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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.

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

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 socio-cultural 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.

Disclosure statement

No potential conflict of interest was reported by the authors.

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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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