We worked in an interdisciplinary research team consisting of two anthropologists, a medical doctor, and a medical sociologist. The analysis was based on an inductive approach. We first read the interview transcripts closely. Thereafter, we coded them in NVivo 11 Pro, using nodes to group relevant content from the wide range of experiences and processes that the patients described. The coding was mainly based on what the participants expressed as important in the interviews, that is to say they used the word "important" in a sentence or we explicitly asked "What has been the most important during this recent period of time?" Other content was coded based on the researchers' interpretation of the materials where the participants implicitly spoke about aspects they felt were important to them over the last few months. Thus, even though we were interested in the stories in terms of gaining a larger picture, our analysis was not a narrative analysis approach as such. Rather, by using NVivo as an organizing tool, we were able to undertake a qualitative content analysis focusing on "characteristics of language as communication with attention to the content or contextual meaning of the text" (Hsieh & Shannon, 2005, p. 1278). Finally, it should be noted that in addition to the process above, we also created mind maps and infographics in order to visualize the analytical ideas we had as they developed. This was experienced as useful both for creating a clearness of thought and as a starting point of interdisciplinary discussions in the research group.

Results

Based on our interpretation of what was important to the participants in our study, we found five categories that the participants emphasized.

(1) *Initial focus on biological goals and conventional treatment*

The participants saw a conventional medical doctor after recognizing symptoms, and receiving the cancer diagnosis was by most of them described as a "shock." At this early stage in the participants' pathways their most important focus was on biological goals. The concept of biological goals is taken from Berntsen et al.'s creation of health concepts and goal typology: "Health is absence of biological malfunction or disease (Goals 1–5). Diseases have a biological basis or aetiology for symptomatology and signs. The goal for care is to remove the cause of disease and relieve symptoms through biological manipulation" (Berntsen et al., 2015, p. 4). Specifically, the participants emphasized early treatment at the local hospital as important, and that their goal was to become rid of the tumour at the point of diagnosis.

They furthermore all had trust in biomedical approaches to treating the cancer, and thus the participants chose conventional treatment and followed their physician's advice. "I wanted to survive," Jacob said when we asked him for his motivation for accepting conventional treatment. Elias had a similar answer: "The goal of the treatment is to live as long as possible and enjoy the time I have left," he said. "I have stopped working. Now I will travel around and get lost." We interpreted the choice of conventional treatment and listening to their doctor's expertise as important for the participants at the moment of getting a potentially life-threatening diagnosis. For some, the medical treatment was explicitly underlined as the most important thing they did during their pathway.

Julie was a participant who also made use of herbal medicine from India and a special diet programme to cope with the cancer itself. She was motivated to follow this as her sole form of treatment, but returned to the conventional system when her doctors refused to postpone her operation. Based on our findings, we thus posit that a patient chooses the intervention that is culturally understood as the best thing to do according to one's goals and the opportunities one has available. "I had no choice," Per said, which can be interpreted as an understanding that there is only one way to survive cancer and that is by receiving conventional treatment.

After the initial conventional treatment, the participants struggled with experienced side effects or adverse events to various degrees. Permanent or temporary stoma, radiation injuries, fatigue, pain, and diarrhoea are some examples. "You pay a very high price to get well," Julie said, who suffered from late injuries and side effects in terms of pain and fatigue. Those who only underwent surgical treatment reported fewer side-effects/adverse events than those who also received cytotoxic drugs and/or radiation therapy.

(2) *Pathways are unique and dynamic*

The next category that emerged was that every pathway or "journey" was unique and dynamic. This is not surprising, as each person is different. They are unique genetically, have a unique repertoire of life experiences, and the cancer was experienced within their unique personal contexts.

Empirically we focused on the individual health and life events deemed important by the participants. In addition to having to cope with the cancer itself and the biological goals related to the disease, managing unforeseen life events not related to the disease was found to be a dominant issue for the participants. These include life course disruptions that may have happened *before* the cancer diagnosis and that had a significant impact *during* the participant's pathway (Salamonsen et al., 2016). Sometimes life events were so dramatic that they overshadowed the concern about the cancer itself and the biological problems the participants experienced in their own bodies.

We uncovered such tendencies within the participants' stories when we asked them the open-ended question regarding what had been most important to them over the last period of time. We have selected a few examples of such events. The examples are meant to illustrate how different pathways have different characteristics and must be understood individually.

The first example is how the loss of her daughter before diagnosis was *the* major topic in our conversations with Eva. The loss of a family member was also a major topic for Mari, whose husband had, some years ago, been diagnosed with the same type of cancer as herself. This was a man that she had taken care of for a long time because of the disease. When she received the diagnosis, she therefore already knew what was awaiting her. Furthermore, when she started her treatment and needed care most, her husband died. Later, she also suffered the loss of a child, and had complications with her treatment.

Another example is Per, who in the first post-surgical period of his pathway regretted having undertaken the operation, despite the fact that the operation had successfully excised the cancer. Prior to the operation, he knew he would have to have a stoma post-surgery, but had been assured by everyone that a stoma would not lead to any problems. That was not the reality for Per, however, as he not only faced unforeseen challenges with the stoma, but also experienced difficulties finding qualified help. Only by taking control and dealing with the health care system in an autonomous way, and by participating in self-management courses and learning through his own experiences, was he able to educate himself and become a "stoma expert." He later began to share his experiences and knowledge with new stoma users in various discussion forums. "I tell new patients that a stoma may cause a lot of problems, because it can," he said. In the last interview, he told us: "Now I can live with it." The stoma was not a problem anymore.

Emma's pathway was again different from the others', as she was not concerned with her cancer at all: "After the doctor said I would be fine, I have not worried about it at all." She told us her main concern, rather, was a fear of Alzheimer's disease as it ran in her family: "I would rather die of cancer than fade away due to Alzheimer's," she said. She was also very concerned with the future of her son, who struggled with mental health issues. He moved in and out of her house during her pathway while he was trying to find a job.

Julie was diagnosed with secondary radiation injuries. She felt that if she had been able to try using herbs and the diet programme as treatment just a little longer before starting her radiation treatment, then she could have minimized the tumour and would have been spared the affliction of the radiation injuries. Suffering from intense pain, the most important thing for Julie during the first period of time was actually managing to sit and stand. Later she emphasized that the most important things for her were being at her cabin, being in nature, picking berries, and visiting her family. Early in the pathway she had a hope of getting back to work, but this later proved out of reach. "The doctor told me that I probably cannot go back to work," Julie said. "The only thing I can do is reconcile myself to the situation as it is." She now receives disability benefits from the government.

In contrast, other participants had very few complaints: Ken commented on the process, stating everything was going smoothly for him. In a similar manner, David told us that he had few complications after the treatments. All he really had to deal with were some problems with diarrhoea, which impacted some of his activities, such as going fishing.

Jacob was in general happy with the services he got from the hospital. He added, however, that

> the health workers should always be reminded to see the whole person behind the diagnosis. Because even though the clinical pathways may be pretty similar regarding the prognosis and things like that, each case is unique and individuals are very different. To really see each person behind the diagnosis is important both for safety and coping for every patient. That again will have an impact on how good of an effect one actually gets from the treatment and how one copes with the pathway as a whole. When a person gets a potentially life threatening disease, the initial thought is death. The aspect of time is therefore very important both on an individual level, but also on a system level.

Jacob here comes to the centre of this second finding. Namely, that though there are generally two kinds of pathways as can be seen by the examples above, i.e., those that are relatively simple and those that are complicated, each patient pathway is unique. The implication for practitioners is to see the person behind the diagnosis

Entangled with the notion of unique pathways is the understanding that what is important to patients is dynamic and changes over time. Patients not only emphasize different things as being important, but each theme unfolds and changes with time. Specifically, we found that patients' needs, preferences, and emotional statuses change individually over time during their pathway, and that the pathway encapsulates events related to both health and life.

3) ***Impact of family and friends in a pathway***

Family was of great importance for the participants, both existentially and pragmatically. Existentially, when you get a potentially life-threatening diagnosis such as cancer, thoughts may be led towards the end of life, and the very real possibility that you may not have much time left. This seems to provoke a realization of "what really matters" in life. Because of this, the participants emphasized that they became more conscious of cultivating their closest relationships during their pathway. For example, for Jacob, the thought of losing his life was equivalent to that of losing his family. This made him realize he needed to try to spend as much time with them as he could. Mari is another example of this, who stated that "material objects have no importance. What really matters is friends and family." This "new" realization made her move from her home town to the place where her children and grandchildren lived.

It was not only becoming aware of their existential nature that occupied the participants' minds as related to the importance of those they had close relationships with. They also emphasized these relationships as being an important part of their healing process. Jacob said, metaphorically, that he "went into a dark place" when he received the diagnosis. "It was a state of darkest darkness," he told us. However, there was no psychiatrist involved in this depressive episode. "It lasted only a day or so," Jacob said. "Family and friends helped me out of it." For Ken, this practical and emotional support came not only from friends and family, but from colleagues as well. "They visited me at the hospital and even offered me economical support if it was needed." Ken said that he was very moved by all the support and care that he received from the people around him.

The participants received practical help from their family and/or friends, and they told us that they received emotional support. However, there were also challenges linked to interactions between themselves and their family and friends. Per, for example, stated: "I don't need anyone. I don't need anyone to feel sorry for me. It will only make the condition worse." Instead of keeping family close, he preferred to keep a distance. He preferred to stay alone. He did, however, attend a self-management support centre for cancer survivors, where he found pleasure in the relationships he built. "I felt better when I heard that others were also suffering. It was not only me," he laughed. For Jacob it was difficult to communicate the diagnosis to his children, and this could had been done differently, he said. Another informant worried about how the children would be treated at school when they had a father with stoma and colorectal cancer, conditions associated with stigma.

Overall, we found the role of close relationships was highlighted as being very important in a cancer pathway and this important role manifested itself in various ways, giving both meaning and healing in the context of cancer. "Care and love are important words during an illness pathway," Mari said:

> It is a unique experience when a child says "Grandmother, wake up! I love you!" All the love and good things the heart can be filled with. You are privileged to be there present with your grandchild, to have walks and explore the world together with her, to see a little flower, a mosquito, and a snail.

4) ***Navigation in the national health care system***

We define "navigation" in the national health care system as a type of knowledge or skill that enables patients to find qualified help. To receive proper help when needed is crucial for patients' health and healing. Failure in care navigation creates extra burdens for the patients by making them frustrated and feel lost, and waiting for treatment is associated with anxiety for both patients and their peers.

The participants praised the hospital's cancer treatment as swift, and they felt they had been highly prioritized. Several of these worked in the health care system themselves, and thus used their professional network to get information and to get things done. Take Mari, who was a health care worker, as an example: she made use of her professional network to get the best surgeons. Coming from within the system also meant she could benefit from her existing knowledge regarding how the national health care system works. She basically had a map and compass with which to navigate the "jungle" of the system. However, despite being content with receiving quick treatment and help, participants felt the processes with regard to receiving test results were too slow, causing them to feel worry and stress.

Participants had to "fight" to get the help they needed, and some often felt lost in the system if they did not know the system from within. Elias, for example, chose to go outside the national health care system and make use of a private doctor to get an earlier examination date. "It would have been six months waiting if I had gone through my family doctor, while it was only two weeks at the private office," he said. This made him feel it was an unfair system. Later in his pathway, however, Elias had problems getting help in conventional health care.

Looking back, we asked him what had been most important during the pathway. “When you get the diagnosis, things are spinning around in your head. You think about this and that, and then you don’t know where to enquire to get things done.” What Elias felt impacted him the most was the lack of knowledge regarding how to navigate the system to get proper help.

Per is another example of a patient who struggled to get proper help. He had to use creativity and “backdoors” to get the care he needed when he was suffering from problems related to his stoma, which created extra stress and burdens for him during a time that was already very difficult. Similarly, Emma experienced the health care system as being slow (long waiting times), complicated, and difficult to navigate as related to her post-operative hernia.

A topic related to navigation is how the national health care services communicate with their patients. Emma thought that the letters from the hospital were cryptic, with Latin words, etc. “I went to my doctor to get the letter translated,” she said, “but even he did not understand everything.” She also got an erroneous letter at one time with information about a tumour in the brain. It was a disturbing experience. Letters from the hospital often led to misunderstandings and worries for the receiver.

“One-time-doctors,” as Elias called them, were another concern with regard to the system. “You have to tell your story over and over again,” he said. “It is a new doctor every time.” Not only was it a burden to repeat one’s story, but Elias experienced that doctors also met him unprepared with regard to his history. This complicated the consultations and was experienced as frustrating.

5) ***Pluralism in health-seeking behaviour***

The participants used a combination of approaches on their path to health and healing. Elias said at one point that “I will not try any witchcraft.” Here “witchcraft” (*heksekunster* in Norwegian) should be interpreted as any kind of practice based on superstitions. When we asked him if he had tried any treatment outside bio-medicine he answered “No.” But continued: “Maybe I have called someone,” and laughed, “someone who you could say has some special abilities.” He confirmed that he had both called and met face to face with two traditional healers or “readers,” which is the direct translation of the Norwegian term *leser*. The practice of “reading” was not considered witchcraft by Elias, as readers, in his cultural logic, belong to a category of professional individuals that hold healing knowledge and power, where it is understood that God acts through the reader. “It does not hurt to try,” he said.

“I will try everything to get well again.” Julie’s attitude towards getting well can be categorized as epistemological individualism. She explored each possibility she came across and learned through experience. We already mentioned above that she tried to deal with the tumour using herbal medicine and a special diet. She also made use of healing and acupuncture outside the conventional health care system.

Mari received healing from two different healers, and underwent a chakra balancing. She had conversations with both the hospital priest and psychiatrist. “They complement each other,” Mari said. They represented existential and psychological aspects of the respective experiences she had gone through. Various objects, such as an angel, a cross, and a praying cloth, were important to Mari. “I hold them in my hand when I need strength,” she said. “They are gifts from people who wish me all the best.” Mari also found it useful to take frequent walks, especially in nature: “Nature gives me inner strength.” She further showed us how she applied positive thinking to negative situations. “I looked at the cytotoxic drug. I thought of it as golden drops,” she said. “Golden drops that are going to heal me.” Psycho-motoric physiotherapy was another treatment that Mari emphasized as important in her pathway to healing. “We work with the physical as well as balancing the thoughts,” she told us.

Per, David, Ken, and Jacob did not use any alternative treatments, according to their understanding of the concept. However, they undertook a combination of approaches to intentionally improve their health after the diagnosis. For instance, diet change, courses to generate knowledge, and various physical activities. We would place these types of activities in the category of “self care.” The point here is to show that there is a complexity of actions on the way to better health in the context of cancer, and that these activities belong both inside and outside the realm of the conventional health care system.

Discussion

We started the introduction by saying that PCC is a goal for patients, health authorities, legislators, and professionals alike, and argued that the development of PCC and better pathways should be based on medical understanding as well as the patients’ perspective of what is important. This is in line with Donabedian (1988) who suggested that assessing the quality of health care involves a three-part approach that consists of evaluating the health care’s structure, processes, and outcomes. This assessment approach is necessary because a good structure increases the likelihood of good processes, and good processes increase the likelihood of good outcomes.

Thus, by considering all three factors a more complete assessment can be made (Donabedian, 1988).

In the above approach, processes include "the patient's activities in seeking care and carrying it out as well as the practitioner's activities in making a diagnosis and recommending or implementing treatment" (Donabedian, 1988, p. 1745). They are thus the sum of all the health-seeking actions in a pathway. Donabedian further made a distinction between technical processes, which are related to the biomedical diagnosis and treatment, and interpersonal processes, which refer to the relational quality of the care delivered, and highlighted how interpersonal processes impact the quality of the technical processes. That is to say, it is through interpersonal exchanges that the patient communicates information that the medical doctor needs to arrive at the correct diagnosis and "preferences necessary for selecting the most appropriate methods of care" (Donabedian, 1988, p. 1744). Furthermore, "privacy, confidentiality, informed choice, concern, empathy, honesty, tact, sensitivity—all these and more are virtues that the interpersonal relationship is expected to have" (Donabedian, 1988, p. 1744). Despite the importance of managing the interpersonal process, however, it is often ignored in the evaluation of health care. Perhaps part of the reason it is ignored is that it is quite challenging to implement PCC in clinical practice (Riding et al., 2017). One way of moving towards the goal of PCC may thus be to start by increasing the focus and understanding of the concept of the patient pathway, since the way we understand the world and act in the world are based on our concepts (Lakoff & Johnson, 1980).

PCC and the patient pathway concept

The common medical understanding of a pathway as a series of clinical interventions and standardized packages for diagnosis gives a limited picture of relevant information if our aim is to provide patients with care that is more person centred. We referred above to Norwegian authorities' definition of a patient pathway as "a holistic, coherent description of one or several patients' contacts with different parts of the health care system during a period with disease" (Helsedirektoratet.no, 2017). However, our findings show that contact with the health care system is only one of the factors patients emphasize when discussing their pathways. This thus begs the question of whether the above definition provides a sufficient understanding of a patient pathway.

Studies have revealed that PCC leads to better health (Berghout, van Exel, Leensvaart, & Cramm, 2015; Coulter & Ellins, 2007; Matalon, 2008; World Health Organization, 2015). PCC, here defined as acting according to patients' values, preferences, and needs (Mead & Bower, 2000), should also be practised because it is ethically correct (Pellegrino & Thomasma, 1987). Patients with chronic diagnoses have pathways stretching over long periods of time, where health care workers acting according to the patients' values, preferences, and needs may be a significant factor in improving the patients' well-being and causing them to experience their care as high quality. This leads to the conclusion that an understanding of the patient pathway as being a purely clinical journey does not fit within the concept of PCC. We thus suggest that the concept of a person-centred pathway may be useful when describing the journey a patient with a long-lasting disease embarks on after diagnosis. By introducing this concept, we move towards an understanding of a pathway that consists of both health and life events (Salamonsen et al., 2016). Not only will the route within conventional health care be present, but so will other matters that influence the patients' condition. Such a concept allows for an implementation of a more holistic understanding that supports PCC, where it contains the perspectives of the professionals as well as the patients.

Stange (2009) reminded us about the problems of a fragmented health care system, highlighting for us how the benefits of finding new ways of thinking and acting about patient care are numerous. However, Stange did not include the aspect of time, which is a key factor when considering pathways. That is to say, a pathway is characterized by many dimensions that are in flux and flow over time. This is seen in the results of our study, where all of the participants used a combination of approaches to cope with their ever-changing situation. There is thus a need to implement care that takes into account the impermanent realities of patients. This will require a dynamic model rather than a static understanding, because a pathway is not only a puzzle with pieces creating a picture, but rather closer to a film evolving and changing over time.

Methodological considerations

Quality of data gathered through qualitative interviews over time

When employing qualitative interviews, as we have done in this study, it is important to be aware that the researcher's presence may affect the data he or she is gathering. For example, respondents may undertake impression management, controlling what kind of information they give the researcher and what they choose to keep "backstage," hidden for the "audience" (Berreman, 1962). This is different from long-time ethnographic fieldwork where participant observation is the most common approach, such as is commonly used in anthropology "to grasp the native's point of view, his relation to life, to realize his vision of his world" (Malinowski, 1922, p. 25). With this in mind, it is interesting to compare the ethnographic method, which this study's first author is familiar with through his background and experience as an anthropologist, with the qualitative interviews in this study.

The material is characterized by people who are open and sincere in sharing their story. We believe that a reason for this is that we held the role of interviewers and not therapists or peers. Thus many of the participants viewed us as neutral persons, which may be why they felt comfortable and safe sharing backstage information with us. Some explicitly told us that they shared aspects of their lives that they had not told anyone before. "I don't throw pearls to swines," Mari said, and emphasized that she was very careful with whom she spoke about complementary and alternative medicine and spiritual matters. Despite the fact that many are met with condemnation when they speak about these topics, they opened up to the interviewers. Some of the participants further used the interviewers to vent their worries and concerns, and some felt relief caused by telling their stories and reflecting over the questions. Such access to the inner life of the participants gives credibility to our data. We can thus conclude that the in-depth and open-ended interviews made us reach our goal, namely to come close to life lived and experience in the context of cancer diagnosis.

Another important factor that helped build trust between the interviewers and participants was that it was a longitudinal study where we followed the participants over a whole year, as was suitable for a pathway study. The trust built over time also affects the depth and transparency of information the participants are willing to share, i.e., it minimizes the level of impression management. Furthermore, by clearly communicating our aim of the study—to learn more about cancer patients' pathways in order to improve future health care—we were able to strengthen the degree of openness and completeness of the responses, as all the participants hoped to help us with this goal. The participants contributed with their perspectives as they wished to help improve future health care and the services provided to future patients.

Validity of sample

Our sample was a small sample of a diagnostically homogenous group of patients. The material was balanced in terms of gender, but all of the informants were adults from northern parts of Norway. Ideally, it would have been interesting to have a more widespread sample with regard to variation in age and cultural background. Another approach could have been to strategically choose patients with particular experiences to go deeper into certain phenomena. For instance, the use of complementary and alternative medicine in a long-term pathway. Despite these limitations, we show that, even though the diagnosis is the same, the individual pathways are unique, while at the same time they share certain patterns or common features.

Validity of coding

The findings are based on codings in NVivo of the participants' own accounts of what has been important and meaningful during their pathway with cancer. The strategy of categorizing sentences and questions with the word "important" and the summative approach of content analysis was aimed at bringing credibility to the study. This approach also required interpretations, which may always be subject to misinterpretation. The co-authors thus reflected upon the first author's coding to ensure a common understanding of coding-concepts across authors. In the writing process, we included an extensive use of quotes to exemplify the participants' perspectives.

Reflexivity

The research group consisted of two anthropologists, a sociologist, and a medical doctor. This composition of interdisciplinary researchers provided a beneficial cooperation that generated knowledge about long-term pathways from a patient perspective. A potential drawback of our team make-up, however, was that our cultural backgrounds were all the same as the participants'. The challenge with studies of our own societies is that it may make the researcher "blind" as there are many cultural ideas and practices taken for granted. We believe this was minimized in the current study as looking into detailed descriptions of life lived with cancer is like studying a different world. It should additionally be noted that deep knowledge about the society in question was at the same time an important resource for the project. All the authors read the interview material. We discussed NVivo coding, synopsis of the stories, and illustrations. An ongoing reflection led to the findings in this article. This process would have been much more difficult and less effective without this common deep knowledge.

A final point regarding the make-up of the research group is that the first author had no previous cancer-related experience or insight, while the others had worked with health and illness issues and aspects surrounding cancer before. Overall, the different backgrounds of the researchers in the group resulted in dynamic and interesting discussions.

Conclusion

The results of this study are important because they contribute knowledge about what matters to patients during their pathway with a serious illness such as cancer. First, the results show that life with cancer affects different aspect of human beings and their relationships. Challenges related to health and illness need to be met with a combination of approaches, both inside and outside the conventional health care system. Second, each pathway is dynamic and evolves in a different way. We therefore argue that a pathway is characterized by its impermanent qualities as it moves through time and space.

PCC is about seeing the person and not only their diagnosis. It is about understanding the individual experience of illness in their unique life context. As we have shown, there are both ethical and pragmatic reasons to work towards implementation of this in the health care system. The aim of achieving PCC therefore leads us in this pathway study to suggest the need for a new pathway concept. This is because the previous understanding of a pathway as a series of contacts with the public health care system is incomplete as it not only does not comprise patients' perspectives, but it also does not include aspects related to patients' life events or the combination of approaches patients undertake with intention to heal or improve their various health issues. We thus suggest that a way to facilitate change in future health care services so that it includes improved PCC in practice may be to start with the language. We suggest that the concept of a "person-centred pathway" may contribute to this aim. This concept includes both health events and life events that are important to the patients themselves. A person-cent red pathway will therefore respect patients' values, preferences, and needs. Furthermore, this understanding must also imply a flexible approach by the social health care system, as person's values, needs, and preferences may change during a pathway.

Overall, a person-centred pathway is a pathway where the patient's individuality in terms of context, life-experience, and life-beliefs are all taken into account. It is a process where patients are seen and heard, and where "what is important to them" is always at centre stage in the process. Applying a person-centred pathway has the potential to humanize and defragment the care experience.

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Ethical approval

The Regional Committees for Medical and Health Research Ethics (REK) approved the study (2009/1293/REK Nord).

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Paper 2

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Patient pathways as social drama: a qualitative study of cancer trajectories from the patient's perspective

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ABSTRACT

Purpose: The number of persons living with and beyond cancer is increasing. Such persons often have complex needs that last, and change, over time. The aim of this study is to get insights of lived experience of person diagnosed with colorectal cancer and to create an understanding of cancer trajectories as a dynamic process. This study thus explores Victor Turner's model of social drama in a cancer care context. Method: Turner suggests that crisis is a dynamic process structured by four phases: 1) breach of norm 2) crisis 3) redressive actions 4) reintegration or schism. The research team employed content analysis to explore material gathered through a series of qualitative interviews with nine Norwegian cancer patients over a period of one year. Results: To the authors' knowledge, Turner's model has not earlier been applied to such materials. The results show that Turner's model of social drama is useful in achieving new and possibly important knowledge on illness trajectories from a lived experience perspective. Conclusions: The model of social drama may contribute to a deeper understanding of the processes patients are going through in long-term illness trajectories, demonstrating that illness is not a static matter.

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Introduction

The number of persons suffering from non-communicable diseases (NCDs), also known as chronic conditions, is increasing both globally (Hajat & Stein, 2018) and in a Norwegian context (Norwegian Institute of Public Health, 2018; Regjeringen.no, 2009). The burden of NCDs is, therefore, a global priority, for instance, seen by the Global action plan for the prevention and control of noncommunicable diseases 2013–2020 (World Health Organization, 2013). Norway is amongst those countries worldwide with the highest cancer survival rates, and the numbers are generally increasing. The country is particularly successful for colorectal cancer survival (Allemani et al., 2018). Consequently, more people will live with cancer in the future (Norwegian Institute of Public Health, 2018) and the number of persons struggling with psychological and physical late effects is growing (Stein, Syrjala, & Andrykowski, 2008). Life with cancer is highly relevant in a Norwegian context and the National Cancer Strategy (2018–22) aims to improve quality of life for the rising number of survivors (Helse og omsorgsdepartementet, 2018). In order to achieve the health authorities' goal of improving patients' pathways, it is necessary to first find theoretical models that can capture the complexity of such pathways. Norwegian health authorities define patient pathways as "a holistic, coherent description of one or several patients" contacts with different parts of the health care system during a period with disease' (Helsedirektoratet.no, 2017). The concept is often understood to be equivalent to standardized care pathways. Such pathways are a series of interventions for a defined patient group within conventional health care and represent only a small part of patients' lives with a condition. We, however, emphasize that the understanding of a pathway should include the personal perspective of the patient and not just the clinical interventions. For clarity, we follow Hansen, Berntsen, and Salamonsen (2018) and the concept "person centred pathways", which indicate that the participants' journeys include all health related events, both inside and outside the conventional health care system. This paper is a result of an interdisciplinary cooperation between a medical doctor, a sociologist and an anthropologist.

Previous anthropological cancer research has focused on various topics such as relationships, technology and hope, carcinogenic environments, politics and inequality, stigma and silence, cancer narratives and support groups in global contexts (McMullin, 2016). Livingston (2012) explores the medical landscape of Botswana. In her ethnography, she follows

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patients, families, doctors and nurses and argues that cancer is something that happens *between* people. The author shows how oncology may build long-term relationships with chronically patients. Hope, technology and inequalities are related topics discussed in the anthropology of cancer. “Biotechnological embrace” gives people hope for a cure (Delvecchio Good, Good, Schaffer, & Lind, 1990), but limited access to the best treatment may reveal human inequality in a society. This is evident in Livingston’s study in Botswana, for instance, where clinical cancer practice often is improvised due to insufficient technological equipment, lack of medicines, instability of knowledge, scarcity of bed space and other challenges.

When we, as a research team, were exploring the material we had collected from cancer patients regarding their patient pathways, a pattern which reminded us of Turner’s (1957) model of social drama emerged. Turner defined social drama as “units of aharmonic or disharmonic process, arising in conflict situations” (Turner, 1974, p. 37). In his model, the anthropologist suggested a dynamic process of four phases in contexts of conflict and crisis: 1) breach of normality, 2) crisis, 3) redressive actions, and 4) reintegration or schism (pp. 38–40). The model of social drama has been widely used by social scientists in the analysis of various crisis situations (e.g., van der Grijp, 2004; Vannini, 2008). To the best of our knowledge, the model has not previously been used in studies to analyze patient pathways. Thus, in order to further provide structure to the process of gaining a better understanding of person-centred pathways, we explore whether or not the model may be transferrable to patients’ accounts of pathways with long-term and severe conditions and if the model has public health relevance.

Together with a focus on the process as a whole, our main interest in this paper is to examine how the participants redress after receiving the cancer diagnosis. Much in line with McMullin (2016) who points out that: “ethnographies can tell us about the diverse modes of community response to suffering” (p. 262). Turner suggested one should carefully study what is going on in this phase as it reveals a society’s capability to resolve the crisis and which mechanisms are brought into play to create stability (Turner, 1974). Applying this notion to patient pathways, we hope to gain an understanding of lived life with long-term severe illness. We also hope to gain insight into how the national health care system, which is an important social agent, operates from the participants` perspective. This is an important goal to achieve, as a model that successfully provides insight into the journeys patients embark on may function as a map. When accurately drawn, such a map will have “a *similar structure* to the territory, which accounts for its usefulness” (Korzybski, 1994, p. 58).

Related to the model of social drama, we also try to understand the illness experience through the concepts of liminality and communitas. The concept of liminality has been applied in numerous previous studies of illness (e.g., Hallstein, 1992; Jackson, 2005; Little, Jordens, Paul, Montgomery, & Philipson, 1998; Mattingly, 1998). Stoller describes and analyzes his own cancer experience by using both communitas and liminality (Stoller, 2004, 2013). Liminality is based on *limen*, meaning threshold. It was originally used to describe the middle phase in rites of passage (van Gennep, 1960). In later works, Victor Turner used and elaborated on van Gennep’s concept, and developed *liminality* to a complex phenomenological concept describing the experience of being betwixt and between states or stages (Turner, 1967, 1970, 1974, 1977; Turner & Edith Turner, 1985). *Communitas* is a phenomenon which often is experienced in the liminal phase. Amongst other characteristics, *communitas* is a spontaneous and intense experience of togetherness and collective joy (Turner, 2012). Understanding liminality and communitas as related to patient pathways may help us comprehending lived experience with cancer. This knowledge may be useful for peers, the health care system and educational purposes. We, therefore, explore our empirical findings in the light of these concepts.

Lastly, the majority of the anthropology of cancer is done in an American context and anthropologists are calling for more research around the world (Burke & Mathews, 2017; McMullin, 2008). This exploration of life with cancer in a Norwegian context is an empirical and theoretical contribution to the field of medical anthropology. Other anthropological cancer research from Norway that could be mentioned is Skowronski’s (2019) recent dissertation about sensations, emotions and embodied relations to local landscapes understood in the context of the aftermath of cancer.

Furthermore, while it is important to explore biomedical models and treatments in the global north, anthropology should also “propose meaningful and practical solutions to the dilemmas confronting those who suffer and die from this disease globally” (Burke & Mathews, 2017, p. 183). For instance, both Mulemi (2015) and Livingston (2012) found that cancer is invisible in individual and social discourses in African countries. This result in a false impression of the extensiveness of the disease and also late diagnosis. Anthropology has the potentiality to address and nuance health challenges in various contexts and from people’s perspectives. “Cancer is a global epidemic” (p. 180), Burke and Mathews (2017), argue. While mortality rates are decreasing in the global north, they are increasing in less developed countries. Burke and Mathews, therefore, suggest to “setting a global agenda for the anthropology of cancer” (p. 179).

The aim of this study was to get insights into life with cancer in Norway and to suggest a dynamic structure of the processes our participants went through.

The Norwegian context

Inglehart (2005) argues that modernization processes are often associated with human development, individualization and secularization of a society. Cultural changes such as individual autonomy, gender equality and democracy may take place as a result of economic development. In general, we assert that Inglehart's ideas apply to a description and understanding of Norwegian society. Equality is a central cultural value in Norway, as well as the other Scandinavian welfare states. This can also be seen in the conventional health care system which functions through egalitarian principles (Rothstein, 1998) such as universal coverage.

"The system is built on the principle that all inhabitants have equal access regardless of social status, income, and geography" (Squires, 2010, p. 42). By paying taxes, the society is collectively responsible for citizens' care in the context of illness (Norwegian Directorate of Health, 2009). The system is largely "free", but in addition to taxes, there are some out-of-pocket expenses for health care services which can be significant for some (Skudal, Bjertnæs, Holmboe, Bukholm, & Røttingen, 2010). However, the economy does not constrain anybody from undertaking conventional cancer care. In contrast to many other countries, private health insurance is not commonly used by Norwegian residents (Squires, 2010). The Norwegian Directorate for Health works to ensure quality of care as well as quality improvements. The focus is particularly on "safety and efficiency, patient-centered care, coordination, and continuity. Health promotion, disease prevention, and elimination of socioeconomic disparities are also targeted as priority areas" (p. 43).

Despite cancer care and treatment being cutting edge, The Norwegian Ministry of Health and Care Services asserts that treatment and care can be improved. A "partnership against cancer" has therefore been established in Norway and consists of Norwegian Cancer Society, the Norwegian Association of Local and Regional Authorities (KS), the four regional health trusts, cancer patient organizations, the Norwegian Cancer Registry and the Norwegian Directorate of Health. The five most important objectives in The National Cancer Strategy 2013–2017 were 1) more user-oriented cancer care, 2) Norway shall be a leading example of good patient care, 3) Norway shall be a leading example of cancer prevention, 4) more patients shall survive and live longer with cancer, 5) the best possible quality of life for cancer patients and their relatives (Norwegian Ministry of Health and Care Norwegian Ministry of Health and Care Services, 2013, pp. 5–6).

Norway has approximately 5.3 million residents. 17.3% of the population are immigrants and Norwegian-born to immigrant parents (SSB, 2018). The Sami population are the indigenous people of Norway. In addition to being a part of Norwegian culture, the Sami people also have their own distinct cultural features, history and language. Norway is at large a secularized country and the conventional health care system has a strong position.

> Scandinavian welfare states like Norway represent a cultural context in which citizens who become ill are supposed to trust and receive health care within the conventional health care system that is officially subsidized and based on biomedical knowledge. (Kiil & Salamonsen, 2013, p. 483)

Different ways of thinking about the patient–doctor relation, knowledge about how the system works and language barriers are only some of the problems present in the public health care (Småland Goth & Berg, 2011).

Complementary and Alternative Medicine (CAM) is a crucial treatment option for many Norwegians. According to NAFKAM's survey of CAM use in Norway, 36% of the respondents reported that they had used CAM once or more in 2016. Massage was the most used CAM treatment, followed by acupuncture, naprapathy, other, zone therapy, copping, osteopathy and healing (Nifab.no, 2018). A study of CAM use in Norwegian hospitals showed that 64,4% of the responding institutions offered CAM at the hospital. Acupuncture, art- and expression therapy and massage were the most frequently used methods (Jacobsen, Fønnebø, Foss, & Kristoffersen, 2015). In Norway, traditional healing practices are still used and in some parts of Norway, it is common to utilize of both traditional healing and conventional care (Kiil & Salamonsen, 2013). Globalization processes as well as Norway's cultural diversity create a medical pluralism in the country, constantly shaped and re-shaped by continuity and change.

In summation, except for out-of-pocket expenses, the Norwegian welfare system covers citizens' expenses of biomedical treatment. Equal access to care is an emphasized ideal in Norway, and in the context of cancer biomedical treatment is the preferred choice for survival. However, the use of CAM and traditional healing are common in Norway, and particularly in the context of cancer. A goal in the national cancer strategy is to become more user oriented and to help provide best possible quality of life for cancer patients as well as their relatives. This shows a direction of not only focusing on cancer as a biological disease, but rather as a multi-dimensional illness. To support persons' journeys in the context of cancer, health authorities need knowledge of what patients are going through over time from a patient perspective. For instance, which needs do patients have and how may these needs change, how do they cope and make sense of their choices? How is persons' life after completing the biomedical treatment? The biomedical aspect of the illness is only a small part from a patient perspective. The model of social drama suggests both a structure for the pathways as a dynamic process, but at the same time, it allows us to grasp patients' lived lives inside and outside of social health care.

Material and method

The research group was made up of a medical doctor, a medical sociologist, and two medical anthropologists. This diversity in backgrounds was experienced as a strength for the project, both because it brought in a variety of knowledge, and because it led to fruitful discussions that arose from different perspectives.

This paper is based on the data and preliminary inductive analysis gained from the PATH (Patients` Accounts of Trajectories to Healing) study conducted by NAFKAM (e.g., Salamonsen, Kiil, Kristoffersen, Stub, & Berntsen, 2016). The research process has been "a round dance between theory, method and data" (Wadel, 1991, p. 129), going backward and forward between the different aspects of the study.

In the PATH study, participants were identified in the electronic patient records of the University Hospital of Northern Norway (UNN). The inclusion criteria were: Aged between 18 and 70 years, diagnosed with rectal cancer Tumor–Node–Metastasis stage I–III (Dukes A–C) within the last 6 months, and having already completed the primary surgical treatment. Due to travel costs only participants who resided less than 500 km from the hospital were approached. In other words, the participants all lived in the northern part of Norway. In 2011, 20 eligible patients were identified and were sent letters of invitation from the research team. Ten of the 20 patients gave written informed consent. One, however, withdrew after the baseline interview. The final PATH study thus included nine patients aged between 54 and 68 years old. It should also be noted that all were Norwegians, that is to say, none with immigrant or refugee background participated.

The researchers then executed a longitudinal qualitative study, where they followed informants over a period of one year. They completed a total of five in-depth interviews with each participant, which included one baseline interview, three quarterly interviews, and one exit interview. Baseline was conducted face-to-face, while the following interviews were undertaken by telephone. The interviews were conducted by the second and third author as well as a research assistant. They encouraged the participants to write diaries during the periods after the baseline interview and each preceding interview. These diaries were to outline the health-related events that participants identified as important. They were shared with the interviewers prior to the semi-structured quarterly interviews. They were used as the starting point for the conversation, which followed an interview guide. For those who did not write diaries, the interview also included a brief exploration of the main health-events since the last point of contact, as the participants remembered them. The aim for both the diary and the interview guide were to get information about both life events and health events that were perceived as important to the participant in the last 3-month period. All interviews were audio recorded and thereafter transcribed.

Longitudinal qualitative research "can add depth and understanding to health care research, especially on topics such as chronic conditions, adherence and changing health policies" (Grossoehme & Lipstein, 2016, p. 1). We wanted all participants to share their experiences of that which had been important after these experiences had been processed. Although, with interviews, we lose the observations and interaction with the participants in their everyday context, to our purpose, the longitudinal qualitative interview approach was the most suitable.

Data analysis methods

All interviews were read attentively with an inductive approach (Bernard, 2011). The research team attempted to step inside the experiences of the persons telling their stories to get a grasp of what it was like to discover and live through the treatment of cancer. The researchers applied no pre-determined framework. The research team started the process of analysing the material by "'playing' with the data and searching for promising patterns, insights or concepts" (Yin, 2014, p. 132).

We chose to use content analysis based on the aim and research questions. Content analysis is "primarily used to identify critical processes" (Lederman, 1991, p. 169) and is beneficial for testing hypotheses and models (Marshall & Rossman, 2011). The aim is to attain a condensed and broad description of the phenomenon, and the outcome of the analysis is concepts or categories describing the phenomenon. Usually, the purpose of those concepts or categories is to build up a model, conceptual system, conceptual map or categories. (Elo & Kyngas, 2008, p. 108)

Krumeich, Weijts, Reddy, and Meijer-Weitz (2001) emphasize a "dialogical" anthropological approach, combining the anthropologist's scientific knowledge with persons' lived experience to avoid ethnocentrism and deepen "anthropological insight into the sociocultural context of health and health behavior, and adds to the critical consciousness of all parties involved" (p. 128). Emic and etic perspectives are here complementary, and were applied to give the richest understanding of the long-term, severe illness as a process.

To identify illness processes in the material, the researchers attempted to "follow the loops" (Barth, 1993, p. 249) by mapping interrelated events. During this process, it was important to pay attention to "the precise pathways taken by patients, plotting decision points over time, and exploring reasons underlying their course" (Orr, 2012, p. 515).

The analysis process continued with the research team making condensed written versions of the interviews as stories, and playing with mind maps and various illustrations to visualize our ideas and categories. The interpretation of our material was then presented and discussed at several forums. We also tried to find empirical data that did not match Turner's model of social drama. We further analyzed by coding interview transcripts using NVivo 11 pro.

The NVivo program is an analysis tool one can use to organize data and ideas (Richards, 1999). We designed a node system, where each stage of the social drama model was classified as parent nodes. Under each of the phases, we created various child nodes or subcategories that were related to the participants' experiences and actions. This allowed us to "draw and link any relationships that [made] sense to [our] understanding of the data" (p. 68). This organization of the data let us easily access participants' accounts of what we interpreted as four phases. The link between the theoretical framework and the empirical content became very useful in the process of verification, group discussions, and writing.

Ethical considerations

This study was carried out according to the Declaration of Helsinki (World Medical Association, 2000) and it received approval by the Regional Committee for Medical and Health Research Ethics and the Norwegian Data Protection Authority. Letters of invitation were sent to all of the participants. The letter also included ethical information. Participation was voluntary. The participants were informed that they were free to withdraw from the project at any time. Information about the project was provided. After the interview process, the audio files were transcribed to text by a transcriptionist who signed a written consent to professional confidentiality. Further, personal information that could identify the participants was deleted from the transcript. All participants are anonymized in the text. Information that could identify the persons was not used.

Findings and discussion: cancer pathways as social drama

Our hypothesis is that pathways with cancer follow the same underlying structure as a model of social drama: breach of the norm, crisis, redressive actions, and reintegration/schism. We explore our empirical findings in light of Turner's model of social drama to determine whether the model is applicable to long-lasting, severe illness pathways. This section will follow Turner's four phases chronologically. We will describe Turner's understanding of each phase and how we interpret this into the participants' experiences.

1) Breach of norm: Recognition of symptoms

In Turner's model of social drama, he described the first phase as occurring when a "breach of regular, norm-governed social relations occurs between persons or groups within the same system of social relations … " (Turner, 1974, p. 38). Bringing this down to an individual patient's pathway, our findings show that the illness as a process started when the participants recognized bodily symptoms. These symptoms were a breach of normal bodily function. Specifically, they all had some kind of stomach problems such as diarrhoea and/or pain. Six of the nine participants observed blood after being on the toilet. "This is not normal," Julie thought after having long-time pain in her rectum. Per said, "I felt healthy. Woke up every morning with no pain." However, he had seen some mucus in his excrements. Since there was a history of cancer in his family, a friend advised him to get a check-up. Some of the participants interpreted the symptoms as being in less serious states. Eva, for instance, thought that the change in her toilet routines was haemorrhoids. The breach of normality motivated all of the participants to consult a medical doctor.

A breach of normal bodily function may be viewed as both an individual and a social matter. When a person becomes ill or notices he or she may be ill, the breach of the norm is experienced by the individual. However, depending on the severity of the illness, it may also disturb the social groups to which he or she belongs, such as family, friends, and work. In a Norwegian context, it expands to a macro level as in principle all citizens are responsible for restoring the health of the sick. The sick becomes entangled in a sociocultural health and welfare system that functions as a redressive machinery responsible for taking care of the patients. Illness is, therefore, a social matter both on a micro level and a macro level.

2) Crisis: receiving a cancer diagnosis

After the initial breach of the norm, the participants all entered the conventional health care system in order to determine the reasons behind the breach of the norm. Each of them consequently received a diagnosis of rectal cancer. Based on their descriptions of this stage, it is clear that the initial breach of norm escalated into what Turner defined as the crisis stage in the social drama model. This stage "is always one of those turning points or moments of danger and suspense, when a true state of affairs is revealed, when it is least easy to don masks or pretend that there is nothing [wrong]" (Turner, 1974, p. 39).

For Mari, her world after the cancer diagnosis was total chaos. Mari had gotten colorectal cancer, the same kind of cancer that her husband had struggled with for years. Jacob experienced a similar sense of chaos. The experience of getting a cancer diagnosis in his own words:

> I was alone on a bus when I received the message about that. It was a very special experience. I immediately felt that I was outside the rest of the world. It was me and the others. And then I went fast into … eh … how do I explain it … the most extreme thoughts on what this could lead to: That one doesn't have a long time left, that one can lose both life and children and wife and all that.

He described getting the diagnosis as giving him a catastrophic feeling, and metaphorically said that he went down to the basement and into the darkest darkness. Mari and Jacob were not alone in having strong reactions. Elias used the word shock to describe the event, and Per said the diagnosis was a mental strain and that he thought about death. Ken said that getting the diagnosis was unreal and that he was rendered speechless, that it was a shock, and that it was a reminder. Emma felt that it was hard to get the diagnosis, and had such thoughts as "this is the end," and "life is unpredictable."

Many of these reactions are in line with the findings of a study that shows that, in addition to the initial "shock", "approximately 16–25% of newly diagnosed cancer patients experience depression or an adjustment disorder with depressed mood" (Osborn, Demoncada, & Feuerstein, 2006, p. 14). However, not all participants experienced this depressed mood. For example, Eva, Julie, and Elias explicitly emphasized that receiving the diagnosis also was associated with a pragmatic attitude. What needs to be done to get well again? For all, however, the crisis was something that could not "be ignored or wished away" (Turner, 1974, p. 39). It required certain redressive actions to be solved.

3) Redressive actions: medical pluralism

The next, and third phase, is characterized by approaching the individual's or the group's problems by undertaking certain actions. "In order to limit the spread of crisis, certain adjustive and redressive 'mechanisms' … informal or formal, institutionalized or ad hoc, are swiftly brought into operation by leading or structurally representative members of the disturbed social system" (Turner, 1974, p. 39). The afflicted individuals or groups have to approach the disturbed situation with certain kinds of actions aiming to resolve the crisis.

> These mechanisms vary in type and complexity with such factors as the depth and shared social significance of the breach, the social inclusiveness of the crisis, the nature of the social group within which the breach took place, and the degree of its autonomy with reference to wider or external systems of social relations. (p. 39)

Depending on the situation, this may involve political processes, legal-juridical processes, and/or ritual processes. Turner gave the latter special attention. In the context of long-term illness, redressive actions intend to restore the health and quality of life in a suffering human being, to bring persons from an ill state to a healthy state. In our material, we met persons who composed their pathways with a wide range of health-seeking strategies. Some compositions were more complex than others. In the initial redressive stage, they all followed the medical doctors' advice regarding conventional treatment and had trust in the conventional health professional's knowledge. Specifically, soon after getting the diagnosis, all the participants had an operation and/or treatment with chemotherapy and/or radiation therapy. In Norway, this represents the institutionalized, formal redressive machinery that is activated when citizens need health care. The medical doctors and the biomedical system are an authority in Norwegian culture with regard to cancer treatment.

However, a life with cancer is not only about removing a tumour. In our material the participants coped with challenges such as fatigue, pain, insomnia as well as stoma. Furthermore, they had to deal with identity problems, changed social roles, fear of dying and losing loved ones. In addition, other life events and/or crises may occur parallel to cancer. Thus, later in their journeys, the participants began composing their individual pathways by using health-seeking strategies outside of the conventional health care system.

The participants used a combination of approaches to meet manifold needs. Some were complex compositions with traditional healing, complementary medicines, talks with priests, prayers, walking, being in nature, humour, physical training, diet change, and own care. Others were less complex and only made use of self-care. We interpret these practices to be health-seeking actions that are ritualized and rooted in Norwegian culture. This understanding is in line with Turner who argued that cultures "obviously affect such aspects as the style and tempo of the social drama" (Turner, 1974, p. 292).

Rituals, in general, may have many different effects on people. For example, a ritual "does not simply make them feel stronger, it makes them stronger" (Olaveson, 2001, p. 94). Redressive rituals are structurally similar to rites of passage as they intend to bring persons or groups from one state to another. They include rituals of affliction, which are used to approach individual health problems (Turner, 1974).

These are therapeutic in nature, and include healing rites performed by ritual specialists to restore health and social stability. It is in the redressive phase that pragmatic techniques reach their fullest expression, and the involved are here at their "most self-conscious and may attain the clarity of someone fighting in a corner for his own life" (Turner, 1974, p. 41).

A few of the participants' individual approaches are described here in more detail. Regard to redressive actions, Eva`s pathway was complex. She had conversations with a Christian priest and a psychiatrist. They had different approaches, but she experienced that they complemented each other. Eva had massages, changed diet and undertook a wide range of physical activities. For sleeping, she used conventional medicine or read a book. "Writing down my thoughts helps me", she said and emphasized diary writing. Humour, positive thinking, being social, spending time at the cabin and picking berries were important for her well-being.

David, Jacob, Ken, and Per had simpler health-seeking profiles, but they also undertook actions outside of the public health care system to improve their health. For example, Per attended different courses to learn to live with a stoma. He also went to Spain to get physical treatment and training. "But the most important things were those I did myself," he said. "I walked five or six hours every day. When I came back, I felt much better than when I left". Our findings suggest that the redressive actions come in many forms and for various aims. The dynamic characteristic of illness and life, in general, may require a person to be flexible and adjust their behaviour according to their needs. It also seems like actions associated with health, such as having walks in a Norwegian cultural context, become even more meaningful in a pathway with cancer where the actions are utilized for the better quality of life in a time of cancer.

4) Reintegration or schism: back to normality or continuous liminality

In Turner's social drama model, reintegration is related to the concept of social equilibrium, where the "new equilibrium is seldom a replica of the old" (Turner, 1957, p. 161). This last phase of the model should thus be understood in broader terms than just a problem being fixed, as not all crises can be successfully resolved. Rather, the outcome of a social drama is reaching a new normality. This can mean either reintegration with a restoration of stability, or the recognition of an irreparable schism.

Overall, normalization and getting back to everyday life were emphasized as important goals by all the participants. According to Hargraves, Behfar, Foxen, Montori, and Terzic (2018) it should also be a goal for health care:

> For patients with cancer in remission or for patients recovering from open heart surgery, the task is to help their psychology overcome the shadow of their diagnosis or the experience of surgery, to recast their life as that of a healthy person integrated in society … resolution of the patient's situation and the reintegration of his life and family cannot be achieved solely by eliminating that threat. (p. 1, 3)

Reaching a healthy state and regaining normal bodily functions were some of the motivations behind undertaking the redressive actions. However, "normal" is a relative concept. In the context of illness, Mattingly's description is explanatory:

> This insistence on the ordinary and the 'normal' carries symbolic messages that people are capable of making the transition from patient to member of society, assuming in some fashion the roles and cares and community that characterize life without disability. (Mattingly, 1998, pp. 165–6)

For patient pathways, equilibrium can be considered on both the individual and social level, where normalization means achieving a new state. It can thus be seen that the last phase in our model is characterized by some ambiguity as the concept of states is equivocal. Despite this ambiguity, we found that patients may reach one or a combination of the following states after the redressive phase: 1) Biomedical health, 2) reconciliation, and/or 3) social integration.

Biomedical health

A state related to a patient's biomedical health would be a natural last phase in the social drama model. The goal of taking redressive actions is to regain one's health. Being finally reported as fit would open for the patient's reintegration into his or her own life as well as into society. Dying or being diagnosed as terminal could be considered irreparable schisms.

Reconciliation

A pattern in the material shows that participants reconciled with their lives as they were, and did not think about how life could have, or should have, been. Mattingly compares the aim of occupational therapy to Danforth (1989) and his description of religious healing, which for instance is …

> … to reformulate people's interpretation of their own condition … people can be healed even if their disease is not cured or their symptoms alleviated. Healing in this sense is comparable to a conversion experience. (Danforth sited in Mattingly, 1998, p. 164)

In a similar manner, Turner and Avison (1992, p. 36) explored propositions drawn from crisis theory that "recognizes life events as representing opportunities as well as hazard." Furthermore, Erikson (1980) argued that when an issue is resolved it does not necessarily imply that it is solved. Rather, resolution of an issue for Erikson …

> … refers to a temporary or enduring positive decision or settling in relation to the personal meanings of the event … when resolved, the individual may emerge from these engagements with a new skill, confidence, or other enabling self attitude that is added to his or her repertoire of responses or coping mechanisms. (Turner & Avison, 1992, p. 37)

Erikson's idea of positive settling as a successful outcome of a crisis, as well as Danforth's and Mattingly's notions of reformulating people's interpretation of their condition, hold a similar perspective as found in Epictetus' (55–135 C.E.) philosophy: We cannot control diseases in our bodies, but we have the capacity to adapt and react to the situation in particular ways (Formisano & Van Der Eijk, 2017).

Our findings correspond with this understanding, and we argue that this is a central feature of the last phase of the social drama model, seen in the context of a long-lasting and complex illness pathway. We may say that this understanding of resolution constitutes the transition into the last phase. Even though Jacob's diagnosis resulted in the permanent stoma, he had learned to live with it and accepted life as it was, and he even got a new and better perspective on life:

> I got a new understanding of that which really matters in life, what one should care for and to carefully select which wars to fight. Therefore, I would say that I am standing on a different platform or level than before. Something different than I had before, and that is in a positive sense. It has been experiences that have been very valuable, and that have led to a perspective on life that is very good. I enjoy life even more now than before.

In the end, he considered himself to be lucky because he had a better worldview than before the diagnosis. Summing up his pathway, Jacob first talked about the dramatic experience of diagnosis. "And after that, one goes through the phases of shock … and realization and reorientation," he said. After a period of worries, he reconciled himself with the situation. In a similar manner, Julie told us that "one goes through a process, and in the end, you have to mentally adjust to the way things *are*."

To our understanding, this demonstrates a successful outcome of a pathway with cancer. Other participants also reconciled with life as it had become. Some even emphasized that they had gained a new and better perspective toward life after the pathway with cancer. This is in line with the findings of the extensive literature on post-traumatic growth and personal growth in the context of cancer (e.g., Moreno & Stanton, 2013; Mystakidou et al., 2008; Porter et al., 2006). However, patients may also struggle with anxiety and depression after a pathway with cancer. For instance, a study of breast cancer patients revealed that the condition may cause post-traumatic stress (Arnaboldi, Riva, Crico, & Pravettoni, 2017).

Social integration

Many participants had a drive to become integrated back into their previous social structures and statuses. Some examples include participants who had goals of going back to work, being able to once again live in their role as a mother, or just getting back to everyday life. Several of the participants said that they realized that family and friends were the most important things in life. This led one of the participants to even move to another city in order to gain closer contact with the family. Being able to achieve these goals can be seen as the patient entering a clear state of reintegration. Mari, for instance, felt that she lost the role as a caring mother during illness. It was important for her to get back to this role:

> I have been so afraid … I just had to use all my energy to cope with the cytotoxic treatment … To one day get back to the point where I could be mom again. And kind of normalize to a state where we all were a family again. We went travelling and I took charge at the check in. Then one of my girls said: Mom, now I suddenly realize that you are on your way back again.

Our material shows that normalization of life after cancer can mean different things to different people and depend on the individual context. For five of the nine participants, this included new perspectives on life. We further argue that the new normality is an outcome of the cultural and ritualized activities undertaken in the redressive process. In a similar way, Mattingly (1998) suggests that …

> … therapeutic plots are secular rituals that help patients make the transition from illness reality to new reality and, even, a new self. This passage occurs along many different dimensions all at once. A healing process involves not only the body but social and cultural shifts as well. (p. 64)

We believe that normality is not a static state. What individuals experience as normal will always be in flux in an impermanent conditioned life. The states of biomedical health, reconciliation, and integration into social structures and statuses are, however, some more or less concrete categories that can be used to understand the last phase of Turner's model in the context of a severe, long-term illness.

However, not all participants found themselves back to a normal life, even after the medical doctors have reported them fit. Many find themselves in a state of being neither ill nor well (Solem, 2018). Stoller (2013) calls this phenomena "continuous liminality", while Little et al. (1998) use the term "sustained liminality". These concepts must be explained in greater detail and understood in relation to liminality in general. We have therefore chosen to elaborate on this in the following discussions.

Liminality—in between states

When receiving the diagnosis, Jacob said that "I immediately felt that I was outside the rest of the world." Mari told us that her world became "total chaos". Elias said that it was like sitting on the outside and looking into a mirror. "It is almost like it isn't you. Very strange." Eva said that the pathway had been like "being in a bubble". A cancer patient in Coreil and colleagues' material said that:

> So this is the night and this is light [pointing at a visual image] so this is a sun and here is the moon with the stars. So when you start, you know, with the cancer, you are in the dark, you don't know anything, you are scared … And then when you pass a key moment, is the transition that you see the sun, like what they say, the light after the tunnel. (LA, 53 years, single) (Coreil, Corvin, Nupp, Dyer, & Noble, 2012, p. 299)

We interpret these statements as experiences of liminality. Turner actually describes liminality as being in a tunnel.

Being liminal relates to being "betwixt and between" states, "a relatively fixed or stable condition" (Turner, 1970, p. 509). It is an experience of chaos, ambiguity and being outside of the world. Liminality for Turner is " … a fructile chaos, a fertile nothingness, a storehouse of possibilities, not by any means a random assemblage but a driving after new forms and structure … " (Turner & Edith Turner, 1985, p. 295). In other words, being in liminality means there is an inherent possibility of change and even transformation. Liminality can be a creative state where new ideas are born and a springboard to a new, better state. But, it may also be destructive depending on the condition and how the individual and the surrounding redressive machinery cope with the problems.

Several social scientists use the term in the context of health and illness research. "In the clinic, patients are caught in a liminal state against their will", Mattingly (1998) argues. She shows how persons with disabled and stigmatized bodies are separated from everyday life. But the separation is also "institutionally marked and increased by the non-ordinary world of the clinic in which they are confined. Here they are divested of their usual surroundings, roles, and occupations. Even their clothes are different" (p. 165). This can also apply to cancer patients' realities.

Stoller (2013) experienced that cancer unfolded as a rite of passage and argued that "cancer forces you, like any neophyte, into a liminal state. The side effects of cancer treatments result in noticeable physical changes—a pale pallor, a slow unsteady gait, hair loss, and a frail body—that set the patient apart from 'normal' people". Stoller makes use of Turner's liminality concept and argues that being in remission is a state of liminality (Stoller, 2009). However, he suggests that Turner's finite view of liminality does not fit with cancer patients' liminality. A cancer patient's experience of liminality never end, he says, in opposite to Turner's rite of passage. While participants of rites of passage leave liminality behind when reintegrated back to a new stage, a cancer patient does not reintegrate to a normal social routine, not heading back to "the village of the healthy" where health is taken for granted, but are continuous in "remission", according to Stoller. Borrowing Maurice Merleau-Ponty's idea, he argues that a cancer patient is always "everywhere and nowhere" and call it "continuous liminality" (Stoller, 2004, 2013).

A similar notion is made by Little et al. (1998) who aimed to understand the experience of having colorectal cancer through the concept of liminality. They believed that "liminality of serious and chronic illness is experienced in two stages—an immediate phase of acute liminality, and an enduring phase of sustained liminality which may last for the rest of the patient's life"(p. 1490). Since the body contains both the cancer and the self, there is an embodiment of the illness, they argue. This ambiguity is also present in Stacey's narrative. After removing her tumour she asked herself: "I was now a cancer patient; or was I?" (Stacey, 1997, p. 4). Malignant cells could have been left behind. Overnight her identity became reinvented and her story became one of uncertainty and unpredictable future, she writes.

With both Little and colleagues as well as Stroller's notion of a lifelong liminality, we are left with an ambiguous understanding of cancer patient's reintegration into society. Several of our participants reported during the interviews (some early in the process) that there was not much more to say, that they had started working and that everything was back to normal. At the same time, the same persons expressed that the shock of cancer had made an impact on their life. We suggest that a solution would be to distinguish between two different aspects of liminality: 1) social status and roles and 2) psychological and existential experiences of cancer. In this way, we can understand liminality with two thoughts in our head simultaneously. A person may integrate back to previous social statuses and roles such as occupation and the role of a strong and caring mother, but at the same time never arrive in the village of the healthy where a healthy state is taken for granted. Back to structure on one level, continuous anti-structure on another.

With continuous liminality and sustained liminality in mind, we are nevertheless left with the question where a pathway with cancer ends? But also, following Stacey (1997) and her cancer experience: when does it all start?

Communitas—collective effervescence

As liminality is about separation from the ordinary world, it may also be experiences of connectedness, joy and relational unity. A phenomenon often associated with liminal phases and rites of passages is communitas.

> For Turner, the liminal is more than a way station between beginning and end; it is a space in which people tend to be humble. It is also a space in which people do what they are told to do—usually without complaint. According to Turner, people in liminal spaces often accept routines of pain. Moreover, people go through this experience together with others, which means that liminality creates a profound, if fleeting, camaraderie, a feeling that erases past distinctions among age, social class, and ethnicity. Turner called this kind of situational camaraderie "communitas." (Stoller, 2013)

The separation from social structure through a breach of the norm in a social drama may lead to a social anti-structure where people are liberated from previous social statuses and not limited to playing certain roles in their interactions. Edith Turner has worked extensively with the concept. Communitas, she argues, is "a group's pleasure in sharing common experiences with one's fellows" (Turner, 2012, p. 2), an intense and spontaneous feeling of togetherness, equality, strong relationships, and being in the same boat. Communitas has similarities with Durkheim's concept of collective effervescence, which is defined as temporary experiences characterized by "intense emotion and excitement, and a bond of community and unity among participants, such that they feel morally strengthened" (Olaveson, 2001, p. 101).

In our material, the social anti-structure may, for example, be observed when the participants are on sick leave and/or are hospitalized. As for Stoller (2013) and his interpretation of the movie 50/50 and his own cancer experience, we view the administration of cytotoxic drugs in groups as a kind of secular, modern rite of passage where communitas may occur. Eva expressed feelings of special bonds to the other patients in the infusion room. "We were joking about what kind of wigs we were going to buy, and things like that," Eva said. "My friend was going to have two. One party wig *and* one for everyday life." Another patient joked about how Eva should call her husband and tell him to make pork rib and sauerkraut. When the food was finished, all the patients could jump into a minibus and eat dinner together.

> … the strongest example of communitas in the world might arguably be found in existential relations and pursuit of mutuality sought out by two strangers receiving infusions in a cancer clinic that is purposefully arranged to give comfort and inspire open discourse. Dark humor, the greatest tool of communitas in frightening conditions, came into its own in the infusion room. (Turner, 2012, p. 80)

Humour was prominent in our material. Another qualitative study of cancer patients in Norway emphasizes the importance of humour during a pathway (Roaldsen, Sørlie, & Lorem, 2015). Humour is not only a collective joy, but an engaging coping mechanism for various aims such as problem-solving, stress and anxiety coping, communication of difficult topics and safeguarding relationships, Roaldsen, Sørlie and Lorem argue. The communitas concept contributes to an understanding of the lived experience of a patient at a cancer clinic and the importance of relationships with other patients.

Contributions of the social drama model

The Norwegian Ministry of Health and Care Services (2013) is aiming for a more person-centred cancer care and improving patients' quality of life. Person-centred care is based on experiences, values, preferences and needs (Thórarinsdóttir & Kristjánsson, 2013). Furthermore, "in recent years health education practitioners have been looking for ways to extend the social psychological analysis of human behavior with approaches that focus on the cultural and social context of human behavior" (Krumeich et al., 2001, p. 121).

According to Todres, Galvin, and Holloway (2009), life is a journey embedded with meaning. They argue a patient may lose their personal journey if the biographical aspect is overseen in health care practices. To avoid dehumanization in health care, the focus on conditions must be combined with attention to persons' biographies. In other words, both who and how a person is, are important. Todres et al. (2009) argue that qualitative health research could be "meaningfully translated into practice in ways that place people as human beings at the centre of care" (p. 68). The postmodern experience of illness is more than a disease. It is a reflection of self and a personal narrative that demands to be understood (Frank, 2013).

The social drama model emphasizes people's perspectives, values, needs and experiences contextualized in an illness process. The model pays close attention to people's journeys, it does grasp how and who people are, and how this may dynamically change over the duration of time. Our use of Turner's model is in line with Todres' and Frank's concerns. By taking both biographical and clinical aspects of people's journeys into account, we think it could be an alternative to clinical pathway models with a sharper focus on humanizing care.

Ailinger (2003) argues that qualitative health research "makes important contributions to the quality of evidence-based practice" (p. 275), such as " … generation of hypotheses; development and validation of instruments; provision of context for evaluation; development of nursing interventions; development of new research questions; and application of Qualitative Outcome Analysis" (p. 275). There is a reciprocal and cyclical relationship between research, theory and practice, and research findings and theories are important for nursing practice (Saleh, 2018). "The primary purpose of theory in the profession of nursing is to improve practice by positively influence the health and quality of life of patients" (p. 18), Saleh argues, but also add that the validation of a theory must be made through practice.

Our use of the social drama model suggests various phases of a pathway with cancer, each with particular features. The model shows changing needs, people's lived experience of undergoing a pathway with cancer as well as treatment choices. Therefore, it could provide social health care with the knowledge that may be used for care planning and person-centred care. The model also introduces concepts such as liminality, continuous liminality and communitas in a cancer pathway context, which are essential in understanding and communicating lived experiences of the patients. We argue that the model also could be valuable in education. A constructive way of working with the findings could be to invite patients, peers and health care workers to a dialogue aiming to construct learning modules for educational purposes and to discuss the practical application of such a model in real life.

Future research

Since this is, to the best of our knowledge, the first time model of social drama has been applied to long-lasting pathways, an interesting approach for future studies is to apply the model at other sociocultural contexts. Moreover, Norway is a country with relatively high rates of immigration. Conducting a research project comparing immigrants' experiences to Norwegians' could show whether or not the model of social drama could translate to this group. Furthermore, the theoretical framework could enlighten how the immigration population experience 1) breach, 2) crisis, 3) redressive actions and 4) schism/reintegration. How are their needs, values and preferences compared to the Norwegians? Which challenges do they experience and in how can health care workers and policy makers improve care for this group. Such a research facilitates for discussions of cultural competency vs cultural humility, which we believe are central for best possible care in a globalized world.

Conclusion

In contrast to the cancer context in Botswana (Livingston, 2012), the access to appropriate conventional cancer care is well developed in Norway and may give the patients hope for healing (Delvecchio Good et al., 1990). The study of cancer pathways in Norway also shows a different picture than the inequality that is revealed in many contexts of cancer (McMullin, 2016). The welfare state's organization is built around the value of equality and the ideal of providing care to all, regardless of persons' social status and economy. The National Cancer Strategy 2013–2017, as shown in the introduction, for instance stated that Norway aims to be more user-oriented in cancer care, to be a leading example of good patient care and to provide the best possible quality of life for cancer patients and relatives.

Illness is not a static matter. We argue that Victor Turner's model of social drama represents a plausible understanding of the processes cancer patients are going through. Even if we have argued that the process begins with the recognition of symptoms and diagnosis, and ends reintegration/schisms, we need to recognize that the beginning and end are uncertain in the context of the larger life story. In the difference to the understanding of a pathway as equivalent to standardized care pathways, the model may potentially grasp all aspects of lived experience with cancer which are understood as important for the patients themselves. By focusing on what is important for the patients, this model relates to person-centred care and may, therefore, contribute to health authorities aim of creating better patient pathways, but are also in line with the national cancer strategy mentioned above. Furthermore, we argue that by looking at the data from the framework the social drama model provides, we have shown Norwegian cancer patients' pathways from the recognition of symptoms, diagnosis, coping strategies and reintegration/schisms. We have also seen that several of the participants got a new perspective on life in the later stages of our study. The use of the social drama model not only contributes to the development of theory in medical anthropology, but also contributes ethnographic data to the anthropology of cancer.

Our research shows how patients' needs, preferences and values may change over time. The social drama model may provide useful conceptual frameworks for health care workers, patient organizations and in educational work to both understand patient pathways and communicate patients' experiences. Communitas is a phenomenon that often appears when patients meet at the hospital, for instance when receiving chemotherapy. An extraordinary experience of unity that may strengthen patients morally, mentally and spiritually. The concept of liminality grasps the ambivalent experience of lived life with cancer, but equally interesting is Stoller (2013) and Little et al. (1998) who note that the liminal state may last for the rest of patients' life. This knowledge should be regarded as important for all working with cancer patients and who may be concerned with human suffering and quality of life in the context of long-lasting conditions.

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Ethical approval

The Regional Committees for Medical and Health Research Ethics (REK) approved the study (2009/1293/REK Nord).

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Paper 3

Hansen, F., Berntsen, G.K.R. & Salamonsen, A. (2020).

Medical pluralism in the aftermath of cancer: health seeking actions and cancer patients' shaping of trajectories to healing.

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Medical pluralism in the aftermath of cancer

Health seeking actions and cancer patients' shaping of trajectories to healing

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Abstract:

Because of better treatment methods for cancer, the number of survivals are increasing in Norway. In turn, the group of people struggling with late effects is growing. This qualitative study explores the complexity of health seeking actions among nine Norwegian persons with cancer; how they shape their trajectories to healing, with a particular focus on the aftermath of cancer. All participated in five interviews over one year. Various health-seeking actions were identified through content analysis, and categorized as conventional, CAM, self-care, religious coping and traditional healing. Medical pluralism particularly flourished in the aftermath of cancer, an ambivalent period after the completion of initial biomedical treatment. We found that the phenomenon is characterized by: 1) implementation of contradicting models of reality and making pragmatic choices, 2) continuity and change of health seeking actions, 3) medical pluralism as a process, and 4) increased use of CAM and self-care to improve health and well-being in situations where the conventional care system has few available treatment options. To support persons with long-term conditions, we need to know how they choose and make sense of their health-seeking activities. We argue that trajectories to healing are dynamic and shaped by people taking choices. This process could be understood in greater depth by applying the concept of medical landscapes.

Keywords: medical pluralism; medical landscapes; health seeking actions; CAM; self-care; medical anthropology, cancer

Word count: 7850 excluding one table

Introduction

Due to better treatments of cancer, the survival rates in Norway are increasing (Kreftregisteret.no 2018). However, many cancer patients experience that they are neither ill nor well in the time after being reported fit and having completed the biomedical treatment. Former cancer patient and anthropologist Stoller (2013) describes it like this:

> At the end of your regimen of treatment, you are not reintegrated into a normal social routine. Instead, you are in remission, which is neither here nor there. In remission, you are continuously betwixt and between. To borrow from Maurice Merleau-Ponty, you are in a space that is everywhere and nowhere. Once cancer has touched your being, there is no going back to a life in the village of the healthy, in which health is taken for granted.

This phenomenon of being neither ill nor well can be related to what Little et al. (1998) call ‘sustained liminality’ and Stoller (2013) ‘continuous liminality’. Frank (2013) speaks about the ‘remission society’ and Sontag (1978) about ‘dual citizenships’- one in the kingdom of the well and one in the kingdom of the sick. In the aftermath of cancer people often struggle with problems such as uncertainty, various negative emotions, pain, existential and social challenges, body image concern and fatigue (Linda et al. 2001; Heydarnejad, Hassanpour, and Solati 2011). An important insight of a pathway with cancer is that ‘restoration of quality of life extends beyond cure or survival and embraces repair of the patient’s confidence and psychosocial well-being’(*Complementary and Alternative Medicine in the United States* 2005, 206).

A useful understanding of the aftermath of cancer may be provided by Little et al. (1998), who introduce an understanding of the experience of serious and chronic illness through the concept of liminality. First, patients experience an acute phase of liminality characterized by disorientation. Later, a sustained liminality manifests as a reconstruction of meaning of their lived life. Sustained liminality, ‘may last for the rest of the patient's life’ (1490), Little et al. argue.

A focus on health seeking behaviour in this phase is important. While conventional care providers have fulfilled their role in terms of completing the provision of cancer treatment, it is still a period or even a life time when many cancer survivors experience not only elation, but also considerable psychosocial distress, fear of recurrence, and uncertainty with regard to their future (Paraskevi 2012; Heydarnejad, Hassanpour, and Solati 2011). The aftermath of cancer is thus a period when people often find themselves on their own in a phase when they have not yet reached 'resolution' and the conventional health care may not have services to meet the persons' needs (Hansen, Berntsen, and Salamonsen 2018).

The research setting

Scandinavian welfare states such as Norway are based on egalitarian principles and universal programs that are not targeted at specific segments of the people, but strive to cover the entire population (Rothstein 1998). The universal programs, such as the bio-psycho-social health and welfare services (hereafter called conventional care) in Norway, 'may give rise to a sense of equal treatment and that the "rules of the game" in society are based on principles of fairness' (Kumlin and Rothstein 2005, 349). In the cultural context of the Scandinavian welfare states, the population is supposed to trust and receive conventional, publicly funded care when they get ill (Bergh and Bjørnskov 2011; Holmboe et al. 2011), but we also know that 'patients with chronic conditions make day-to-day decisions about self-managing their illnesses' (Bodenheimer et al. 2002, 2469). Multiple studies show that approximately 50% of persons with cancer engage not only in conventional care, but also in CAM (Horneber et al. 2012). The conventional health care system in Norway is based on scientific biomedical and evidence based knowledge in approaching the citizens' health problems (Kuhnle 1999). However, Norwegians with long-term conditions value and seek out knowledge, skills, methods and expertise, not only within conventional health care, but from any sources deemed legitimate and helpful.

> Despite this politically initiated illness behavior, an unknown percent of patients in Northern Norway turn to traditional healers who they actively use or would consider using when facing illness or crisis. Traditional healers are non-professional and noncommercial therapists who are closely connected to the local culture and world-views. (Kiil and Salamonsen 2013)

“Reading” is a form of traditional healing frequently used in Northern Norway. The healer reads healing prayers. Laying on of hands is another form of traditional healing where the healer lay his or her hands on the patient and uses his or her body as an instrument for an external supernatural power (Langås-Larsen et al. 2017). Norway is a secular country, but Christian ideas and practises are still important for many. A religious belief may take on another dimension during severe illness when existential questions rise. According to Eriksen (1996) the adoration of nature is a vital part of the identity of ethnic Norwegians. In kinder garden and primary school, the wilderness and nature experience is considered beneficial, and is central to many activities. Historically, the Lutheran faith in Norway has not drawn sharp distinctions between nature and culture. Rather, nature has been embraced and the church emphasize nature as an ideal place for meditation and reflection. Leaving the house for a walk is associated with peace, mindfulness, quietness and getting in touch with your inner self, Eriksen argues. This sociocultural context may potentially generate a complex web of health-seeking actions, and it is thus important to learn more about how persons with chronic diseases navigate through a landscape where multiple choices of care are available and frequently used.

Resurgence of medical pluralism

There is an increasing interest in the heavily debated concept of medical pluralism, as for instance reflected in Anthropology and Medicine’s special issue (vol. 23, 2016) on the topic. Referring to Cant, Penkala-Gawecka and Rajtar (2016) write:

> The ‘resurgence’ of the concept has happened not only because of the growing popularity of complementary and alternative medicine (CAM) [but also because of] the public health care funding crisis that is putting pressure on governments to change their health care policies. (129)

Such a resurgence provides an opportunity to explore health seeking choices in various contexts from a pluralistic perspective.

Medical pluralism originated from a study of Asian medical systems (Leslie 1976), and ‘implies that in any one community, patients and their carers may resort to different kinds of therapies, even where these have mutually incompatible explanations for the disorder’ (Hsu 2008, 316). Furthermore,

> …medical pluralism as a term suggest[s] that a cosmopolitan, Western, modern, scientific biomedicine [does] not have monopoly over health care, as [has] been taken for granted in medical circles, but that it [is] competing with a plurality of professionalized traditional medical systems. (317)

Since its inception, the concept has received much criticism and social scientists are searching for new concepts describing the phenomenon in question (Hsu 2008). Syncretism is a concept often used within religious studies, but it is also used as medical syncretism in studies of health and illness. It is a social phenomenon when several traditions merge into a fusion of various elements (Ringgren 1969). Medical pluralism simply state that there is a co-existence of traditions in a society, syncretism is more specific in how these traditions relate to each other within a community. Drawing on landscape theories from works such as Hirsch (1995), Hsu (2008) suggests “medical landscapes” as alternative to medical pluralism. We will therefore discuss our empirical material in light of medical syncretism, medical pluralism and medical landscapes later in this paper.

The concepts health-seeking behaviour, CAM, self-care and traditional medicine

Health-seeking behaviour is closely related to the concept of medical pluralism, and refers to the process individuals go through when constructing their patient pathways (Igun 1979). The concept may be defined as an ‘individual’s deeds to the promotion of maximum well-being, recovery and rehabilitation’ (Poortaghi et al. 2015, 2). This includes more than the individuals’ interactions with the conventional health care system: ‘It seeks to construct healthy approaches through every day practices facilitating the feeling of “belonging” via spiritual and religious practices and also the use and consumption of materials such as food and forms of treatments and therapies’ (3). Here we categorize health-seeking actions as conventional treatment, self-care, CAM, religious coping and traditional healing (see table 2). The goal may be social, spiritual, biological, and/or psychological. CAM is defined and understood in various ways. Since this study was conducted in Norway, we apply the definition of alternative treatment used in Norwegian legislation:

> Alternative treatment is understood to mean health-related treatment which is practiced outside the established health services and which is not practiced by authorized health personnel. However, treatment practiced within the scope of the established health services or by authorized health personnel is also covered by the term alternative treatment when the methods employed essentially are used outside the established health services (Lovdata 2003).

Complementary treatment is understood as alternative treatment alongside with conventional methods, and alternative as instead of the conventional treatment. Various definitions and interpretation of CAM may be problematic with regard to comparison of studies. Kristoffersen, Fonnebo, and Norheim (2008) therefore suggest an accumulative model describing extent of exposure to CAM in six levels. Level six includes all CAM use, including prayer. Furthermore, ‘prayer, physical exercise, special diets, over-the-counter products/CAM techniques, and personal visits to a CAM practitioner are successively removed from the model in a reductive fashion’ (ibid., 911). This model gives us a tool to precisely describe what we include and exclude in our use of the concept. Since we exclude physical exercise and prayers as CAM, and include special diets, over-the-counter products/CAM techniques and personal visits to CAM practitioner, the CAM users in our paper is defined by level 4 (CAM 4) (ibid.). One should also note that traditional healing is excluded from our use of the CAM concept, and instead defined as traditional medicine. World Health Organization (WHO) defines traditional medicine as ‘the knowledge, skills and practises based on the theories, beliefs and experiences indigenous to different cultures, used in the maintenance of health and in the prevention, diagnosis, improvement or treatment of physical and mental illness’ (WHO 2018).

A commonly used definition of the concept of self-care is that it encompasses ‘those processes that permit people and families to take initiative, to take responsibility, and to function effectively in developing their own potential for health’ (Norris 1979, 487).

Aims and research question

Current health policy programs define person-centered care as an overarching goal (Helse og omsorgsdepartementet 2001). To support a person’s self-care, it is necessary to understand how persons with long-term conditions choose and make sense of their health-seeking activities. To the best of our knowledge, no previous studies have investigated the concept of medical pluralism related to the aftermath of cancer. A clear and focused study of the health care alternatives people have and which choices they utilize in context of illness may provide us with a better understanding of health seeking behaviour (Stoner 1986). Thus, this paper explores which health seeking choices the participants made and what characterize these choices.

Material and methods

Ten persons diagnosed with colorectal cancer participated in a longitudinal study. They all had residence in the northern part of Norway and were between 54 and 68 years old. The baseline interview was conducted in autumn 2011, after which we conducted quarterly interviews for one year. The research group included a medical doctor, a medical sociologist, and a medical anthropologist. All together 46 interviews were conducted, by the second and third author and a research assistant. One of the participants withdrew after the baseline interview. The main focus was whatever the participants emphasized as having been important during the last three month period. A semi-structured interview guide was used with a focus on open-ended questions. The intention was to guide the participants in telling their stories. A content analysis was applied in order to analyse the categories of health seeking actions as well as the characteristics of medical pluralism (Hsieh and Shannon 2005). As outsiders, the analysis is our etic perspectives, descriptions, conceptualizations and interpretation of the insider, emic experience of lived life with cancer (Spiers 2008).

NVivo 11 pro was our preferred tool to systemize findings into nodes (Richards 1999). We present a table (Table 1) showing all the participants' treatment choices, each representing an individual care pathway construction.

After identifying and coding all health-seeking actions, we found that these could be categorized as conventional, CAM, self-care, religious coping and traditional healing. Some pathways were complex and included combinations of these categories.

Other pathways were far less complex and the participants used only a few self-care practices in addition to the conventional cancer treatment.

Table 1: Health-seeking actions.

	Health-Seeking Actions in Nine Pathways with Cancer				
Patient	**Conventional**	**Self-Care**	**CAM (level 4)**	**Religious coping**	**Traditional healing**
PER	• Surgery • Chemotherapy • Radiation therapy • Physical therapy	• Spending time with peers, friends and family • Physical activity: taking walks • Stoma care courses			

	Health-Seeking Actions in Nine Pathways with Cancer				
Patient	**Conventional**	**Self-Care**	**CAM (level 4)**	**Religious coping**	**Traditional healing**
EVA	• Surgery • Chemotherapy • Psychological treatment • Sleeping medication	• Spending time with family, friends and peers • Physical activity: taking walks, swimming, bicycling, strength training • Hobbies: reading books, solving sudoku and crosswords, writing • Being in nature • Positive thinking • Picking berries and being at the cabin • Courses in cancer coping • Use of humour • Professional networking	• Supplements: turmeric • Point drainage massage	• Conversations with priest	•
KEN	• Surgery	• Spending time with family, friends and peers • Hobby: reading books			

	Health-Seeking Actions in Nine Pathways with Cancer				
Patient	**Conventional**	**Self-Care**	**CAM (level 4)**	**Religious coping**	**Traditional healing**
JULIE	• Surgery • Chemotherapy • Radiation therapy • Physical therapy • Chiropractic treatment • Home nursing services	• Spending time with family, friends and peers • Hobby: hand work • Being at the cabin • Travelling • Help from a friend for housework	• Visits to a spiritual healer • Special diet program • Use of herbal medicine • Acupuncture		
ELIAS	• Surgery • Chemotherapy • Pain medication • Sleeping medication • Oxygen therapy • Blood-thinning medicine	• Spending time with family, friends and peers • Physical activity: taking walks • Hobby: reading books • Being in nature, picking berries, being at the cabin • Positive thinking • Use of humour • Self-hypnosis • Solitaire • Reflections on life	• «Electric machine» for leg pain		• Visits to a traditional healer («reader»)

	Health-Seeking Actions in Nine Pathways with Cancer				
Patient	**Conventional**	**Self-Care**	**CAM (level 4)**	**Religious coping**	**Traditional healing**
MARI	• Surgery • Chemotherapy • Radiation therapy • Physical therapy • Psychological treatment	• Spending time with family, friends and peers • Physical activity: taking walks • Hobby: hand work, making and watching art, writing diary • Being in nature • Professional networking	• Supplements: anti-oxidants • Chakra balancing • Olive oil	• Religious objects: praying cloth, angels and cross • Prayers • Conversations with priest	• Visits to two traditional healers
JACOB	• Surgery • Chemotherapy • Radiation therapy	• Spending time with family, friends and peers • Physical activities: running, skiing, swimming and taking walks • Professional networking • Positive thinking			

	Health-Seeking Actions in Nine Pathways with Cancer				
Patient	**Conventional**	**Self-Care**	**CAM (level 4)**	**Religious coping**	**Traditional healing**
EMMA	• Surgery	• Spending time with family, friends and peers • Physical activity: taking walks • Hobbies: painting, handwork and being at the art club • Being in nature and picking berries • Hobby: reading books • Philosophical thinking • Drink more water • Restoration of house			
DAVID	• Surgery • Imodium • Nutritionist consultation • Home care	• Spending time with family, friends and peers • Diet change			

Participants’ practices

All participants used a combination of approaches to cope with their illness and related challenges. We have chosen to represent Julie’s case because 1) she had a complex pathway, 2) it illustrates lived life and health seeking actions in the aftermath of cancer and 3) she was the only participant who considered alternative treatment instead of conventional treatment which illustrate interesting dynamics in her trajectories to healing. The case approach is chosen because it is a useful way to come close to the lived life experience. According to Yin (2014), a case can itself function as a communication means and provide insight into a phenomenon for specialists as well as non-specialists.

Julie's pathway

Julie's case differs from the other participants' in that she was the only person who considered a treatment alternative to biomedicine in order to cure the cancer. One theme in her story was therefore choice of biomedical treatment versus CAM in the acute phase. Adverse effects, coping with pain and interpretation of symptoms were important sub-themes related to Julie's decision-making. Another important theme was Julie's relationship with friends and family, including the importance of spending time together in nature, at the cabin and travelling. We have chosen to structure the presentation of Julie's pathway into the different interviews or 'conversations' in order to make clear what happened and when. The main focus is to display Julie's health-seeking actions in context of the challenges she intended to approach.

First conversation

The first meeting with Julie was eight months after she received her diagnosis. She had had symptoms for months that she thought were due to haemorrhoids. It was a Saturday night when Julie observed blood in the toilet and decided to take her symptoms more seriously. She went to the medical doctor on Monday, he said it was not cancer. However, the test results told a different story: Julie had colorectal cancer.

Julie became preoccupied with the idea that food and herbal medicines can cure cancer. She took courses and read books related to this, and visited a CAM provider who applied methods including herbal medicine and special diet. Julie wanted to postpone the conventional treatment and use a particular diet in combination with herbal medicine from India. She mainly ate vegetables, such as peas, carrots, and broccoli, and had a low carbohydrate intake. A family member, who also had cancer, had experienced good results using this method. However, this approach was not supported by the medical doctors and Julie decided to follow their advice. She went on sick leave and started conventional treatment. ‘Everything went very fast,’ she said. Since the tumour was relatively big, she first needed chemotherapy and 25 radiation therapy sessions, then an operation. The tumour got smaller. ‘And I have my own philosophy about that, it was not only the radiation therapy that made the tumour smaller, it was the diet too,’ Julie said.

Julie had terrible pain after the operation. She could not sit until six weeks afterwards. She had several consultations for the pain, but every time she got different answers and nobody could really help her. One theory the medical doctors had was that the pain probably was caused by the stitches at the end of operation being done too tight. Julie also experienced radiation as “awful”, with a painful open burn injury. In addition, Julie had a stoma, which ‘is an artificial opening, made by a surgeon, that allows faeces from the intestine to pass into a stoma bag’(Coloplast.com 2018). The bag is glued to the skin around the stoma, and changed as needed. It was challenging to change the stoma bag because of the pain from the operation and radiation injury. Julie did not talk much about the stoma, however. Instead, her main focus was centred around the pain. Julie wanted to get back to work, but because of the pain, she was not ready to start working yet.

Julie had support from her family. ‘My family wants me to get well,’ Julie said. They planned a trip that they would take together, something Julie really looked forward to.

Second conversation

The most important thing for Julie, during the preceding three-month period and outlined in her diary, had been to manage to stand and walk again. The pain described in the first conversation had diminished, but she was still sore. ‘In general I feel like I am well. Now I struggle with my hips, mostly the right, but I am now starting to get pain in the left one too. I also have pain in my lower back,’ Julie explained. She suspected that it was related to the conventional cancer treatment as other patients had described the same symptoms, and it was not until after the surgery, chemotherapy, and radiation therapy that these symptoms became prominent.

To cope with the hip problem, Julie had received treatment from a chiropractor with good effect, and she had made an appointment with a physiotherapist. Because of her physical state, a friend of Julie was helping her with housework.

‘I will try everything to get well again,’ Julie said. ‘I am that kind of person. Trying all possibilities. Everything.’ However, she admitted that she now ate her normal diet again, as she had gotten bored of the special diet. She attributed the disappearance of the tumour to the herbal medicine. She had been on a wonderful trip with her family and it felt good ‘to get a break from everyday life’. Now that she could stand on her feet again, she had also enjoyed spending time at her cabin and being in nature. Julie emphasized travelling and being at the cabin as the most important events last three months.

Third conversation

‘It feels like I am well, and there has not been much to write about (in the diary). It is mostly about everyday life, what I enjoy doing and things like that,’ Julie told us. ‘But my leg still bothers me, and it is getting worse and worse.’ As in conversation two, the most important thing for Julie during the past three months had been spending time at the cabin, being on small trips, and visiting family. ‘And the weather has been nice too, which makes it nice to be outdoors.’ She had hoped to spend more time in nature, but the continuous hips and back pain made it challenging.

Julie tried to find out what caused these problems, but the medical doctors still had no answers. Like in the second conversation, Julie claimed that these problems were caused by the biomedical treatment. After a long period of waiting, she finally had an appointment with a physical therapist, but the treatment made her hips even worse. Julie said that she was still planning on visiting another physical therapist. One who knew some ‘special tricks.’ ‘I do not give up easily,’ she said, and perceived herself as a strong person who finds solutions to problems.

Fourth and fifth conversations

Since Julie because of practical reasons was not able to participate in the fourth conversation, the fourth and fifth interview (with summary of the last 12 months) were merged together.

During the last period, Julie experienced increased pain in her hips and lower back. ‘I almost could not manage to stand on my own feet. It felt like my skeleton would not carry me,’ she said. The medical doctors had confirmed her suspicions: that the pain was due to her bone structure having been harmed by the radiation therapy. To treat the pain, Julie had visited a spiritual healer. ‘I can feel that the treatment has helped me [a lot],’ she said.

During this period Julie lost hope of ever returning to work, as the medical doctors had concluded that she would never be able to do so, and that she had to be cautious. Julie was therefore in the midst of applying for disability pension: ‘You go through a process and you just have to mentally adjust to the way things *are*.' To keep herself active she had begun doing crafts and participating in social gatherings.

In the last interview, Julie reflected over her pathway in retrospect. She emphasized the importance and effectiveness of correct diet and the Indian herbal medicine for removing her cancer tumour. With hindsight, Julie now believed that if she had had time to think it through, she would not have chosen conventional treatment. Julie explained that 'if I had removed the tumour with the herbal medicine, then I would not have had all these injuries I now have.'

Shaping of pathways

One way of understanding how Julie and the other participants shape their pathways is through Barth (1981) and his 'Models' which explain how a social form is generated by people taking choices. Values, that the actors seek to achieve, organize the choices and the acts. The seeking of certain values must be understood in the context in which the action takes place as well as which available possibilities and constrains the actor has in the situation of choice. In a pathway with cancer, health and survival would be such values, which also correspond to *health seeking* actions.

In order to survive, biomedical treatment was the preferred choice for the participants in this study. It was considered the most effective choice to achieve survival and there are no economic or other structural barriers in Norway against that decision. However, potential side effects were an issue, especially for Julie who considered not to use biomedical treatment. She thought an herbal and diet program would have the same effect on the cancer, and less side effects. Norway is a globalized country which result in a more complex landscape of treatment possibilities. However, Julie could not get her preferred Ayurvedic medicine because of Norwegian import laws. Such structural regulations represent an example of restrictions affecting persons' treatment choices and how they shape their pathways.

The postmodern experience of illness is a reflection of self (Frank 2013; Little et al. 1998), which add another dimension to how the Norwegian participants shaped their trajectories to healing. The purpose of hiking and being in nature from a Norwegian perspective is 'peace and quiet, as it is often construed, is contemplation and spiritual peace… you leave civilization and all its comforts and depravity behind to get in touch with your inner self and feel like an authentic person' (Eriksen 1996). For many Norwegians, hiking and being in nature seem to be meaningful in the aftermath of cancer when both physical, mental and spiritual strength are ingredients in building oneself up again after being broken down. Moreover, Julie's disability forced her to change her way of thinking and she had to regulate her activities in line with her ability and energy level. To live life as it is, and not thinking how it should had been, were an important mentality in the aftermath of cancer.

Shaping of a pathway is a search for a better life through approaching needs by undertaking health seeking actions. Cancer not only affect the physical body, but the participants also had psychological and existential concerns that were approached by a pluralism of approaches. Attitudes such as "it does not hurt to try" and hope for a healthier life were incentives for choosing CAM and traditional healing. Shaping of pathways could be understood as a pursue of benefits and avoiding of losses (Barth 1981, 102).

What characterizes medical pluralism in a pathway?

Implementation of contradicting models of reality and making pragmatic choices

Whether we are discussing health-seeking actions within biomedicine, self-care, CAM practices, traditional medicine or religious coping, we can argue that they all carry the potential of formulating people's *models of and for reality*. That is to say formulating their conceptions of a general order of existence and at the same time providing people with models of how to act in this world, in the same way that Geertz (1993) stated religion does. We could also think of people's treatment choices in terms of "habitus", namely cultural structures or dispositions that are embodied through lived life experiences and structure our preferences, the way we think, act and adapt to social institutions (Bourdieu 1984, 1977). In fact, we have shown how medical systems often represent different models of reality when it comes to health-seeking actions, and that these models are sometimes contradicting. For example, Julie chose both biomedical cancer treatment, herbal treatment and spiritual healing. The latter methods are not recognized by biomedicine as effective and evidence-based treatment of cancer, thus the medical doctors' advice to start biomedical cancer treatment as soon as possible. Mari emphasized biomedical treatment as the most important during her pathway, but at the same time made use of healing, prayers and got power from objects such as a praying cloth, a cross and a wooden angel. She had conversations with a Christian priest as well as a psychologist because these persons talked about different aspects of life and therefore complemented each other. The participants found themselves in a position where they did not have to choose either biomedicine or CAM. They could choose and compose their paths in the ways they found most pragmatic, according to their values, preferences and needs.

'There is more between heaven and earth', one of the participants expressed, and emphasized the importance of 'trying all possibilities'. Approaches to own health in context of long lasting illness may represent such an exploration and evaluation of possibilities through epistemological individualism. Learning from own experiences and 'listening to own body' may be important as an addition to biomedical approaches to healing: ‘Individuals may combine elements of different philosophical and spiritual traditions to craft their own life perspectives. Although most of medicine does not deal so directly with assumptions about human existence’ (Tilburt and Geller 2007, 820). This seems to support what other ‘anthropologist[s] studying health-seeking strategies and practices point out, that people’s choices are generally pragmatic, and combining various therapies is commonly observed’ (Penkala-Gawęcka 2016, 150). Moore and McClean (2010) argue that we ‘move within and between “magical” and “scientific” worlds as and when we need to, or when it suits us, and this is context bound’(266). As we have showed, perceived possibility, belief, hope for a healthy life and personal experiences mattered for the participants’ choices in addition to scientific approaches

Medical pluralism is a sociocultural phenomenon with continuity and change of health seeking actions

As argued by Wiley and Allen (2013), humans do not live isolated from their ecological and sociocultural surroundings. Our worlds are shaped and reshaped by various processes. We thus argue that habitus is dynamic and subject to various inputs regarding methods of coping and healing. Patients may want to relate to traditional healing methods that they find beneficial and at the same time implement new elements to their health-seeking repertoire. In context of globalization and increased cultural flow (Appadurai 2002), new forms of health seeking actions are frequently introduced through media, internet, migration and so on. According to Barth (1967), how people manage to arrange their life through new allocation of time and resources may generate social change. Barth argues that people’s behaviour is channelled by the goals they wish to achieve, which possibilities and restrictions they have as well as their beliefs and values. Furthermore, new kinds of actions may result in systematic change within a society, depending on the feedback: if the benefit of the action is great, the action is likely to be imitated by others. We therefore argue that external influences, for instance through globalisation processes, may generate change in how people think and act in order to achieve better health in context of illness. Practices such as yoga, acupuncture and ayurvedic medicine are examples of “imported” health practices. They may be conventional in the country of origin, but generate change an implement in the contemporary CAM landscape in Norway.

Medical pluralism as a process

We have already argued above for how a pathway may be shaped by using Barth (1981) of how social forms are generated by actors making choices. Medical pluralism as a social form is generated by a process of people making choices under influence of restrictions and opportunities in context of long lasting illness. The system may affect the individual, but the individual may also affect the system by making choices. In addition, the available treatment choices as well as the patients’ needs are in constant change. This creates a dynamic situation where condition, context, needs and choice of health-seeking actions vary. The result of biomedical treatment in terms of side-effects was interconnected with Julie’s aftermath of cancer. Coping with pain became a central part of her life. She looked forward to start working, but found herself unable to continue her previous work. Mental adjustments, family, nature and travelling were important for her identity and well-being.

Increased use of medical pluralism to improve health and well-being in situations where the conventional care system has few available treatment options

When the curative cancer treatment is over, conventional health care takes on a less active role. However, the ill persons continue to struggle with complex and possibly changing needs (Salamonsen et al. 2016).

At the moment of diagnosis the patients' needs are acute. In this early phase patients have 'biological goals' and conventional health care is most often the preferred choice in order to survive (Hansen, Berntsen, and Salamonsen 2018). Even if the initial cancer treatment is successful, the patients later have to cope with the aftermath of cancer such as life with stoma, identity problems, practical problems, getting back to 'normal' life, and anxiety related to the possibility of relapse. There may also be challenges regarding sexual life, sleep, fatigue, and existential questions. Due to the wide array of problems and a more passive conventional health care in this post-treatment phase, this may be the most challenging time for some persons with cancer (Salamonsen et al. 2016) and approaches outside of the biomedical sector were preferred to meet their needs.

Medical pluralism, syncretism and medical landscapes

Norwegian patients has access to plural health seeking options within their pathway. We will here discuss some theoretical frameworks within medical pluralism that may be helpful in understanding health-seeking choices in the aftermath of cancer.

Syncretism is often used within religious studies and is a problematic concept. It is a social phenomenon when two or more traditions merge and become a new fusion consisting of various elements (Ringgren 1969). On an individual level, we could argue that the participants in our study build their pathways by combining elements from different traditions, and that all elements merge into one construct without any regard to the paradoxes of contradicting philosophies of the merged traditions. From this perspective, we could argue that individuals' construction of a pathway is characterized by syncretism. However, if we view syncretism as a product and unity of different traditions coming together as one, as a socially acknowledged new tradition, the concept may not fit our empirical material. Our interpretation of the health seeking choices in

Norway, are that the participants understand the traditions as separate entities and not as a fusion. Using a metaphor, they pick and choose from various “Chinese dishes”, but are not blending them into a new recipe. Another possibly fruitful theoretical angle, is Kleinman (1980) sectors of health care. Here folk sector, professional sector and popular sector are illustrated through three interconnected circles. Where the circles overlap, the boarders of the traditions meet and in this case, the syncretism concept will be relevant. A good example may be integrative health care: ‘There are many definitions of “integrative” health care, but all involve bringing conventional and complementary approaches together in a coordinated way’(National Center for Complementary and Intergrative Health 2008, 1). When therapies from various traditions are combined in individually constructed treatment approaches to meet different needs of a patient, for instance within a biomedical domain, it could be regarded as syncretism.

According to Hsu (2008), medical landscapes ‘provide a theoretical framing for future studies of medical pluralism’ (320).

> Rather than invoking a clearly bounded culture concept with a culturally adept healer in its centre, the notion of ‘medical landscapes’ implies social processes, relatedness and movements between foregrounds and backgrounds, and across boundaries (Hsu 2008, 320)

While medical pluralism merely states the coexistence of several medical traditions, medical landscapes provide us with theoretical understandings of plural health seeking actions that are dynamic and therefore suitable for a study of long lasting illness. In this study, we found that medical pluralism was characterized by implementation of various models of reality, continuity and change, being a process and that pluralism increased in later parts of the pathway. These findings correspond to the theoretical understanding of dynamics and movements found in the medical landscapes concept. The participants were not bound to one healer, but crossing boundaries between traditions, contexts and cultures. They made use of already existing maps of the landscape, but also utilized their inner compass to explore new parts of terrain (Barth (2004). Table 1 shows how people with the same diagnosis choose different paths to what they believe leads to better health and well-being. Utilization of various forms of treatments has been emphasized as important to cancer patients in Norway in order to meet various needs (Hansen, Berntsen, and Salamonsen 2018). We suggest that movement and straddling of borders of traditions and worldviews, adaptation of local and global knowledge is a strength for a person´s coping with cancer and its various late effects, in Norway. A theory may be that the individuality of the Norwegian society generates an attitude of taking responsibility for own health, and since long lasting illness often is a dynamic journey, flexibility with regard to health-seeking actions is the preferred way to navigate in medical landscapes.

Methodical considerations

A longitudinal approach with in depth qualitative interviews has allowed us to come close to lived life in context of a pathway with cancer. According to Lambert and McKevitt (2002) one of anthropology’s contributions in health research is documenting details of everyday life, social processes and context. Theoretical frameworks within anthropology, such as medical pluralism and medical landscapes, are useful tools by which to explain cultural and social aspects of health and illness.

Conclusion

The remission society is growing. Cancer patients are a group that often suffer long after they have been reported fit and find themselves in a continuous liminality. This phenomenon represents a relatively new problem generated by better biomedical treatment regard to survival. To be able to support these people, we need to develop more knowledge from a patient perspective about which need they have and how they shape their pathways. This longitudinal study show that in a Norwegian context, people choose biomedical treatment to survive and move between various medical landscapes in the aftermath of cancer. They experience that the social health care has few available options in this phase, and make use of religious coping, self-care, CAM and traditional healing to meet their needs. Practices associated with health and healing in Norwegian culture, such as hiking, being in nature and traditional healing, were particularly meaningful in context of cancer. At the same time, participants were open for new methods of coping such as yoga. We found that a pathway is dynamic and complex. Movements in medical landscapes may be a useful conceptual framework and alternative to medical pluralism when analyzing long-lasting, complex illness trajectories. This paper also contribute with empirical descriptions of lived life with cancer in a Norwegian context. In addition to medical anthropology, this knowledge may be beneficial to health care professionals, patient organizations, policy makers as well as patients, and to stimulate to future discussions regarding how the support for persons with chronic disease may be improved.

Disclosure statement

The authors reports no conflicts of interest in this work.

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Appendix 1

Ethical recommendation Regional Ethics Committee, REC South East A

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK sør-øst	Anette Solli Karlsen	22845522	18.12.2014	2009/1293/REK sør-øst A
			Deres dato:	**Deres referanse:**
			16.12.2014	

Vår referanse må oppgis ved alle henvendelser

Gro Rosvold Berntsen
NST, Universitetet i Tromsø

2009/1293 Kreftpasienters behandlingsforløp – hvilke forløp er best?

Forskningsansvarlig: Universitetet i Tromsø
Prosjektleder: Gro Rosvold Berntsen

Vi viser til søknad om prosjektendring datert 16.12.2014 for ovennevnte forskningsprosjekt. Søknaden er behandlet av leder for REK sør-øst på fullmakt, med hjemmel i helseforskningsloven § 11.

Vurdering

REK har vurdert følgende endringer i prosjektet:
-Ny medarbeider. Stipendiat Frank Hansen knyttes til prosjektet som medarbeider.

Komiteens leder har vurdert søknaden og har ingen innvendinger til de endringer som er beskrevet.

Vedtak

Komiteen godkjenner med hjemmel i helseforskningsloven § 11 annet ledd at prosjektet videreføres i samsvar med det som fremgår av søknaden om prosjektendring og i samsvar med de bestemmelser som følger av helseforskningsloven med forskrifter.

Dersom det skal gjøres ytterligere endringer i prosjektet i forhold til de opplysninger som er gitt i søknaden, må prosjektleder sende ny endringsmelding til REK.

Av dokumentasjonshensyn skal opplysningene oppbevares i 5 år etter prosjektslutt. Opplysningene skal oppbevares avidentifisert, dvs. atskilt i en nøkkel- og en datafil. Opplysningene skal deretter slettes eller anonymiseres, senest innen et halvt år fra denne dato. Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder for «Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse- og omsorgssektoren».

Prosjektet skal sende sluttmelding til REK, se helseforskningsloven § 12, senest 6 måneder etter at prosjektet er avsluttet.

Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jf. helseforskningsloven § 10 tredje ledd og forvaltningsloven § 28. En eventuell klage sendes til REK sør-øst A. Klagefristen er tre uker fra mottak av dette brevet, jf. forvaltningsloven § 29.

Med vennlig hilsen

Knut Engedal
Professor dr. med.
Leder

Anette Solli Karlsen
Komitesekretær

Kopi til: *vinjar.fonnebo@uit.no*; *postmottak@uit.no*

Dr Gro K Rosvold Berntsen University of Tromsø NST, 9038 Tromsø	Regional committee for medical and health care research ethics in the South Easter Region – A (REC South East A). P.O Box 1130 Blindern No-0318 Oslo
Date 20th of april 2010 Your ref:	Phone: 22 84 46 66 Fax: 22 85 05 90

Our ref:2009/1293a	E-mail: Jorgen.hardang@medisin.uio.no Webpage: http:// helseforsking.etikkom.no

2009/1293a Cancer patients pathways – which pathways are best?

We refer to your letter with answer to our comments dated the 12th of april 2010 and the revised protocol where answers to our comments have been included.

The committee approves that the project can be implemented in accordance with the application and the response that has been given to the committees comments.

The approval is contingent on the project being implementd as it is described in the application and the protocol and the regulations that follow from the health research legislation.

If you make changes in the project the project leader must send a statement describing the planned change to the committee.

The research data collected by the project must be kept secure and safe – see the Privacy-regulations stipulation, chapter 2 and the health directorates guide for "Privacy and information security in research projects within the health and care sector" (http://www.helsedirektoratet.no/samspill/informasjonssikkerhet/norm_for_informasjonssikkerhet_i_helsesektoren_232354). Data that can be linked to a person must be deleted as soon as they are no longer needed, at the latest at the projects end date.

This approval is valid until the 31.12.2014. The project is required to send an "end of project" statement on a separate form, see the health research act § 12, within 6 months of the projects end date at the latest.

We ask that all requests are sent to our web portal: http://helseforskning.etikkom.no or on e-mail to: post@helseforskning.etikkom.no.

Please refer to our case reference number in any correspondence.

Yours sincerely

Gunnar Nicolaysen (sign) Prof. Dr. Med Leader – committee A	Katrine Ore Consultant

Copy: University of Tromsø by Vinjar.fonnebo@uit.no

Appendix 2

Letter of invitation

Kreftpasienters behandlingsforløp **14. desember 2010**

Til:

Forespørsel om deltakelse i forskningsprosjekt

Vi skriver til deg fordi du har fått en kreftdiagnose i tykk- eller endetarm i løpet av de siste 6 månedene.

I denne situasjonen kommer du til å måtte gjøre en rekke valg i forhold til egen helse.

Helsetjenesten har få tradisjoner på å se sykdomsforløpet gjennom pasientens øyne. Vi er en gruppe forskere ved Universitetet i Tromsø og Universitetssykehuset Nord Norge HF som er opptatt av å kartlegge og forstå pasientenes egne valg i forhold til helse.

Vi håper du vil lese gjennom vedlagte informasjon om studien vår. Dersom du vil delta i studien må du signere samtykkeerklæringen og returnere den til oss i vedlagte konvolutt.

Har du spørsmål om studien så kan du ta kontakt med:

- Studiesykepleier: Kristin Iren Jensen – (Jobb telefon: 77 66 92 12, E-post: kristin.iren.jensen@unn.no)
- Forsker: Anita Salamonsen – (Mob telefon: 971 25 135, E-post: anita.salamonsen@uit.no)
- Prosjektleder og forsker: Gro Berntsen - (Mob Telefon: 905 18 895, E-post: gro.berntsen@telemed.no)

Med hilsen

Tromsø

Terje Risberg
Overlege - Kreftavdelingen

Terje Risberg

Tromsø

Rolv Ole Lindsetmo

Rolv Ole Lindsetmo
Overlege - Kirurgisk avdeling

Appendix 3

Letter of invitation with declaration of consent

Forespørsel om deltakelse i forskningsprosjekt

Å forstå kreftpasienters behandlingsforløp

en helhetlig beskrivelse av valg og resultat av egen behandling skolemedisinske, komplementære og alternative behandlingstiltak hos kreftpasienter

Bakgrunn og hensikt.

Dette er et spørsmål til deg om å delta i en forstudie (pilotstudie) før en større forskningsstudie (hovedstudien).

Når en person får kreft, vil han/ hun stå i en valgsituasjon hvor han/ hun må forholde seg til skolemedisinske tiltak. I tillegg vil noen velge å supplere med egen behandling eller behandling fra alternative behandlere. Alle tiltakene blir til sammen til en tiltakskjede.

I forstudien er formålet å få inntrykk av:

1. hvilke tiltakskjeder kreftpasienter gjennomfører, både innenfor og utenfor det skolemedisinske tilbudet. For å danne oss et bilde av hvordan slike tiltakskjeder ser ut, må man gjennomføre en regelmessig kartlegging av tiltakene.
2. om andre viktige hendelser i pasientenes liv er av betydning for deres behandlingsvalg i denne perioden.
3. hvordan en slik kartlegging best kan gjennomføres. Vi vil undersøke hvordan spørreskjemaene og intervjuer fungerer, og hvordan pasientene opplever datainnsamlingen. Forstudien består av en detaljert kartlegging av noen utvalgte pasienters forløp.

Vi trenger i tillegg noe bakgrunnsinformasjon om kreftsykdommen og den behandlingen du velger å motta fra helsetjenesten. Dette vil vi be om å få lov å hente ut fra din medisinske journal på sykehuset. Det vi lærer av denne forstudien vil få betydning for gjennomføringen av en større hovedstudie. I hovedstudien vil vi i tillegg kunne undersøke om noen tiltakskjeder er bedre for pasienten.

Hva innebærer deltakelse i forstudien?

Studien varer i ett år fra du inkluderes. Du vil bli invitert til et oppstartsintervju med en av våre forskere. Du vil bli bedt om å fylle ut et omfattende spørreskjema ved studiens start og slutt. En gang i måneden vil du motta et en pasientdagbok og et spørreskjema som du fyller ut på papir og sender tilbake til oss. Hver tredje måned vil vi kontakte deg og avtale et oppfølgingsintervju basert på dagboken. Alle intervjuene blir tatt opp på bånd.

Tid og sted for det første intervjuet avtaler vi direkte med deg i tråd med dine ønsker. Reiseutgifter inntil 1000 Nkr for tur - retur vil bli refundert for det første intervjuet. Oppfølgingsintervjuene vil i hovedsak skje per telefon.

Oversikt over gangen i studien:

Hendelse	Når	Hvordan	Utsendt/ Gjort
Informasjon og samtykke til deltakelse	Ved rekruttering	Forespørsel pr brev	X
Første spørreskjema	Ved oppstart	Tilsendt i posten før første intervju	
Første intervju	Ved Oppstart	Ansikt til ansikt i Tromsø	
Dagbok og kort spørreskjema	Månedlig	Finnes i studiepermen	
Intervju på grunnlag av dagboka	Hver 3. Måned	Intervju per telefon	
Siste spørreskjema	Etter 12 måneder	Finnes i studiepermen	
Siste intervju	Etter 12 måneder	Intervju per telefon	
Uthenting av informasjon fra medisinsk journal	Etter 12 måneder	Gjøres av studiesykepleier	

Mulige fordeler og ulemper

Du vil ikke få noen fordeler eller ulemper ved å delta. Du vil heller ikke få noen fordel eller ulempe om du ikke deltar eller ønsker å trekke deg. Informasjon som du gir til studien vil ikke være tilgjengelig for helsetjenesten, og vil ikke påvirke behandlingen du får.

Hva skjer med informasjonen om deg?

Informasjonen som registreres om deg skal kun brukes i forbindelse med studien. Alle opplysningene vil bli behandlet uten navn og personnummer eller andre gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Listen oppbevares nedlåst. Det er kun medarbeidere knyttet til prosjektet som har adgang til navnelista. Den forskeren som skal intervjue deg, vil kjenne navnet ditt. I oppfølgingsintervjuene vil vi bruke pasientdagboken som grunnlag.

Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres. Informasjonen om deg lagres ved sykehuset i 15 år etter at studien er avsluttet. Studien vil avsluttes ett år etter at siste pasient er inkludert. Behandlere i helsetjenesten vil ikke ha tilgang til den informasjonen som du gir til studien.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke fra 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/oppfølging.

Dersom du har spørsmål til studien, kan du kontakte studiesykepleier Kristin I. Jensen (jobb tlf nr: 77 66 92 12), Prosjektleder dr. med Gro Berntsen (Mobilnr: 905 18 895) eller professor og overlege ved kreftavdelingen. Terje Risberg (jobb tlf nr: 776 26765).

Kapittel A- utdypende forklaring av hva studien innebærer

Denne forstudien er del av en internasjonal studie. Pasienter fra fire land, til sammen 240 personer, skal inkluderes i pilotstudien. 60 pasienter med kreft i henholdsvis prostata, bryst eller tykktarm/ endetarm vil delta i forstudien. Studien er ment å gi bedre forståelse av hvordan pasienter selv påvirker sin behandling ved alvorlig sykdom. Studien søker å svare på følgende spørsmål: Hvilke behandlinger velger pasienter innen skolemedisin og alternativ behandling, og hvorfor gjør de det? Hvordan kan slike kartleggingsstudier best gjennomføres? Er noen behandlingsforløp bedre for pasienten enn andre?

Det er planlagt å starte en internasjonal studie med totalt 5000 deltakere på bakgrunn av resultatene i denne forstudien.

Kapittel B - Personvern, biobank, økonomi og forsikring

Personvern

Denne studien er kommet i stand som et samarbeid mellom Universitetet i Tromsø og kreftavdelingen ved Universitetssykehuset Nord-Norge. Autorisert studiepersonell med taushetsløfte/plikt vil gis innsyn i relevante deler av din journal og i de opplysningene du avgir gjennom studiens spørreskjema/ internett registreringer. Opplysningene som avgis til studien vil ikke være tilgjengelig for de som behandler deg i helsetjenesten.

Opplysninger som hentes ut fra journalen er medisinske opplysninger som for eksempel den eksakte kreftdiagnosen (inkludert stadium), hvilke medisiner du har brukt under kreftbehandling, resultater av kreftundersøkelser og blodprøver. Vi vil bruke navn og personnummer for å finne din journal, men verken navn eller personnummer vil bli registrert på studiens papirer. Der brukes kun din studiekode. Studien gjennomføres i henhold til Personopplysningsloven. Dine interesser med tanke på beskyttelse av data ivaretas av Personvernombudet på sykehuset.

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.

Økonomi

Du får ingen økonomiske fordeler eller ulemper ved å delta i studien. Det koster ingenting å delta. Du vil måtte bruke noe tid på å fylle ut pasientdagbok og spørreskjema hver måned og snakke med intervjuer hver 3. måned. Det gis ingen økonomisk kompensasjon for den tiden som medgår i studien.

Studien er finansiert gjennom forskningsmidler fra Kreftforeningen. De finansierer lønn til studiesykepleier og forskerne som har ansvar for studien. Dersom du blir enige med intervjuer om å møtes for å gjennomføre intervju, refunderer vi reiseutgifter inntil 1000 Nkr for tur-retur.

Forsikring

Alle deltakere er dekket mot uhell gjennom norsk pasientskadeerstatning.

Informasjon om utfallet av studien

Vi vil publisere utfallet av studien i internasjonale tidsskrift. Vi ønsker også å informere våre deltakere om utviklingen av studien og resultatene fra den. Vi vil registrere adressene til alle deltakere som ønsker utfyllende informasjon om studieresultatene underveis i studien. Slik informasjon vil da bli sendt til deg når resultatene foreligger.

Samtykke til deltakelse i studien – Deltaker kopi – Denne beholder du selv

Jeg er villig til å delta i studien

Dato, prosjektdeltakers signatur

Dersom du velger å delta i studien så vil vi kontakte deg for å avtale tid og sted for oppstartsintervjuet. Vennligst oppgi hvordan du foretrekker å bli kontaktet – sett ett eller flere kryss:

E-post: ☐ Oppgi e-post adresse:

……

Telefon: ☐ Oppgi telefonnummer:

……

SMS på mobiltelefon: ☐ Oppgi mobiltelefon nr:

……

Vanlig post: ☐ Oppgi foretrukket postadresse:
……

……

Når den utfylte samtykkeerklæringen er returnert, vil du motta et spørreskjema som skal fylles ut før første intervju. Du vil bli kontaktet via din foretrukne kommunikasjonskanal med invitasjon til det første intervjuet.

For studieadministrasjonen:

Jeg bekrefter å ha gitt informasjon om studien til studiedeltaker

----
(Signert, rolle i studien, dato)

Samtykke til deltakelse i studien – Undertegnes og sendes i vedlagte frankerte konvolutt til:

Universitetet i Tromsø

NAFKAM v. Anita Salamonsen

0098 Oslo

Jeg er villig til å delta i studien

Dato, prosjektdeltakers signatur

Dersom du velger å delta i studien så vil vi kontakte deg for å avtale tid og sted for oppstartsintervjuet. Vennligst oppgi hvordan du foretrekker å bli kontaktet – sett ett eller flere kryss:

E-post: ☐ Oppgi e-post adresse:

……….

Telefon: ☐ Oppgi telefonnummer:

………

SMS på mobiltelefon: ☐ Oppgi mobiltelefon nr:

………

Vanlig post: ☐ Oppgi foretrukket postadresse:
………

………

Når den utfylte samtykkeerklæringen er returnert, vil du motta et spørreskjema som skal fylles ut før første intervju. Du vil bli kontaktet via din foretrukne kommunikasjonskanal med invitasjon til det første intervjuet.

For studieadministrasjonen:

Jeg bekrefter å ha gitt informasjon om studien til studiedeltaker

----
(Signert, rolle i studien, dato)

Appendix 4

Interview guide

Pathways Baseline Interview Guide – 22. January 2010 (EM)

Takk for at du har sagt ja til å delta i denne pilotstudien og dette intervjuet.

Jeg vil gjerne minne deg om at:

1. dette intervjuet taes opp på bånd.
2. All identifikasjon taes bort før analysene gjøres.
3. Du kan be om å stoppe intervjuet når du måtte ønske det.
4. Intervjuet tar ca 30-60 minutter, avhengig av hva som har skjedd med deg disse tre månedene.

Oppstart med tid, sted og deltakers studie ID.

Forklar meningen med intervjuet:

1. **Før vi begynner å snakke om de behandlinger du har gjennomført siden du ble diagnostisert med kreft, kan du fortelle litt om hva du gjorde for din helse og velvære før du fikk diagnosen?**

2. **Kan du beskrive hvordan du reagerte på diagnosen?**

3. **Hvordan har diagnosen påvirket livet ditt?**

4. **Vi skal nå snakke om de behandlinger du har gjennomført siden du fikk kreftdiagnosen.**

    1. **Hvilke behandlinger anbefalte din lege etter at du fikk diagnosen?**
        1. **Hvilke behandlinger bestemte du deg for å få?**

2. **Når mottok du disse behandlingene?**
3. **Hva håpet du å oppnå med disse behandlingene?**
4. **Kan du beskrive hva som førte til din beslutning om å motta disse behandlingene?**
5. **Hvordan var XX behandlingen for deg? (spør for hver behandling, fysisk, emosjonelt, osv.)**

2. **Noen kreftpasienter blir også behandlet av annet helsepersonell knyttet til kreftomsorg, som psykologer, ernæringsterapeuter og andre terapeuter/rådgivere. Etter at du fikk kreftdiagnosen, fikk du noen behandling fra noen slike personer?**
    1. **Hvilke behandlinger bestemte du deg for å få?**
    2. **Når mottok du disse behandlingene?**
    3. **Hva håpet du å oppnå med disse behandlingene?**
    4. **Kan du beskrive hva som førte til din beslutning om å motta disse behandlingene?**
    5. **Hvordan var XX behandlingen for deg? (spør for hver behandling, fysisk, emosjonelt, osv.)**

3. **Hvilke andre behandlinger vurderte du å bruke etter at du fikk kreftdiagnosen? (spør om KAM terapier og utøvere)**
    1. **Hvilke behandlinger bestemte du deg for å få?**
    2. **Når mottok du disse behandlingene?**
    3. **Hva håpet du å oppnå med disse behandlingene?**
    4. **Kan du beskrive hva som førte til din beslutning om å motta disse behandlingene?**
    5. **Hvordan var XX behandlingen for deg? (spør for hver behandling, fysisk, emosjonelt, osv.)**

4. Etter at du fikk kreftdiagnosen, hvilke andre ting gjorde du selv? (spør om endringer i kosthold/diett, trim, stressredusering, røykeslutt)

  1. **Hvilke behandlinger besluttet du å få?**
  2. **Når mottok du disse behandlingene?**
  3. **Hva håpet du å oppnå med disse behandlingene?**
  4. **Kan du beskrive hva som førte til din beslutning om å motta disse behandlingene?**
  5. **Hvordan var XX behandlingen for deg? (spør for hver behandling, fysisk, emosjonelt, etc.)**

5. Ta nå et minutt og tenk på de behandlingene du fylte ut før intervjuet for å se om det er andre behandlinger vi ikke har snakket om som du ønsker å dele?

6. Hvilken type/kilde med informasjon brukte du i beslutningene dine om behandling?

  1. **Var denne informasjonen hjelpsom/ikke hjelpsom?**
  2. **Hvilken informasjon manglet?**
  3. **Påvirket ditt forhold til omsorgsutøverne dine beslutninger?**

7. Når du ser tilbake på dine gjennomførte behandlinger, ville du ha tatt de samme beslutningene nå? Hvis ja, hvorfor? Hvis nei, hva ville du ha endret på og hvorfor?

8. Av alle tingene du har gjort siden du fikk kreftdiagnosen, hva mener du har vært viktigst? Hvorfor?

9. Mange kreftpasienter opplever andre viktige hendelser i livet etter å ha fått diagnosen, slik som å gifte seg, miste jobben eller flytte til et nytt sted. Hvilke andre viktige ting har hendt med deg og/eller din familie på denne tiden?

(**Viktige hendelser:** dette er hendelser som du føler er viktige for deg i livet ditt. Det er hendelser man kanskje ville skrive i en dagbok, eller diskutere med en nær venn eller som tar opp mye av din tid, energi og tankevirksomhet. Livshendelser kan være relatert til sykdommen din eller til helt andre ting i livet ditt**)**

1. **Hvordan føler du at XX (livshendelse) har påvirket deg?**
2. **Hvordan føler du at XX (livshendelse) har påvirket din behandling/pleie?**
3. **Hvordan føler du at XX (livshendelse) har påvirket din respons på behandling/pleie?**

10. Familie og venner er ofte involvert i kreftpasienters erfaringer. Hvem, hvis noen, har vært viktig for deg etter at du ble diagnostisert med kreft?

1. **Hvordan har de vært viktige?**

11. For de som har barn som bor hjemme, spør: har dine barn påvirket dine beslutninger vedrørende behandlinger? Hvordan? Kan du gi noen spesifikke eksempler?

12. For deg, hva i livet har påvirket deg mest i hvordan du har tatt beslutninger om behandlinger? Spør: Behandlingene du har valgt? Tro, verdier? Hendelser i livet? Andre mennesker?

13. Når du ser tilbake, hva er de viktigste resultatene/målene med ditt behandlingsforløp (behandlinger)?

14. **Du har snakket om flere behandlinger i dag. Hvordan ser du at dine behandlinger medvirker til å hjelpe deg å oppnå dine mål**

    1. **Hvilke utfordringer, hvis noen, har du opplevd i forbindelse med dine behandlinger?**

15. **Hva gjør du for å takle dine behandlinger og/eller din kreftdiagnose? Spør: Kan du gi noen eksempler på måter du reduserer stress eller bekymringer? Kan du gi noen eksempler på hva som fungerer bra og hva som ikke fungerer så bra?**

16. **Hvis du skulle beskrive denne tiden siden du fikk kreft med ett eller to ord – hva ville du spontant si da: _______________________.**

Utdyp i forhold til hvilke elementer som er viktige for pasienten (eks: Behandling, familie, styrke eget ve og vel etc.)

17. **Er det andre ting vedrørende ditt behandlingsforløp du vil fortelle meg?**

Pasientdagbok

Helt til slutt vil jeg gi deg pasientdagboken som vi ønsker at du skal fylle ut.

Gi deltaker dagbok + frankert konvolutt.

Deltakerne skal orienteres kort om de kvartalsvise intervjuene. Denne orienteringen skal inneholde følgende informasjon:

Målet med de kvartalsvise intervjuene er å få kunnskap om de viktigste hendelsene i tida etter en kreftdiagnose.

Alle Helse hendelser – dette er hendelser som er forårsaket av eller knyttet til din sykdom. Vi vil gjerne vite om

1. alle hendelser hvor en eller annen type helsepersonell er involvert. Ta med både skolemedisinske, alternative og/eller komplementære behandlere.
2. hendelsene som du selv iverksetter for å bedre helsen din. Dette inkluderer ting du sluttet med, som for eksempel å slutte å røyke.
3. andre hendelser du mener er viktige i forhold til din opplevelse av helse og sykdom (for eksempel: en alvorlig bivirkning av behandlingen du mottar).

Viktige livshendelser – dette er hendelser som du føler er viktige for deg i livet ditt. Det er hendelser man kanskje ville skrive i en dagbok eller diskutere med en nær venn, eller som tar opp mye av din tid, energi og tankevirksomhet. Livshendelser kan være relatert til sykdommen din eller til helt andre ting i livet ditt.

De kvartalsvise intervjuene tar utgangspunkt i en dagbok/kalender som du fører over alle helsehendelser og de livshendelsene som er viktige i livet ditt. For å hjelpe deg til å huske relevante hendelser/ tiltak, vil vi gi deg denne kalenderen/dagboken. Her ber vi deg skrive ned hva du gjør fra dag til dag og uke til uke for å håndtere din kreftsykdom. Vi ber deg også skrive ned de livshendelsene som er viktige for sykdommen din eller for helt andre ting i livet ditt. Du får med deg denne orienteringen om utfylling av kalenderen/dagboken.

Kopi av intervjuguiden til deltakeren.

Innsendingsprosedyrer dagbok ---sender pasienten kopier av de innsendte dagbøkene til hjelp ved de kvartalsvise intervjuene

Forklar logistikken rundt pasientdagbøkene:

1. Mottar en ny dagbok i starten av hver måned.
2. Deltaker sender den utfylte dagboken i retur.
3. Når vi mottar dagboken så skanner vi den, og sender den i retur til pasienten.

Forklar at hensikten er at begge parter skal ha den samme dagbøkene som utgangspunkt for det kvartalsvise intervjuet.

DE KVARTALSVISE INTERVJUENE

Takk for sist!
Mitt navn er XX og jeg er …….

Takk for at du har sagt ja til å delta i denne pilotstudien og dette intervjuet.
Jeg vil gjerne minne deg om at:

- dette intervjuet taes opp på bånd.
- All identifikasjon taes bort før analysene gjøres.
- Du kan be om å stoppe intervjuet når du måtte ønske det.
- Intervjuet tar ca 30-60 minutter, avhengig av hva som har skjedd siden sist.
- **Oppstart med tid, sted og deltakers studie ID.**

- Hvis intervjuer har dagbok fra pasienten : Gå til intervjuguide A.
- Hvis intervjuer ikke har dagbok: Gå til intervjuguide B.

Interview guide for the last interview

DET SISTE KVARTALSVISE INTERVJUET

Takk for sist!

Mitt navn er XX og jeg er …….

Takk for at du har sagt ja til å delta i denne pilotstudien og dette intervjuet.

Jeg vil gjerne minne deg om at:

4. dette intervjuet taes opp på bånd.
5. All identifikasjon taes bort før analysene gjøres.
6. Du kan be om å stoppe intervjuet når du måtte ønske det.
7. Intervjuet tar ca 30-60 minutter, avhengig av hva som har skjedd siden sist.
8. **Oppstart med tid, sted og deltakers studie ID.**

1. Hvis intervjuer har dagbok fra pasienten : Gå til intervjuguide A.
2. Hvis intervjuer ikke har dagbok: Gå til intervjuguide B.

1. Intervju Guide A:

Takk for at du har fylt ut dagboka!

Vi tar utgangspunkt i dagboka du har fylt ut for de tre månedene siden forrige intervju. Jeg sitter her med din dagbok foran meg. Det vil være til hjelp om du har den foran deg nå også.

Har du den foran deg? (Hvis nei - > improviser slik at du får til en situasjon, evt seinere, hvor intervjuet kan gjennomføres med dagbok. Tilby å sende ut dagboka på nytt).

Har du spørsmål før vi begynner?

Tyding av håndskrift og tekst som grunnlag for punching:

La oss begynne med å få en oversikt først. Jeg har sett over dagboka før møtet vårt. Jeg forstod ikke riktig…. XXX. Kan du forklare hva som står…. (sikre at tyding av dagbok er slik at vi kan punche hendelsene i dagbokformat i etterkant).

Hvor mye tid har du til dette intervjuet i dag? Planlegg i lag i forhold til hva dere tror dere rekker.

Dersom dere sammen vurderer det slik at det er registrert for mange hendelser til at man kan rekke over alle – Gå til intervjuguide A1.

Dersom dere sammen vurderer det slik at dere kommer til å rekke å snakke om alle registrerte hendelser – Gå til intervjuguide A2.

2. A1

La oss starte med å lage oss en plan over hva vi vil bruke tida på ved å markere de viktigste hendelsene først. Når du ser på dagboka – hvilke hendelser er det du opplever som viktigst? Disse kommer vi tilbake til. *I samarbeid med deltakeren – Marker de viktige hendelsene i dagboka.*

Nå til de andre hendelsene som er mindre viktige. Er det noen hendelser som kan grupperes slik at vi kan snakke om dem samlet? *Marker gruppehendelser sammen med deltakeren og gi gruppen et ad-hoc navn. (Eks – alle cytostatika behandlinger).*

Er det noen av de gjenværende hendelsene som det er viktig å få tid til å snakke om? *Marker disse.*

Det som nå ikke er markert – det rekker vi kanskje ikke å se på i detalj.

La oss starte med den første av de viktigste hendelsene. Det som skjedde på dato X:

1. Kan du fortelle meg med dine egne ord hva det var som skjedde?
2. Hvem var involvert?
3. *Dersom pasienten selv hadde en aktiv rolle* - > Hva var det du ville oppnå med dette? Hva fikk deg til å handle/ velge slik?
4. Hvorfor eller hvordan var denne hendelsen viktig for deg? Hvordan påvirket den deg?
5. Hvordan vil du vurdere eller evaluere hendelsen? Var dette bra/ vanskelig/ nøytralt etc?

Loop til neste hendelse – til alle viktige hendelser er gjennomgått.

Så går vi videre til de grupperte hendelsene. La oss starte med gruppe X.

1. Kan du fortelle meg med dine egne ord hva det var som vanligvis skjedde ved disse hendelsene?
2. Hvem var involvert?
3. *Dersom pasienten selv hadde en aktiv rolle* - > Hva var det du ville oppnå med dette? Hva fikk han/ hun til å handle/ velge slik?

Loop til neste gruppe med hendelser – til alle gruppehendelser er gjennomgått.

Så går vi videre til de mindre viktige hendelsene som vi ble enige om å gå gjennom. La oss starte med dato X.

1. Kan du fortelle meg med dine egne ord hva det var som skjedde?
2. Hvem var involvert?

3. *Dersom pasienten selv hadde en aktiv rolle - >* Hva var det du ville oppnå med dette? Hva fikk han/ hun til å handle/ velge slik?

Loop til neste hendelse – til alle mindre viktige hendelser som deltakeren ønsker å snakke om er gjennomgått.

1. Er det noe vi har glemt?
2. Er det noe annet du har lyst til å si om din situasjon?
3. Er det noe du vil si om hvordan det er å delta i denne studien?

(For de tilfellene hvor intervjuer har skrevet dagboka på grunnlag av tlf samtalen-> Nå har jeg laget en dagbok med de viktigste hendelsene notert. Vil du ha en kopi av denne tilsendt?)

Gå videre med oppsummeringsspørsmålene på side 6.

4. A2

La oss starte med de viktigste hendelsene først. Når du ser på dagboka – hvilke hendelser er det du opplever som viktigst? *I samarbeid med deltakeren – Marker de viktige hendelsene på dagboka.*

La oss starte med den første av de viktigste hendelsene. Det som skjedde på dato X:

1. Kan du fortelle meg med dine egne ord hva det var som skjedde?
2. Hvem var involvert?
3. *Dersom pasienten selv hadde en aktiv rolle - >* Hva var det du ville oppnå med dette? Hva fikk han/ hun til å handle/ velge slik?
4. Hvorfor eller hvordan er denne hendelsen viktig for deg? Hvordan påvirket den deg?
5. Hvordan vil du verdsette eller evaluere hendelsen? Var dette bra/ vanskelig/ nøytralt etc?

Loop til neste hendelse – til alle viktige hendelser er gjennomgått.

Så går vi videre til de øvrige hendelsene. La oss starte med dato X.

1. Kan du fortelle meg med dine egne ord hva det var som skjedde?
2. Hvem var involvert?

3. *Dersom pasienten selv hadde en aktiv rolle - >* Hva var det du ville oppnå med dette? Hva fikk han/ hun til å handle/ velge slik?

Loop til neste hendelse – til alle mindre viktige hendelser som deltakeren ønsker å snakke om er gjennomgått.

1. Er det noe vi har glemt?
2. Er det noe annet du har lyst til å si om din situasjon?
3. Er det noe du vil si om hvordan det er å delta i denne studien?

(For de tilfellene hvor intervjuer har skrevet dagboka på grunnlag av tlf samtalen-> Nå har jeg laget en dagbok med de viktigste hendelsene notert. Vil du ha en kopi av denne tilsendt?)

Gå videre med oppsummeringsspørsmålene på side 6.

4. Intervjuguide B:

Ha tomme dagbok ark foran deg som du fyller ut etter hvert som dere går gjennom guiden.

Da går vi gjennom de tre siste månedene slik du husker dem.

Kan du si først si noe om hvorfor du ikke har fylt ut dagboka? Hvordan kan vi evt. gjøre dette enklere for deg?

La oss gå gjennom de tiltakene du har gjennomført og hendelsene som har opptatt deg. Ta det viktigste først.

1. Jeg vil gjerne at du gir meg, som best du kan en oversikt over alle helsehendelser de siste tre månedene. Dette er hendelser som er forårsaket av eller knyttet til din sykdom.
    1. alle hendelser hvor en eller annen type helse personell er involvert . Ta med både skolemedisinske, alternative og/eller komplementære behandlere.
    2. hendelsene som du selv iverksetter for å bedre helsen din. Dette inkluderer også ting du sluttet med, som for eksempel å slutte å røyke.
    3. andre hendelser du mener er viktige i forhold til din opplevelse av helse og sykdom (for eksempel: en alvorlig bivirkning av behandlingen du mottar).
2. Viktige livshendelser – dette er hendelser som du føler er viktige for deg i livet ditt. Det er hendelser man kanskje ville skrive i en dagbok, eller diskutere med en nær venn eller som tar opp mye av din tid, energi og tankevirksomhet. Livshendelser kan være relatert til sykdommen din eller til helt andre ting i livet ditt.

Forsøk å få en oversikt i dagboka slik at du kan lage en liste som blir utgangspunkt for videre samtale.

Vi må ta stilling til om vi rekker å snakke om alt vi har skrevet ned her. Hva tror du?

*Dersom dere sammen vurderer det slik at det er registrert for mange hendelser til at man kan rekke over alle – **Gå til intervjuguide A1.***

*Dersom dere sammen vurderer det slik at dere kommer til å rekke å snakke om alle registrerte hendelser – **Gå til intervjuguide A2.***

Intervju-guide for oppfølging etter 12-måneder

1. Hvordan ser du på de valgene du har tatt i forhold til behandlingen(e) for din kreftsydkom?

2. Hva hadde du størst nytte av? Kan du beskrive dette?

3. Er det noe som har skapt bekymring og uro for deg?

4. Er det noe du angrer på?

5. Er det noe du ville ha gjort annerledes (hvis det ikke er besvart til nå)?

6. Hvilke råd har du til behandlerne / kreftomsorgen? *(både utenfor og innenfor offentlig helsetjeneste)*

7. Hvis du skulle beskrive ditt pasientforløp fra du fikk kreft til nå med noen få ord – hvilke ord vil du bruke?

8. Har du forandret deg i løpet av dette året?

Nå har jeg noen få spørsmål om å delta i denne studien:

9. Hvordan var det å delta i studien? Hva likte du, hva likte du ikke?

10. Hvis det ikke kom opp:

    1. Var denne studien relevant for deg? Hva likte du best? Og minst?

    2. Var skjemaene lette å fylle ut?

    3. Var det for mange intervjuer? For mange spørreskjemaer? Noe annet?

    4. Har du forslag til hvordan vi kan forbedre denne studien?

    5. Har du noen spørsmål?

11. Er du interessert i å motta en rapport om denne studien?

Tusen takk for at du har bidratt med dine erfaringer, tid og ressurser i denne studien.