

“My cancer is not my deepest concern”: life course disruption influencing patient pathways and health care needs among persons living with colorectal cancer

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Background: The concept of “patient pathways” in cancer care is most commonly understood as clinical pathways, operationalized as standardized packages of health care based on guidelines for the condition in question. In this understanding, patient pathways do not address multimorbidity or patient experiences and preferences. This study explored patient pathways understood as the individual and cultural life course, which includes both life and health events. The overall aim was to contribute to supportive and targeted cancer care.

Materials and methods: Nine Norwegian patients recently diagnosed with rectal cancer Tumor-Node-Metastasis stage I–III participated in qualitative interviews, five times over 1 year. Five patients later participated in a workshop where they made illustrations of and discussed patient pathways.

Results: Patient pathways including both health and life events were illustrated and described as complex and circular. Stress, anxiety, and depression caused by life events had significant disruptive effects and influenced patient-defined health care needs. The participants experienced the Norwegian public health service as focused on hospital-based standardized cancer care. They expressed unmet health care needs in terms of emotional and practical support in their everyday life with cancer, and some turned to complementary and alternative medicine.

Conclusion: This study suggests that acknowledging life course disruption before cancer diagnosis may have significant relevance for understanding complex patient pathways and individual health care needs. Approaching patient pathways as individual and socially constructed may contribute important knowledge to support targeted cancer care.

Keywords: biographical disruption, colorectal cancer, life course disruption, Norway, patient-centeredness, patient pathways, person-centered care, supportive cancer care, unmet health care needs, complementary and alternative medicine

Introduction

Colorectal cancer is the third most common cancer worldwide, with nearly 1.4 million new cases diagnosed in 2012. A rapid increase in the incidence of colorectal cancer is seen in Norway, with the highest rate of colorectal cancer seen in women worldwide in 2012.¹ The majority of cases occur in people over the age of 60 years, and approximately 55% occur in more developed countries. As treatments and therapies improve, the population of survivors also increase.^{1–3} Several studies show that living with colorectal cancer leads to significant and negative changes in people’s physical, emotional, sexual, and social functioning. This includes living with a stoma, continuing fatigue, altered bowel

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habits, and continued fears of recurrence. Persons living with colorectal cancer often feel that their identity and self-image are threatened by the consequences of their condition and are at significant risk for anxiety and depression.^{4–8}

What is a patient pathway?

In medicine, the terms “pathway” and “patient pathway” are often understood as clinical pathways or care pathways operationalized as standardized packages of health care based on guidelines for the condition in question. Such guidelines outline the process of care most likely to produce the desired medical outcome and are important instruments in achieving positive health outcomes.^{9–11} However, clinical pathways and guidelines most often address single diseases and do not focus on coexisting multimorbidity or on patient experiences and preferences that may influence patients’ health care needs. In this paper, we explore and discuss “patient pathways” from a patient perspective, understood as incorporated into socioculturally constructed life courses. The experience of receiving a cancer diagnosis and undergoing cancer treatment is important in this understanding of patient pathways, but equally significant is what individuals perceive as important in their everyday life with cancer. Not only “health events”, but also “life events” are included in our understanding of patient pathways. 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. We hypothesize that understandings of the patient pathway as a clinical pathway correlate with the anthropological concept of an “etic” understanding. Etic analyses refer to the development and application of models derived from the analyst’s theoretical and formal categories, such as biomedical knowledge. By contrast, “emic” analyses stress the subjective meanings shared by a social group and their culturally specific model of experience.^{12–14} In this study, colorectal cancer patients’ individual life experiences are understood in light of their cultural contexts.

Aims and research questions

The overall aim of this qualitative, longitudinal study is to contribute to supportive and targeted cancer care. Here, the concept of “supportive care” is understood as treatment/care given to improve the quality of life of people who live with serious illness such as colorectal cancer and its sequelae.

Understanding different types of individual patient pathways may provide health care personnel, researchers, and health policy makers with an enhanced understanding of patients’ health care needs, treatment preferences, and decision making. The research questions under investigation are as follows:

- How did the participants illustrate their individual patient pathways?
- What did the participants describe as the most important health and life events affecting their patient pathways?
- What were the participants’ experiences from the public health care system?

Materials

Eligible participants were identified in the electronic patient record of the University Hospital of Northern Norway, which in 2011 served a population of approximately 500,000 people. Participants should be between 18 and 70 years of age and should be diagnosed with rectal cancer Tumor–Node–Metastasis stage I–III (Dukes A–C) within the last 6 months. They should have completed their primary surgical treatment and have their residence <500 km from the hospital. In the autumn of 2011, 20 patients who fulfilled the recruitment criteria received letters of invitation. Ten patients gave written informed consent and were included in the study; of them, one withdrew after the baseline interview. Nine patients aged between 54 and 68 years at baseline completed the study. During the study, all participants were invited to regular, 3-monthly health care follow-up visits to identify early signs of cancer recurrence. Demographics are presented in Table 1.

Methods

Data collection

Data were derived from in-depth interviews and participants’ drawn and written illustrations of their patient pathways (Figures 1 and 2). A qualitative, open-ended research design was chosen because we wanted to explore subjective and experience-based patient perspectives.¹⁵ We sought idiographic knowledge and wanted “thick” descriptions of individual and unique aspects of experiencing illness.¹⁶ Inclusion of patients continued until only a small amount of new information was obtained in additional interviews. We carefully monitored when redundancy began to occur, and the data was then deemed to be saturated.¹⁷

Qualitative interviews

We understand in-depth interviews as being interactional, reciprocal, and reflexive processes.¹⁸ Face-to-face baseline

Table 1 Demographics

Characteristics	Number of participants (n=10)
Sex	
Female	6
Male	4
Age (years)	
Median (range)	61 (53–68)
Education	
Secondary education	3
High school or equivalent	2
Trade/vocational diploma	3
Bachelor degree	0
Masters/professional degree	2
Marital status	
Married or living with a partner	7
Not married	3
Living	
Alone	3
With children	0
With spouse/partner	5
With spouse/partner and children	2
Work	
Unknown	1
Employed full time	2
Employed part time	1
Self-employed	2
Unemployed	0
Retired	1
Disability income	3

interviews took place at a research center during the autumn of 2011. These interviews lasted between 45 and 150 minutes and gathered information related to prediagnosis, health behaviors, the diagnostic experience, treatment recommendations and choices, health care needs, information-seeking behavior, and evaluation. In the next phase, the participants were asked to write diaries on health and life events for four periods of 3 months. These diaries were used as a basis for the discussion of important health and life events in three quarterly telephone interviews and a closing interview. Four of the patients did not want to or did not manage to write diaries.

In these cases, a semistructured interview guide focusing on health and life events during the last 3 months was used for the quarterly interviews that lasted from 20 to 80 minutes. Twelve months after the baseline interview, face-to-face closing interviews lasting from 40 to 120 minutes were conducted. These interviews reviewed participants' perspectives on health and life events during the last year. The 46 interviews were conducted by either the first author (a sociologist), the last author (a physician), or an experienced research assistant, all trained in qualitative interviewing. The interviews were digitally recorded and transcribed verbatim by a professional transcriptionist.

Illustrations of patient pathways

Approximately 10 months after the closing interviews, five participants and five researchers met in a workshop focusing on how to illustrate, interpret, and support patient pathways. As a first step, the participants were asked to illustrate their personal pathways as figures/text on paper without any further guidance. The first author moderated this part of the workshop and took notes on the participants' comments. These notes were presented to and confirmed by the participants, and included in the data material.

Analysis

We used an inductive approach, and the qualitative content analysis was based on the participants' descriptions of, and reflections on, their experiences from life before and after cancer diagnosis.¹⁹ In the first evaluation step, the materials were studied intensively to gain a general understanding of the main investigated issues. In the second step, the materials were reevaluated and coded in NVivo10 qualitative software, starting with line-by-line coding of ideas, themes, and concepts. Afterward, secondary substantive codes were developed, summarizing key concepts across the data.¹⁹ During the interviews, the theme "disruptive life events before

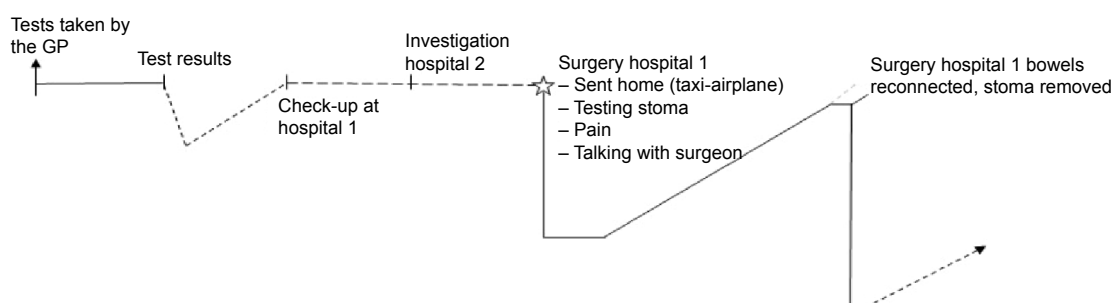


Figure 1 Hannah's illustration of her patient pathway.
Abbreviation: GP, general practitioner.

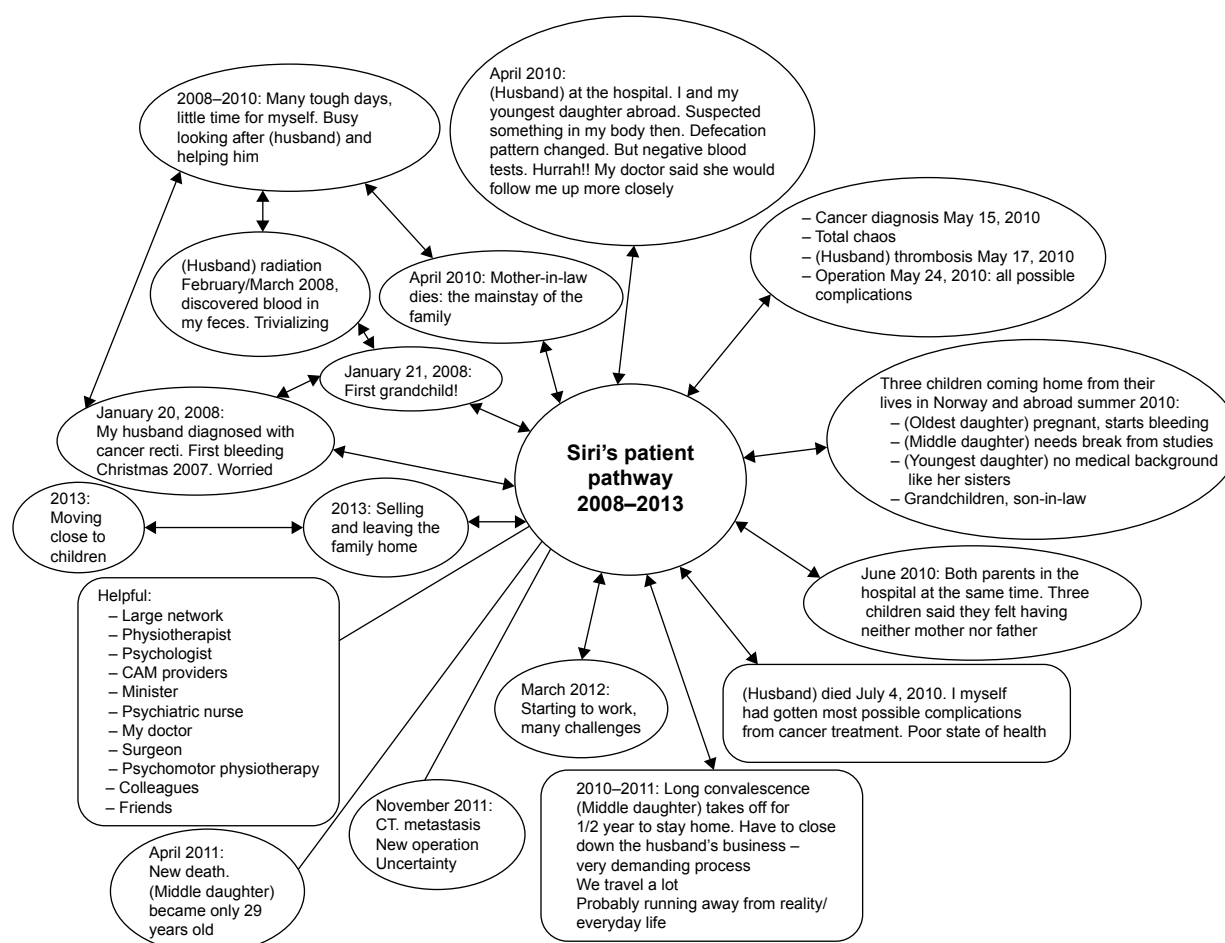


Figure 2 Siri's illustration of her patient pathway.

Abbreviations: CAM, complementary and alternative medicine; CT, computed tomography.

receiving the cancer diagnosis” was brought up by seven of nine participants as being of significant importance to their lives with cancer and their health care needs. Experiences from health and life events after cancer diagnosis were also described in terms of life course disruption both in interviews and in the workshop. Empirical and theoretical understandings of biographical disruption from the research literature were thus applied for further interpretations of patient pathways. We aimed at generating empirically and theoretically based hypotheses for further research in an abductive methodological approach where theoretical and empirical knowledge interacted and produced new in-depth knowledge.²⁰

Ethical considerations

The study was conducted according to the Declaration of Helsinki.²¹ It was approved by the Regional Committee for Medical and Health Research Ethics and the Norwegian Data Protection Authority. The participants received letters of invitation, including ethical information. Voluntary participation as well as the participants’ option of withdrawal at any time was emphasized both prior to and during the

study. Information about aims and research procedures was provided. Cancer patients may be considered potentially vulnerable people.²² The research team thus aimed at conducting the interviews and the workshop with sensitivity to the needs and abilities of each participant.²³ The transcriptionist signed a written consent to professional confidentiality and personal information that could identify the participants was deleted from the interview transcripts. This paper contains two participants’ illustrations of patient pathways (Figures 1 and 2) and a further description of them in the text. In the case illustrated in Figure 2, the participant expressed that she and her family wanted to share her pathway also in terms of possible recognizable information. This participant has signed an extended form of consent and has approved the descriptions of her case in this paper.

Results

In the following section, we first present results on illustrations of patient pathways and thereafter link these findings to the interview material. Finally, we present the participants’

self-defined health care needs held against their experiences from cancer care within the public health care.

How did participants illustrate their patient pathways?

The illustrations turned out to be rather different, depending on how the participants interpreted the concept of patient pathways. The participant "Hannah" said that she understood patient pathways as a concept including health events only. Her illustration was linear, starting with the first visit to the general practitioner because of symptoms that later were connected to the cancer disease (Figure 1).

Without words, however, this figure in addition to important health events also includes information about how "Hannah" managed during the patient pathway, illustrated by the "ups and downs". In a cancer care perspective, it is interesting to notice that two major down periods followed periods of hospitalization, and that "Hannah" illustrated that she was on a lower level than ever before when she participated in the workshop. At that time, she had her intestines reconnected and stoma removed, and her physical condition seemed to be better than ever since starting her cancer treatment. When asked about her illustration of "ups and downs", "Hannah" explained that they illustrated a very bad mental health status and thus significant unmet health care needs.

Three participants, including "Siri" (Figure 2), created complex and circular illustrations that included life events: "Siri" placed herself in the middle of a range of life and health events that often were interwoven. She attributed many events and changes not only concerning the cancer, but also other negative health and life events both before and after the cancer diagnosis. These events significantly influenced her patient pathway and self-defined health care needs. Consequently, in her perspective, "Siri's" patient pathway started already in 2008, 2 years before she was diagnosed with cancer. We have here categorized such events as "disruptive events" and "life course disruption".

Disruption in patient pathways

"Disrupted life courses" might appear when expectations about the future are not met, typically when one is facing serious illness.^{8,24–27} Bury²⁴ introduced the concept of biographical disruption as a concept used to confer chronic illness as a disruptive event, a major kind of disruptive experience or critical situation. The experience of living with long-lasting cancer has been compared to the experience of chronic illness with respect to biographical disruption.⁸ Life events and experiences that individuals do not anticipate may have significant and potentially negative consequences.

Becker²⁵ argues that while continuity in life might be an illusion, it is an effective one because it organizes people's plans and expectations. We explore disruptive events with relevance for the participants' everyday life with cancer and possible patient-defined health care needs linked to life course disruption and managing a disrupted life course. The most important disruptive health and life events affecting the participants' patient pathways described in relation to the point of diagnosis are described in Table 2.

The participants experienced shock, trauma, uncertainty, and disruption receiving the diagnosis and living with cancer. This affected their health and identity and, consequently, their self-defined health care needs. Such aspects of biographical disruption in cancer patients have already been explored and analyzed in other recent studies.^{8,28} An unexpected finding, however, was that seven of nine participants expressed that their cancer was not necessarily their deepest concern with respect to quality of life and well-being in their patient pathways. Stress, grief, anxiety, and depression caused by life events before cancer diagnosis had significant disruptive effects on their daily lives and their prospects and expectations of the future. This is an underexplored and possibly

Table 2 The most important disruptive health and life events affecting the patient pathway in a sample of colorectal cancer patients

Disruptive events related to the cancer diagnosis and life with cancer	Why disruptive?
Before diagnosis: the illness and death of significant others	Emotional burdens: loss, grief and mourning, shock, anxiety, anger, uncertainty, guilt, unwanted changes, less able to care for other family members, depression Practical burdens: economy, job combined with home care and hospital visits, housekeeping, moving
At point of cancer diagnosis	Shock, trauma, anxiety, uncertainty, grief over "the lost, expected life"
After diagnosis: disruptive health events	Uncertainty, lack of food, lack of care, bad prognosis, difficult visits to the hospital Diarrhea and stoma disrupt social life, work life, and sex life Fatigue, depression, anxiety
After diagnosis: being an ill parent and partner	Uncertainty, guilt, grief, depression Negative change in sexual identity Practical and emotional issues related to the stoma Guilt Grief for the disrupted marriage and sexual relationship
After diagnosis: not being able to work	Grief for the loss of network and identity

important aspect of disruption in cancer patients and, therefore, vital in the further analysis and discussion.

Disruptive life events before diagnosis: “my cancer isn’t my deepest concern”

Three of the seven participants who reported disruptive events before cancer diagnosis lost close relatives in the years before they themselves became ill: a husband, a child, a sister, or old parents. Others had adult children suffering from serious physical and mental illness, needing extensive care and support from their parents. Many had worried for, and/or taken care of their loved ones for years and were “totally exhausted” when they themselves became ill. Some seriously wondered whether their cancer was caused by these disruptive life events.

For one participant, her first thought when she received the cancer diagnosis was that “This is the end!” She expressed that this reaction was based on previous disruptive events. She had lost her beloved sister to cancer some years before and was still trying to cope with the burden of assisting her sister through years of tough treatment: “She suffered through so much pain to no avail.” Another close relative suffered from Alzheimer’s, and so the participant described sad visits and sorrow. After having been diagnosed with cancer, this participant was more worried that she could get Alzheimer’s than the prospect of the cancer spreading.

The participants who had adult children struggling with serious illness worried a lot about their children’s future if they themselves should die from cancer. They strongly expressed that the public health care system did not take their long-term worries and burdens as caretakers seriously, and they felt exhausted. One said:

I want to decide about my time myself [to become healthier] and that is not possible when your adult child has moved in with you and is not working [...] He struggles a lot mentally, and I worry for him all the time [...] I want him to go to an institution [...] I want to be able to take care of my own health, but no-one listens.

Another participant had an adult son who had been a victim of violence, and he had both physical and psychological problems that affected his parents’ lives significantly: “All the time there is something [...]” This son had many bad experiences from the public health care system: “Too much drugs, too little care.” This participant expressed in retrospect during the workshop that:

Maybe the best cancer care I could have received when everything was chaos and fear, was that the healthcare

system took care of our son. I wasn’t allowed to really engage in my own healing process, and I still worry about what happens to my son if I should die from cancer after all.

A third participant had lost an adult child to suicide and struggled to accept that she was allowed to survive cancer and thus survive her child. When asked about her health care needs, she was really shocked that she had never been asked about her emotional needs although both doctors and nurses were aware of her loss.

Other participants, like “Siri” in Figure 2, had lived longtime with seriously ill partners before they themselves were diagnosed with cancer. They described a life constantly circling around the illness of their spouse. “Siri”, for example, had taken care of her husband, his business and their children, followed her husband to all consultations, made healthy food, and had no focus on her own health. When she herself was in need of aid with her daily activities, her husband had died:

I had experienced the whole process before, and having the same diagnosis was totally chaotic [...] I thought: “This is absurd” [...] It was horrible for my husband, and he thought that there had been a rub-off effect [...] It was a shock [...] so much to handle [...] for a long period of time I wasn’t able to act.

“Siri” experienced extensive treatment complications, and at the same time, her husband’s condition became worse. Her burden became heavier because she was not able to be there for her dying spouse: “Sometimes I have thought that I would go mad [...] the grief reactions have been extended, just had to live through the chaos.” Although “Siri” had many positive experiences with public health care, she had to express her needs and initiate and coordinate a program of health care herself in this extreme situation. The cancer had to be treated, but her responsibility for the three children, her grief, fatigue, and anxiety were also serious threats to her physical and mental health and her ability to cope with the cancer.

How did the participants experience the care offered within the public health care compared to their self-defined health care needs?

In general, the participants were rather pleased with the public health care system as far as receiving surgery, chemotherapy, and radiation in hospital settings were concerned: “It was very effective and well-functioning.” Several had personal resources such as financial assets, health education, and a

powerful network that made their access to health care easier. Some had health insurances that gave them swifter access to the care they needed. A nurse said that her education and network were really important:

I feel that I can ask for those professionals I consider to be best qualified, and I get appointments quickly. They don't put blocks in my way, they rather open the doors they are able to open.

When returning home from the hospital, however, most participants experienced a range of practical and emotional problems. The participants' self-defined health care needs included emotional needs caused by depression, anger, anxiety, loss, and physical pain. In their opinion, they needed help to analyze and cope with the current situation – their disrupted life course. They expressed the need for help to define and accept their current situation, to be able to prioritize their resources, and to be open and reflected: “It is hard to ask for help and express and accept that you may be depressed, but I really feel that it would helped to have someone walk together with me.” They often found it difficult or impossible to figure out what help they were entitled to, and eventually where to find it. Consequently, “Hannah”, “Siri”, and two other participants decided to use complementary and alternative medicine (CAM) paid out-of-pocket to deal with their health care needs not met within the public health care system. They said that they wanted to relate to health care providers who were able to communicate in an equal and open-minded way and engage in individual practical and emotional reflections. They also stressed the need for seamless care, based on humiliating and stressful experiences when shifting between hospital and home-based care. Specially trained cancer nurses, CAM providers, and one-on-one peer support would be helpful initiatives to meet emotional and practical needs.

Discussion

Understandings of patient pathways in public health care systems

The participants experienced a public health service with a main focus on rendering evidence-based medical services and less focus on individual, self-defined health care needs. In general, the participants were pleased with the more or less standardized cancer care they were offered in the hospital. In their everyday life with cancer at home, however, many experienced gaps between the services they were offered and their individual needs. Despite an increasing focus on biopsychosocial approaches to health care,²⁹ Western public health care systems are dominated by a biological understanding

that predisposes them to ignore or underperform with regard to the personal needs of the patient. They are fragmented and highly specialized systems where patients must integrate services for all conditions themselves. It has been argued that such health care systems may actually become an additional burden for patients already struggling.³⁰ The importance of person-centered care,^{29,31} seamless care,^{32,33} and patient involvement is strongly emphasized in recent studies, and public policy documents across Western countries.³⁴ There is still a long way to go, however, to change the everyday clinical practice and explore and address patients' individual needs.^{34,35} In this situation, we argue that a stronger focus on both eliciting and addressing life events that shape the patient pathway should be a priority.

How can life course disruption be understood in cancer care?

It is thought provoking that seven of nine patients recruited in a university hospital setting express that life course disruption before cancer diagnosis significantly influenced their patient pathways and health care needs. To understand disruption, Becker²⁵ argues that we must understand cultural definitions of normalcy with regard to health, sex, family, relationships, etc. As demonstrated (in Figure 2 and Table 2), the patients in this study constructed both life events, before cancer and living with cancer, as biographically disruptive events with ongoing physical and psychosocial impact. The crucial importance of such contextual factors has also been emphasized in other studies of biographical disruption.^{36,37} Life course disruptions are often experienced as happening through events despite being the cause of, or part of, an illness. Because of earlier dramatic experiences of biographical disruption, some participants perceived their cancer experience more as part of a biographical flow³⁶ and a total burden of disruption, than an intense crisis linked exclusively to receiving and handling cancer. Such intense crises are described in other studies of life course disruption that do not focus on the significance of life events before cancer diagnosis.^{8,28} So far, important individual differences in biographical construction of “the lived self” have been largely ignored in the disruption literature and clinical settings. Treating all cancer experiences as universal may result in poorly designed interventions and, in turn, low outcomes for particular people.^{36,37}

Disrupted patient pathways, emotional needs, and management

According to the results of this study and other recent studies of people living with colorectal cancer,^{7,38,39} these patients often have considerable emotional needs. Although patients

mobilize their personal resources to manage a disrupted life course/biography,⁴⁰ such patients still express strong needs toward the public health care system.

Health care professionals' responses to complex emotional needs may thus be a key in building individualized, targeted cancer care and a trusting relationship between patients and the public health care system. According to Becker,²⁵ the stories people tell about themselves are a way to articulate and resolve core, universal problems and to avoid or heal biographical discontinuities. Such a clinically relevant link between emotional work and the handling of life course disruption (in terms of biographical work) has been established in the literature.^{25–27,37,41,42} Studies have also revealed that 50% of all cancer patients turn to CAM during their patient pathways.⁴³ Their use of CAM is often linked to experiences of biomedical focus, failing communication, and unmet health care needs in conventional health care systems.^{35,44–47} The participants pointed at specially trained cancer nurses as the most suitable health care professionals to cover complex health care needs in their everyday life. This is in line with Kidd et al,⁴⁸ who in their work argue that:

Interventions to promote self-care should focus on helping people to preserve their self-identity, as well as managing the emotional toll and physical side effects associated with cancer treatment.⁴⁸

“Siri” and “Hannah” demonstrate an ability to navigate within the collected set of health care, CAM, and social services to find the services that will cover their needs, whereas other patients may be more at loss and not able to elicit the resources that cover their needs. These variations reflect not only different personal styles of problem solving, but perhaps also differences in “health literacy”, as for instance “Siri” has a professional health provider background. Health literacy is, according to Sorensen et al,⁴⁹ skills allowing the person to access and apply health information to cover your personal health care needs. Systematically building health literacy in patients with long-term care needs, such as cancer patients, is one of several promising approaches to improve personalization and quality of care.⁵⁰

Emphasizing patient experiences concerning health care needs may add to the development of a clinical methodology for implementing individual and targeted cancer care. As argued by Coulter et al,⁵⁰ in the *British Medical Journal* in 2014:

People's emotional and practical response to illness and the responsiveness of health providers and systems to their needs is crucial, ... it matters hugely to all users of health

care and because it has a direct influence on the other dimensions of quality.⁵⁰

This is indeed still a challenge. In the Norwegian context, physicians have been characterized as “courteous but not curious”, systematically neglecting patients' values and existential emotional needs.^{51,52} Current high-quality web sources for “supportive cancer care” also demonstrate the lacking focus on individual patient pathways and emotional needs.⁵³ Potential conflicts between professional goals and patients' personal goals for care in patient pathways have so far received little attention. If personal goals for care are set above professional goals, this may clarify and resolve tension between potentially conflicting goals⁵⁴ for patients with disrupted patient pathways. A more patient-centered communicative approach and focus on patients' individual and changing concerns and treatment goals throughout the patient pathway may strengthen patient-centered care and enhance the understanding of patient pathways.

Methodological considerations

If one aims at fully and properly understanding a patient pathway, we argue that a research design which promotes an open approach to the field should be used, preferably with repeating in-depth interviews or mixed qualitative methods. Qualitative research addresses research questions that are different from those considered by clinical epidemiology and “has the ability to pursue systematically the kinds of research questions that are not easily answerable by experimental methods”.⁵⁵ The obvious critique against qualitative studies is the lack of generalizable evidence. In assessing the quality of qualitative studies, we can thus ask whether the credibility of our claims is supported by sufficient evidence.⁵⁶ We posit that the empirical and theoretical interpretations developed in this explorative study have power as hypotheses for further research.²⁰ Todres et al⁵⁷ argue that through its illumination of people's perspectives and experiences, qualitative research contributes a particular type of useful evidence for caring practices. Qualitative research has therefore the potential to be meaningfully translated into practice in ways that place patients at the center of care.⁵⁷ With respect to confirmability, researchers from three study sites were involved in the international PATH study and agreed on the study design.^{47,58} Furthermore, the disruption literature corresponds very well with the perspectives of the participants in this study.

Conclusion

In this study, colorectal cancer patients' individual life experiences understood in light of cultural contexts were included

in the understanding of the concept of patient pathways. The study adds to the body of literature exploring how to enhance supportive care for cancer patients. It reflects on the importance of biographical disruption, not only related to receiving the diagnosis and living with cancer, but also with respect to disruptive events before becoming a cancer patient. We argue that the understanding of patient pathways should include patients' perspectives to be able to map and better meet the health care needs of the individual patient. In our opinion, the disruption literature adds to a deeper understanding of the concept of patient pathways that may be of relevance to achieve the goal of supportive cancer care. Former experiences of disruption may position cancer patients in a vulnerable situation, and they may thus have particularly complex health care needs. Furthermore, this study adds to the disruption literature in terms of the significance of understanding illness experiences as part of a biographical flow and a total burden of disruption. The results may function as valuable input to further research initiatives to support health care professionals in their quest to provide individualized, targeted support at each stage and aspect of a patient pathway.

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Disclosure

The authors report no conflicts of interest in this work.

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