


Living in Rural Areas and Receiving Cancer Treatment Away From Home: A Qualitative Study Foregrounding Temporality

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Abstract

We used explorative interviews to gauge (inter)personal, physiological, and emotional challenges of seven rural cancer patients who traveled long distances to cancer treatment centers. After a thematic analysis, we foregrounded experiences of temporality by using a phenomenologically inspired approach. The analysis resulted in three themes: (a) An epiphany of “what really matters in life”—time gains new meaning, (b) Feeling out of sync with others and own body—striving for coherence and simultaneity, and (c) Being torn between benefits of home and treatments site—time and distance as a tangible aspect of traveling and being away. Under these themes, 13 meaning units were generated, which reflected changes in temporality. During treatment, life primarily revolved around repeating circles of travel arrangements, staying on top of treatment schedule, and synchronizing a home life with a life away from home. Nurses should provide comprehensive care to enhance stability in cancer patients’ temporal experiences.

Keywords

cancer, rural healthcare, experiences, Iceland, illness and disease, qualitative, phenomenology, conceptual foregrounding

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Introduction

Cancer diagnosis and treatment are difficult for patients and their relatives (Henson et al., 2020; Ugalde et al., 2019). For cancer patients who reside in rural areas, psychosocial and physical distress seems to be augmented compared to those who live near the treatment site (Fitch et al., 2021; Levit et al., 2020). The intensified experiences of patients living in rural areas may partly be explained by the long distances that they need to travel and by the time they need to spend away from the support and comfort of their family (Levit et al., 2020; McGrath, 2015; Wagland et al., 2015). Furthermore, the long and repeated journeys increase the physical, mental, and economic burden of cancer (Butow et al., 2012; Loughery & Woodgate, 2015). The geographical distance between home and place of treatment may avert people from seeking healthcare and may play a role in decision-making, for instance, related to treatment options (Baldwin & Usher, 2008; Loughery & Woodgate, 2015; Sparling et al., 2016). In an Icelandic context, the rough mountain roads and, at times, unfavorable and harsh weather conditions further add to

difficulties of seeking treatment in the urban areas (The Icelandic National Audit Office, 2018).

Cancer prognosis is worse in patients living in rural areas than those living in urban areas (Blake et al., 2017; Gunn et al., 2020). Among features influencing this trend is that many rural cancer patients are diagnosed at a more advanced stage and have less access to specialized interdisciplinary services (Abou-Nassar et al., 2012; Coory et al., 2013; Levit et al., 2020). Results from a research study conducted in Nebraska ($N=1,912$) indicated that journeys lasting >160 minutes adversely affected survival within the first year after stem cell therapy, regardless of other patient-related factors and type of cancer or treatment (Abou-Nassar et al., 2012).

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The results of most studies included in a systematic literature review ($N=37$; 12 qualitative studies) conducted by Butow et al. (2012) indicate an augmented need for psychosocial support in rural cancer patients. If healthcare professionals appropriately address these issues, the support might increase the well-being of patients and their families. A more recent review ($N=23$; 10 qualitative studies) further underscores the importance of establishing a good network where cancer patients living in rural areas receive professional advice and interact with people in a similar situation (Loughery & Woodgate, 2015). Bonding with people in a similar situation motivates patients; it makes them feel less alone and gives them the required boost to enhance their health-related behaviors (Anbari et al., 2020).

Studies comparing the quality of life of cancer patients in rural areas to those in urban areas show contradictory results. On the negative side, researchers have reported poorer quality of life in patients living in rural areas due to less physical activity and a higher burden of symptoms (Butow et al., 2012; Gunn et al., 2020). However, on the positive side, rural cancer patients tend to report less distress and better psychosocial well-being than their urban counterparts. Distinctive features adding to the positive experience in the countryside were an innate trust in their local society, the beautiful landscape, and tranquility (Gunn et al., 2020; Loughery & Woodgate, 2015). Furthermore, the cultural uniqueness and being part of a little society where everyone knows and helps each other provide many patients with inner strength (Pesut et al., 2010; Rogers-Clark, 2002).

Comparatively, few studies have examined individuals' experiences of receiving cancer treatment away from home. Extant qualitative studies predominantly focus on particular subgroups, such as those with breast cancer (Loughery & Woodgate, 2019; Rogers-Clark, 2002), malignant blood disorders (Wagland et al., 2015), or cancer patients requiring palliative care (Devik et al., 2017; Pesut et al., 2010; Yeung et al., 2022). The focus of these studies has also been diverse, such as the experience of staying at home during treatments, alterations in social relationships, and experience of psychosocial support (e.g., Baldwin & Usher, 2008; Pascal et al., 2015). Only a few recent qualitative studies exist, and none within an Icelandic context. During the last 5 to 10 years, substantial improvement has occurred in cancer treatment and communication technologies which may influence the experiences of rural cancer patients. Thus, there is an apparent need for up-to-date knowledge on patients' experiences that may be transferable to a broader group of cancer patients.

When people are confronted with life-threatening diseases such as cancer, it urges a pursuit to seek meaning within the embodied experience that will more or less abruptly interfere with the daily cadence of life; habits, identities, body image, memories of the past and dreams for the future, and how people encounter the "now" (Toombs, 1987). Temporality is one of the existentials within phenomenology and is reflected in clock time and lived time. Lived time,

which is a synthesis of the past, present, and future, is weaved together with time as experienced by a person. James Aho notes the following:

. . . the present, my presence here and now, is experienced from a standpoint of my past and my future. By my *past*, we mean the shared historical background of practices and beliefs that influence how things count and matter to me now. By my *future*, we mean the social possibilities (roles, occupations, and relationships) that I can press into, that shape my self-interpretation, and that culminate in my own death. Taken this way, time is not something I can actually lose, "manage," "save up," or "sell," for it is not something that I ever really possess or have power over, like I do a car or a house. Rather I *am* time, and—as a finite, future-anticipating, historically situated *way of being*—my time ends when I do. (Aho & Aho, 2009, p. 41; emphasis in original).

Clock time is often comprehended as objective time; 1 hour is an hour for everyone and can be externally validated by another person whereas lived time denotes subjective time. To exemplify, 1 hour can be an eternity if you are waiting for a test result or be passing in an instant if you are engaged in a highly exciting activity. From a phenomenological standpoint a complete distinction between clock time and lived time seems somewhat arbitrary—because clock time is always experienced by someone who also lives *through* time or as Sokolowski (2000) writes: ". . . internal time is a condition for the appearance of objective time" (p. 133). Thus, clock time and lived time inhabits the same person and has the potential to provide important experiential insights of changed temporality that nurses could act on and which can be unveiled among others through patients' narratives. These narratives, in their turn, can be used by nurses to assist patients with making "Life-story revisions" (Leder, 2021) or providing other means of meaningful support.

When investigating experiences with a phenomenological frame of mind, subjective experiences should be considered alongside its intentional worldly correlate to reach an account of how patients seek meaning within their engagement with the world—an understanding that ultimately could help nurses to optimize healthcare (Klinke et al., 2014). Thus, the aim of this study was to explore the experience of patients who have received cancer treatment distant from their own home and, in particular, to gauge (inter)personal, physiological, emotional challenges while emphasizing changes in temporality.

Materials and Methods

Study Design

This study was conducted using a qualitative design underpinned by phenomenology (Merleau-Ponty, 1945/2012; Zahavi, 2019a) and ideas of thematic analysis (Braun & Clarke, 2019). Within recent years Zahavi has argued that phenomenology should be applied in a more practical and accessible manner

when used in qualitative nursing studies. The end goal is not to understand the essence of a particular nursing phenomenon but rather to enable new insights that help nurses comprehend their patients and optimize caregiving and solutions to the healthcare challenges that patients face (Zahavi, 2019b). Zahavi (2019b) furthermore highlights that healthcare professionals that wish to draw on phenomenology in their qualitative research projects: “. . . should look to it not as a rigorous method, but as an open-minded attitude and theoretical framework that can be used in conjunction with a variety of methods” (p. 8). We drew on phenomenology by using conceptual foregrounding as a methodological tool to capture existential changes in participants’ experiences. Conceptual foregrounding provides a pragmatic structure conducive to integrating phenomenology into qualitative research projects and gauging bounded aspects of embodied experiences (Fernandez, 2020; Klinke & Fernandez, 2022). Thus, we used a thematic analysis to analyze the interview text systematically and “temporality” as a conceptual lens to further deepen the description of experiences of cancer patients living in rural areas and receiving cancer treatment away from home.

Setting and Participants

The study was conducted in Iceland, which is the most sparsely populated country in Europe, with approximately 371,600 inhabitants spread over the area of 102,775 km² (Statistics Iceland, 2020). The rural population, denoting people who lives in agricultural areas or villages with less than 200 inhabitants, was 22,359 in 2020 (Statistics Iceland, 2020). There are no private hospitals in Iceland, and the primary cancer treatment center is in the capital of Reykjavík. There is also a tertiary cancer clinic in Akureyri in the Northern part of Iceland. The Icelandic social insurance system covers most healthcare costs for all legal residents. The number of newly registered cancer cases in 2020 was 1,681 (World Health Organization, Globocan, 2020). Many patients with cancer need to travel long distances to receive cancer treatment. The weather conditions in Iceland are highly unpredictable. Often during the winter, the roads in rural areas become blocked with snow accumulation and domestic flights are frequently cancelled.

Participants were purposefully chosen, and we included men and women from different parts of Iceland who had received medical cancer treatment or radiotherapy with/without surgical treatment at The National University Hospital of Iceland in Reykjavík. Participants were between 25 and 65 years old and had completed their cancer treatment within the previous half to 5 years. They had all needed to travel at least 2 hours to the place of treatment. Time of travel denoted the time required to travel from one’s doorstep to the place of treatment during the most optimal weather conditions. The exact sample size was not pre-determined. Patients with chronic cancer forms, level 4 cancer, those not in remission, or diagnosed with other conditions that could influence results, were excluded. A clinical nurse specialist established

contact with potential participants and obtained oral permission for the researcher (Halldóra Egilsdóttir) to contact them and provide additional information about the study. If the participants showed interest, the time and place for data collection was decided. At the face-to-face meeting, participants signed informed consent.

Data Collection

A frame of questions was employed, inspired by phenomenology, to elicit descriptions regarding what it was like to be embodied, experiencing, imagining, feeling, and so forth when receiving cancer treatment away from home (Høffding & Martiny, 2016). The goal was to obtain descriptions of significant experiential dimensions, in particular related to temporality. Topics covered in the interviews encompassed experiences of the cancer diagnosis, traveling between home and place of treatment, anticipations in daily life, and change of priorities. Furthermore, we encouraged in-depth detailed descriptions of important moments and how participants structured their time and prioritized it compared to before cancer. Participants were encouraged to use metaphors or analogies when reflecting on their experiences. An exploratory attitude was maintained during the interviews to obtain profound detail on issues concerning temporality. In general, questions were raised to enhance the flow of each interview rather than in consecutive fixed order (Høffding & Martiny, 2016; Klinke & Fernandez, 2022). Toward the end of each interview, the researcher summarized main points and invited the participants to reflect even further and add to their narrative. Data collection occurred between October 2018 and January 2019 in a private location of each participant’s choice. In six out of seven instances, the researcher traveled to the participants’ homes. One interview was held in a home-like location at the Faculty of Nursing. Before the interviews the researcher (Halldóra Egilsdóttir) had spoken to the participants over the phone and spent face-to-face time with them to build up trust. The 60 to 90 minutes recorded interviews (Mean 78 minutes) were transcribed. Field notes, for instance related to the researcher’s reflections, descriptions of interview settings, geographical location, flow, and participants’ non-verbal responses, were incorporated into the transcripts before they were analyzed. In particular, we noted available healthcare services in the rural area and other relevant services, such as restaurants, that were important for the participants’ experiences (Phillippi & Lauderdale, 2018). After completing the interviews, the participants answered a standardized questionnaire providing background information, such as age at diagnosis, mode(s) of transportation, and the approximate number of trips to the treatment site.

Data Analysis

Data analysis was highly collaborative and occurred in two interrelated tiers. In the first tier the in-depth interviews were analyzed using a primarily inductive data-driven collaborative reflexive thematic analysis (Braun & Clarke, 2019;

Table 1. Overview of Participants' Characteristics—Travels and Treatment.

Characteristics of participants and travels							
Age at diagnosis	34	50	38	53	63	38	48
Sex	Female	Female	Female	Male	Female	Female	Male
Transportation to treatment	Own car	Air and own car	Own car	Bus	Air and bus	Air and own car	Air and own car
Approx. transport time during optimal weather conditions (hours)	3–4	3–4	>4	>4	2.5	>4	>4
Approx. number of trips	72	21	30	50	22	14	45
Types of cancer treatment							
Surgical treatment			✓	✓		✓	
Radiation therapy			✓	✓		✓	✓
Chemotherapy	✓	✓	✓	✓	✓	✓	✓
Stem cell transplantation	✓ ⁰			✓ ^d			✓ ⁰

⁰Own stem cells.

^dStem cells from a donor.

Terry et al., 2017). Key phrases were drawn forth and their meaning interpreted. All researchers reflected together and individually and immersed themselves in the analysis and creation of themes and content under each theme in a recursive manner to create a coherent nuanced account of the experience. Inclusion of new participants ceased when depth and richness were evident in tier 1 (sufficient information power to fulfill the goals of the analysis) (Braun & Clarke, 2021). In the second tier, emphasis was put on describing and interpreting changes in temporality and meaning units related to temporality were highlighted and presented in a table (Marianne Elisabeth Klinke, Helga Jónsdóttir). Finally, the individual transcripts were revisited to ascertain that the descriptions and interpretations reflected significant aspects—and variations—of the experience (Halldóra Egilsdóttir, Marianne Elisabeth Klinke).

Ethical Considerations

The institutional ethics committee at Landspítali University Hospital approved the study (32/2018). This approval is in concordance with the declaration of Helsinki (World Medical Association, 2018). Thus, participation was voluntary, and all participants signed informed consent. Patients were invited to contact a psychologist if they encountered issues, they had difficulties dealing with after the interviews.

Results

Two men and five women participated in the study. At the time of diagnosis, the average age of participants was 46 years, range from 34 to 63 years. They had different types of cancer and had received different types of treatment. See Table 1 for an overview of treatment forms, the number of treatments, and the approximate length of transportation time.

The length of cancer treatment ranged from 6 months to 3 years. Apart from receiving treatment, participants also traveled for diagnostic investigations, radiology, biopsies, and blood transfusions. In most instances, the stay lasted only for a few days; however, sometimes, the stay extended for months. All participants had lived in the rural area for several years and had their major network and/or closest family there. Four participants had children living at home. Three themes were generated during the analysis: (a) An epiphany of “what really matters in life”—time gains new meaning, (b) Feeling out of sync with others and own body—striving for coherence and simultaneity, and (c) Being torn between home and treatments site—time as a tangible aspect of traveling and being away.

Descriptions and quotes are in the following subsections used to substantiate the content and variations under each theme. Bolded words in quotes represent emphasis. While some contextual details are provided others are withheld or changed in ways that protect participant identity. Thirteen meaning units related to temporality are presented in Table 2.

a. An Epiphany of “What really Matters” in life—Time Gains New Meaning

Before the diagnosis, participants' beliefs about their future were somewhat “naïve” and seemed to originate in a fundamental belief about their indestructibility. This belief came to an abrupt halt at the time of diagnosis. Receiving the cancer diagnosis was a life-defining timepoint “*It's such a big word, 'cancer' [. . .] you just imagine the worst.*” The importance was reflected by the fact that the participants provided remarkably detailed information about their exact whereabouts in the time surrounding the diagnosis. For instance, people they were with, time and dates, weather, highlights of the news that exact day, clothes they were wearing, and other factors. One woman, who was a healthcare professional and

Table 2. Meaning Units Reflecting Changes in Temporality.

Themes	Meaning units
An epiphany of “what really matters in life”—time gains new meaning.	<p>The diagnosis is a life-defining moment in existence. An appreciation of the past in a new way leads to what is important in life. Sometimes patients regret not living according to what is truly meaningful in life prior to the diagnosis.</p> <p>The usual predictability in daily life has changed. Plans do not reach far into the future, but they are controlled by the bodily symptoms of treatment and travel.</p> <p>The patients live more in the now and appreciate things in a new way. The slowing down of inner time helps provide a new, intensified appreciation of meaningful events. Time sometimes seems to pass slowly when foregrounding “what matters” in daily life. It allows people to enjoy previously taken-for-granted events. A sometimes paradoxical, almost ecstatic feeling of happiness occurs within an unhappy situation.</p> <p>Important timepoints and feelings are brought to the forefront and explicitly reflected upon in own self-narrative.</p>
Feeling out of sync with others and own body—striving for coherence and simultaneity.	<p>The patients experience feelings of solitude if it is impossible to (re)align their own time perception with other people’s time perceptions. For instance, when other people do not fully comprehend their reality away from home, or when they realize time has passed at home without them, that is, when they have not been able to keep up-to-speed with important moments of transition while away for treatment.</p> <p>The patients experience an awareness of the temporal structure of the body. The body is finite. A sudden realization that the body has changed is sick and differs from the habitual body. The profoundness of perceived bodily change is strongly motivated by a change in intersubjective relations, for instance, due to different gazes, behaviors, and touches from others.</p> <p>An emotional mask of cheerfulness sometimes prevents sharing and closeness with others. A private way of dealing with symptoms desynchronizes the intersubjective sharing of important experiences.</p> <p>Physical symptoms are seen as a blessing and a curse. It was dealt with by making symptoms positive, for instance, by interpreting difficult symptoms as something that helps conquer the cancer. The patients negotiate their own endurance through times with many side effects, making time pass more quickly during uncomfortable situations and slowing down during enjoyable situations.</p>
Being torn between home and treatment site—time as a tangible aspect of traveling and being away.	<p>The patients feel physical and emotional distance to others or extreme closeness. Being away for treatment life is a different world than one’s personal network.</p> <p>The patients live in a relentless treatment loop where they need to stay on top of their treatment schedule, go away for treatment, come home, endure symptoms, get better, plan for the next trip, and so on, repetitively. The loop entails prolonged waiting times, waiting to get home, waiting to leave for treatment, and waiting to get better. This waiting time creates a hollow space in time.</p> <p>The patients negotiate time well spent while racing with the usual clock time. Concerns about delays in transportation, that is, due to weather, could adversely affect timely arrival at the treatment site or coming home in time after treatment—this troubled patients’ life world experiences.</p> <p>The patients or families spend money on traveling, cars, and other issues that need to be solved on the spot without contemplating the long-term financial consequences.</p> <p>The patients experience the temporal fragmentation of treatment between two worlds.</p>

highly engaged in family life and activities in the rural society, stated: *“I sat in the car with my husband. It was on a Monday at 15.45. We were on our way home after shopping. My phone rang. Everything was normal, but after two minutes, it wasn’t anymore ...”*

Most had only encountered slight symptoms prior to the diagnosis, and the real distress surfaced after the treatments began. When the initial blow had diminished, participants took a pragmatic stance to keep the ramifications of the disease, treatment, and traveling at bay. For instance, by an almost objectification of the disease and trying to consider it a distinctive life project *“it’s just your new job [. . .] you just have to work on it until it’s completed”* and being on top of transportation between treatment place and home *“this. . . somehow resembles running a mini-business.”* This analogy reflected multiple lifeworld changes that the participant associated with running a business. For instance, needing to stay away from home during longer treatment trips and

concerns about making her cancer treatment fit her family’s rhythm and other (social) obligations.

Even though many had planned not to let their everyday lives revolve around cancer, this decision remained in stark contrast to its widespread impact. From the time of diagnosis, the intrusiveness transpired as ongoing disruptions where their bodily well-being, emotional life, and social life were in a constant state of flux. One participant compared it to having a child: *“It reaches the same importance and impact in your family’s everyday life, but in a negative way.”* The participants’ freedom and predictability in everything they did or wanted to do were controlled by the treatment, bodily symptoms, traveling, and staying away from home and needing to find a new flexible structure in their everyday life.

All decision-making primarily revolved around keeping the family functioning, beating cancer, and staying alive. These ambitions were used to downplay less important issues. In retrospect, many participants were surprised by

their ability to uphold a fairly positive mindset: “*I was kind of a zombie, I just did what I had to do. It’s strange, but I was actually quite happy.*” A participant described how he had gained a new appreciation of life and felt very much alive at the moment, although he needed to struggle to move forward to maintain agency over his life and body:

*I find it quite remarkable that when you’re about to lose everything and that you may actually die, your way of experiencing life changes [the participant subsequently illustrates this change by providing an analogy of moving forward with your feet stuck in soft quicksand on a beach]. You need to move forward to prevent yourself from sinking even deeper. However, the sand only allows you to move **extremely** slowly [. . .]. When you move so slowly, you really start to sense things to the fullest, and you just somehow feel and experience everything differently. You experience the sand’s exact effects on your skin, your body’s position, and the effects of your every single movement [positively and negatively]. You become so unbelievably focused and situated in the ‘now’ [. . .]. You notice everything and the small things, and you have time to really look around you, to just feel, enjoy, and notice **everything**.*

His ability to notice important elements of life had been amplified simultaneously as slowing of time occurred compared to the objective pace of time. The continuity of his time perception remained intact, but the dynamics somehow changed to allow for the intentionality of pointing toward things/persons/acts of everyday life that have personal value but had featured more in the background. These important issues were brought forth and thematized. The cancer diagnosis and whole situation of needing to travel and being away from home commanded immediate and continuous reflection where participants needed to scrutinize their usual norms and habits that pre-reflectively used to guide their lives.

The participants described a sometimes-paradoxical sensation of happiness while recognizing the severity of their situation. This experience presents a juxtaposition between rediscovering what is important in life with the imminent threat of losing this connection. These diverse sensations caused emotional turmoil, which one participant described as “*seeing life through the eye of the hurricane*” —implying blurry, stormy surroundings while being situated within a vacuum. Many participants wondered why they needed to be so sick to open their eyes to what mattered in life. These mesmerizing contemplations encompassed, on the positive side, what one patient described as “*the gift of cancer*” because they learned to prioritize and act differently—their priorities transformed from doing more with less time to spending more time with less but important issues—leading to personal growth. However, the realization could also be painful, for instance, when realizing that one’s way of prioritizing had been wrong. The fact that they had conquered cancer colored their feelings because: “*not everyone with cancer gets well.*” Cancer remained a part of the participants’ temporal experiences and continued to pose a subtle threat.

b. Feeling out of Sync with Others and Own Body—Striving for Coherence and Simultaneity

Traveling was a determinate element interweaved into the cancer experience where participants sought predictability of “what comes next.” When participants were at home, they engaged with their relatives in an immediate reciprocal way. It was easier to “read” each other and recalibrate to changes than when the physical vicinity was broken. Conversely, the repeated acts of traveling to the city for treatment created temporal distance to one’s closest family and habitual surroundings. In situations where difficulties arose in emotional synchronization between participants and other people, it caused feelings of solitude. Such feelings, for instance, occurred when other people did not fully comprehend their reality away from home or when participants realized that time had passed and they had not been able to keep up-to-speed with important moments of home life.

Spending time with the family played a pivotal role throughout the illness trajectory. Therefore, it was tough to leave for treatment knowing that your family and friends were worried: “*My daughter woke up every single night, she felt awful when I was away. It was so difficult not being there for her.*” Separation was especially hard during events such as holidays and family anniversaries. Participants did their best to talk openly with their children while they were away. They tried to focus on simple things in everyday life to help them visualize that everything was okay and to provide comfort and closeness:

I recall many phone calls where my children cried. I used a lot of energy to tell them about the nice and ordinary things that I was doing, even though it was just drinking a cup of tea or having been out for a walk. I told them: ‘I’m not just sitting here, alone crying.’ But these phone calls did hurt, and often it took time to recover afterward [mother receiving treatment while children were at home miles away].

Some had considered moving closer to the capital area but decided against that: “*I just wanted my children to have a haven where they could keep up their daily routines.*” Still, it was difficult if both parents were away. So often the spouse stayed at home to care for the children but sometimes the children also accompanied their parents to the treatments. It had a relieving effect when participants witnessed how their children relaxed when they got acquainted with the treatment surroundings and how they managed to get around in the capital. Bringing adult relatives also had a similar positive effect.

Patients’ ability to partake in work- and social activities were curtailed. They were concerned about others taking care of their usual duties, losing their job, and missing out on important moments with their friends and family. This was further complicated if they were unaware that their treatment appointments could be modified:

I was scheduled to have chemo right before New Year's Eve. Then I would not feel well [at the new year party], or I might not have made it home [if the weather was terrible]. I thought they were very strict with the timing of the treatment. But when I finally dared to ask, it was no problem to reschedule.

Information provided during treatment appointments could be overwhelming, and it was important to have help to sort out the information. Feelings of isolation prevailed if there was no one close to share the experiences with:

It's difficult for your partner to truly understand if he isn't there with you during this tremendous journey [in situations where he needed to be at home]. It creates a huge void. I could sense my husband somehow distanced himself from me. He put up an invisible shield; he could barely hug me [. . .], he was so scared. But I desperately needed the closeness.

The profoundness of perceived bodily change was highly motivated by a change in intersubjective relations, for instance, due to different gaze, behavior, touch, and proximity with others.

Affective synchronization could also be set off tune by the changes occurring in other parts of participants' lives. Many had shared and unspoken agreements and division of everyday tasks between them and others which became muddled because of changes in affordances and capabilities of the sick body. The participants' values, sense of time, and physical activities changed because of the disease and treatment, and it could be difficult for other persons to realign with the existential changes that the participants underwent. A divide between them and other persons also occurred when they set up a mask and pretended that everything was fine. Hence, the feeling of needing to protect their family sometimes stood in the way of emotional sharing and closeness. Participants created their private rhythm to deal with their symptoms and would at times shut other people out or cover their negative emotions under a coating of light-heartedness.

The bodily frailty which exacerbated after treatment was perceived in different ways. Some were concerned if they had too few symptoms because "what if the treatment didn't work" and equated more intense symptom severity after treatment with a better likelihood of "killing cancer." Others were grateful for more quality time when symptoms were not too apparent. In all circumstances, guidance in how to prioritize the energy in times of shortcomings was important "It really took me by surprise, how my strength just vanished [after chemotherapy] Right when things started to improve, it was time for another treatment." Even patients without visible symptoms had challenging side effects of their treatment. The relentless loop of getting better and preparing for treatment and then reaching the bottom, again and again, was tiring. To come through the most challenging timepoints, participants either focused on living 1 minute at a time or even bargained with themselves to endure the symptoms: "If I go [. . .] to this or that event, it might cost me a lot

of energy, but then I can rest more while being away [during treatment]." They also used this argumentation to live through the rough times because they knew that their side-effects would eventually diminish. However, sometimes patients were almost incapacitated and could not perform activities that they associated with normality, and other times it caused confusion when they reached a peak where they felt energetic and healthy while intellectually knowing that they were still very sick. The participants' descriptions often contained the poles of being utterly optimistic and feeling utmost despair during different times and perceptual acts.

Changes due to cancer and the treatment also could change participants' physical appearance and cause deviation from the perception of having a normal body. The body not only felt unfamiliar; it was uncanny when the changes suddenly was noticed:

I looked into the mirror, and there were only the eyes, the blue color of my eyes, that I recognized. I was completely hairless everywhere, [with] no eyebrows or anything. My face was round and puffy. I was white somehow, and . . . my body [was] just lifeless. . . I was somehow physically dead or my body slowly shutting down [. . .] but my soul was still there.

A sudden realization that the body had changed, was sick, and differed from the habitual body moved awareness of the temporal structure of the body as finite to the forefront. During treatment many participants tended to mitigate the impact of cancer. They only fully comprehend later how sick they had been: "When I see photos [of me during treatment], it pops to my mind: Wow, I was really, really sick!" The invisible effects of the treatment were also debilitating and persisted, even during remission: "Even though your body on a superficial level looks healthy, everything is fucked up." It was difficult for patients to pass on a superficial level as having normal abled bodies when they were exhausted. If other people expected too much of them, it could cause tension.

Extended family, friends, neighbors, and other residents at home provided valuable support. The support took many forms, for example, looking after children and pets and substituting for participants at work—which was particularly important for those who were self-employed, for example, farmers. Some had also received money from fund-raising organized by their community. The degree of support was considered unique: "People you barely knew said 'I have a place in the city, you're welcome to stay there [. . .] if help was needed, it was offered."

Conversely, the social proximity was at times a bit too much: "I experienced good intentions but also fear, somehow [pause]. This is such a small community, and if someone gets cancer, it's always someone that you know." Compassion could be uncomfortable if attention were constantly brought to the disease. Different strategies were used to protect oneself: "Exiting the grocery store could be challenging when dealing with maybe five different people padding your

shoulder, looking you in your eyes and asking, 'how are you? Well, you just repeatedly said: 'Everything [is] fine' [even though it was not].'" Thus, occasionally it was a relief to get away: "When I came to the city, I crashed. . . I didn't have to put up a happy face."

c. *Being Torn Between Home and Treatments Site—Time as a Tangible Aspect of Traveling and Being Away*

In planning and actual traveling between home and treatment site, participants often became explicitly aware of time, not being late, and being on a schedule. Many issues within daily life revolved around coordination, and practical issues related to traveling. The time spent on these issues eclipsed the time spent on their home, family, and work. After treatment ended, the deep-seated impact of traveling was fully realized:

It's one thing to be diagnosed with cancer and have to deal with it, and at the same time be completely torn between these two worlds [treatment site and home]. Every three weeks I was traveling back and forth. I felt like I was a yo-yo, just bouncing back and forth.

The home could be a powerful force once treatment was completed. The almost magnetic pull toward home was illuminated in one participant who drove for hours to get home immediately after treatment:

I just needed to go home no matter what. But it was a speed to get there before the side-effects kicked in. My mom was very concerned; she often said: 'Why are you doing this to yourself?' This could be dangerous. Why? Well, that's simply because. . . hello! I'm just on my way home! I need to admit that I was not listening to my body and not completely realistic about my limits [. . .]. So there I was, boosted with steroids [given in the chemotherapy], utterly hyperactive, I didn't hesitate at all [humorous]!

The eagerness to get home stood in sharp contrast to the physical and mental distress of getting home in time, considering that a certain risk was involved.

It typically took a couple of days for the participants to recover when they finally got home. Then as soon as the body began to recover, preparation for the next trip began. The traveling was physically demanding and the preparations daunting, but it was a necessary precondition for beating cancer: "I just needed to plan this 120%. Everything needed to be accurate so [that] I could receive chemo on schedule." The opposite poles of home and place of treatment unnaturally compartmentalized the participants' lives, making them feel divided. The repeated periods that participants spent waiting to get home and waiting to leave for treatment, created a hollow space in time.

Practical issues were used to divert participants thoughts from "unproductive" fear about the future and to mobilize

the energy required to accomplish necessary tasks, such as arranging travel. Travel arrangements, however, were a source of endless speculations: "What's the weather like? Maybe I'll need to leave some days earlier if the weather forecast is bad." If the weather conditions were unfavorable, they could also cause fear of not getting home as planned. Before leaving home, the responsibility of children or animals often had to be handed over to others. Accommodations and flights had to be arranged, and necessities packed: "I lived in a suitcase for two years! I didn't give it much thought then, there was no other option, but it was so, so tiresome." Deciding and planning of travels relied on a merge between participants subjective time perception versus an objective schedule, that is, when transportation was available and scheduled chemo time. But there was still a window of free will. For instance, deciding upon the exact means of transportation, whether they preferred a late or early arrival in the city, and if they wished to leave for home immediately after treatment or would opt to dwell in the city after treatment.

It jeopardized the financial security when participants had to pay out of pocket for flight fares, sometimes not knowing when or if they would be (fully) reimbursed. Other unpredictable expenses also frequently surfaced, such as broken cars. Some bought better cars to increase the security and reliability of traveling: "We took a mortgage to buy a new car because of the trips [. . .]. If we had lived in [the capital], this wouldn't have been a problem."

Partners' travels were rarely compensated and this, alongside absence from work and loss of income could add up to a considerable amount of money. The participants described how they spend money in a way that they would otherwise not do. They just solved needs on the spot without considering how it would affect their financial situation in the long run.

Having convenient and financially covered access to accommodation in the capital were important but not always available. Being forced to find own solutions and contemplate issues such as: "Where could I stay? Is there anyone I know in the city?—are they at home? Busy? Will I be imposing?" was difficult. Staying with distant relatives or acquaintances during treatment could be energy-consuming: "You cannot tell the people that you are staying with that they can't cook this or that! [laughs] or they can't use that perfume." Furthermore, not all knew their way around in the capital, which contributed to feelings of estrangement and loneliness. On the contrary, when staying at home in secure surroundings, feelings of insecurity arose because participants were separated from the specialized services. They seldomly complained or called for solutions: "When I made this choice, to live in the countryside, I also made a choice to put up with traveling."

Stays in the city were often used to gain specialized support: "There is such a good network for cancer patients [. . .] I would have liked to have this closer on a day-to-day basis." While participants were in active treatment, they could contact the staff at the oncology ward. Nevertheless, many felt

left to themselves to deal with side-effects: “*You’re always dealing with side effects [. . .] some of them are ‘normal’, others not, but you don’t always know.*” The need for diverse support remained after the treatment finished, but the access to help decreased because of fewer trips to the city.

Some remote healthcare was available which mainly found a place over email or by phone:

Talking just by phone creates a shield between you and the healthcare professionals. If they had been able to see my facial expressions, they would be able to evaluate much better how I was really doing. If I had had the opportunity to be in contact with ‘my’ [primer] nurse [. . .] like once a week, just a short ten-minute talk, where we could see each other, that really would have made a difference.

Participants approached the local healthcare services if they had unbearable side effects or other intruding symptoms. In these situations, it was important that the local healthcare professionals were knowledgeable:

I felt very vulnerable; [. . .] I could never be sure of meeting the same physician twice. Nobody for sure knew my case. I remember getting answers like: ‘Well, don’t you just want to wait and see?’ [. . .] Obviously not, otherwise I would not have sought help. Being life-threatening sick and needing to struggle to get proper treatment [pause] is really just . . . so hard.

Integrating diverse forms of services between home and the treatment site was primarily left to the participants. One participant described a situation where she got sick. She contacted her local physician, who questioned her condition and said that she could call an ambulance by herself, if she felt the need to do so. It awoke uncertainty:

Am I sick enough to go to the emergency in the city, to make use of an ambulance [two and a half-hour ride]? Because at this time, I could walk and stand on my feet. It made me think, am I really that sick? I wasn’t unconscious or anything. I ended up calling the emergency line for an ambulance but also needed to reply to their questions; ‘so what’s wrong?’ I felt so stupid and hysterical [. . .]. I walked to the ambulance by myself [. . .]. But on the way [to the city], I got really sick. I was running a high fever but refused paracetamol and other treatment. I just didn’t want to arrive at the emergency room without any measurable symptoms [so people would think she wasn’t sick enough to use an ambulance]. I was so, so sick when we finally arrived, over 40 degrees and not fully conscious. I was admitted straight away [with neutropenic fever].

There were examples of how participants deliberately lengthened their stay in the capital to undergo tests that could have been performed in the countryside. The mere thought of explaining their condition and informing the local healthcare workers about their treatment was too overwhelming, so they opted not to involve them. The direct (tele)communication between rural and urban treatment sites was not formalized

but perceived by patients as something that could help bridge the temporal fragmentation of their treatment.

Discussion

The rural residence had a decisive effect on the participants’ experiences of cancer treatment. It showed how distinct stress factors are involved with the need to attend such treatment away from home. The repeated separation between the cancer patient and their closest personal support network was difficult. Surprisingly, the true impact of traveling and being away from home were first realized after treatment had ceased. Receiving cancer treatment away from home surpassed more than transversal losses of predictability, control, freedom to act, and familiarity with the world, as Toombs (1987) described, which thwart an individual’s pace of life. On a more positive note, the participants’ situation also led to important discoveries about prioritizing time and the epiphany of what mattered in life. Carel (2021) similarly speaks about illness in general:

Illness is a profound and life-changing event. Falling ill or receiving a diagnosis of a serious illness requires the ill person, and those around her, to stop and take stock of life as it has been and maybe from now on. This often leads to a reconsideration of values and goals, and a need to renegotiate ways of being that previously characterized the ill person’s life (p. 200).

These similar newfound insights created a springboard for our participants to re-prioritizing their actions. Meaningful experiences were connected to how the participants implicitly and explicitly talked about time. Nurses’ acknowledgment of temporality as one of the essentials of human existence helps them ask the right questions to allow patients to construct a coherent narrative. Thus, to identify situations where patients require support.

Talking about time or temporality in the context of cancer is not unique for this study. Several research studies have suggested that how temporality, or the notion of time, is affected for cancer patients in general merits more attention (Martino & Freda, 2016; Rasmussen & Elverdam, 2007). A recent qualitative study ($N=9$) has used a phenomenological line of thought to describe the temporal paradox of chemotherapy for women with ovarian cancer (Moskalewicz et al., 2021). The researchers identified inconsistencies in the experience of time perception during treatment with chemotherapy—where time at some point accelerated and at other points slowed down. This experience was related to the cyclical nature of the chemotherapy and the side effects of the treatment. Our study adds another aspect of importance, namely the unique situation of time when considering the distance between the home and treatment site and between the person with cancer and their closest network and homelife. The cyclical nature is also related to the arrangement of travels and other practical issues common for all

types of cancer and treatments received in a treatment place far from home.

The findings suggest that individuals living in rural areas need more support with organizing and managing their travels and with synchronizing homelife and treatments. In line with the results seen in other studies, the repeated journeys took their toll on limited energy resources and tended to cause worsening of bodily symptoms (Hegney et al., 2005; McGrath, 2015; Pesut et al., 2010). The relentless and repeated travel preparations can be nerve-racking, particularly when considering the additional financial costs and insecurity associated with unpredictable weather conditions (Butow et al., 2012; Loughery & Woodgate, 2015). The participants did not focus much on these issues during treatment, but the full impact was realized afterward. It is unlikely that patients open dialogue regarding these issues during active cancer treatment, which further underlines the importance of nurses addressing these concerns. Cancer patients need help navigating and seeking solutions that resonate with their unique needs. A recent study ($N=170$) found that young rural cancer patients with less education and money needed more intensified support from healthcare professionals (Palmer et al., 2020). Individuals receiving treatment away from home are prone to financial strain (Passwater & Itano, 2018). The reasons for this concern have, among other issues, been traced to increased costs associated with maintenance of vehicles, costs related to childcare, and loss of employment in comparison to cancer patients living in more proximity to the treatment site (e.g., Newton et al., 2018; Pisu et al., 2017; Ross et al., 2021).

Several qualitative studies have emphasized that the distance from specialized services might enhance the psychosocial ramifications of cancer and treatment (e.g., Butow et al., 2012; Hegney et al., 2005; Loughery & Woodgate, 2015). In line with these results, we also found definite aspects related to the residence that added to the burden of cancer patients living in rural areas. Given the modern technology, it was quite surprising how underused online communication was. The participants communicated with specialists over emails and phone, albeit too little. Recent literature has emphasized the beneficial aspects of using technological solutions to help bridge the service and information gap between rural and urban cancer patients—related to individual communication and letting patients meet other persons living in other rural parts of the country (Anbari et al., 2020). Internet educational resources targeting the unique subjective needs of the cancer family might be developed, implemented, and researched strategically.

Witnessing the distress that close family members encountered deeply affected the participants. It is well-known that relatives of patients with cancer are under significant strain (Loughery & Woodgate, 2015; McGrath, 2015). Paying attention to the relatives' needs and well-being is paramount given the interchangeable relationship between close family members and the patient. Distress in patients may affect the

relatives in a negative way and vice-versa (Northouse, 2012). An Icelandic cross-sectional study reaching 223 relatives of patients with cancer showed that 20% were anxious, and 41% had depressive symptoms 1 to 5 years post-diagnosis (Friðriksdóttir et al., 2011). This study did not focus solely on families living in rural areas. However, we hypothesize that levels of anxiety and depression may be even higher in that population because of increased psychosocial burden and costs. For example, everyday responsibilities may rest on the spouse when the person with cancer is away from treatment. Surprisingly the level of psychological distress in cancer patients ($N=217$) who lived close to the place of treatments and those who needed to dwell away from home during treatment proved to be similar in a former Icelandic study conducted by Hjörleifsdóttir et al. (2007). However, when scrutinizing these results, they essentially reflect our participants' experiences. Patients in the study by Hjörleifsdóttir et al. (2007) were assessed while still undergoing active treatment. In this exact time period, our participants lived in the "now" and primarily focused on attending to practical tasks associated with the cyclical nature of traveling and treatment. They clearly expressed that the additional strain from traveling first surfaced with full power after ending treatment.

The burden of traveling has a decisive impact on the progression of cancer treatment. In extreme cases, the strain caused by traveling, in particular during winter in cold rural regions, and absence from one's family, may cause people to discontinue their cancer treatment prematurely (Celaya et al., 2006; Loughery & Woodgate, 2015). The participants in our study had very high treatment adherence, but they also had access to a rich, supportive network which might play a decisive role in that context. The exact effect of distance on cancer patients in Iceland remains unknown, but is probably similar to the impact described in research studies conducted in other countries. Our results share many common aspects of research carried out in Canada and Australia. These two countries are comparable to Iceland concerning the limited access to specialized healthcare services in rural areas.

The findings raise questions about how to best meet the need for increased support for individuals living in rural areas and receiving cancer treatment away from home. The described gap between local healthcare and specialized services shows an opportunity for improvement. Passwater and Itano (2018) suggest that hospitals designate a navigator to assess the required needs for optimizing healthcare services for cancer patients in rural areas and diminish factors that obstruct such service provision. Simultaneously assistance should also be provided with a broader array of social and financial challenges cancer patients face living in rural areas and receiving cancer treatment away from home. A nurse navigator would also lessen the patient's responsibility of planning treatment and arranging travels cost-effectively. His role would also be to explore how individual-dependent aspects of the treatment should be structured and how

continuity could be optimized. For instance, by being an intermediary contact for the local medical staff. Using telecommunication or web-based services for follow-up by nurses is promising for promoting quality of life for individuals with cancer (Basch et al., 2016; Fridriksdóttir et al., 2018; Mooney et al., 2017).

Although participants were few, the data contained a wealth of information that presented rich results. The core of these participants' experiences of living in rural areas and receiving cancer treatments away from home did not seem to differ between the various types of cancer and gender. All participants, at the core, were confronted with identical existential and practical problems, although their idiosyncratic experiences differed.

Conclusion

The experiences of rural cancer patients who travel long distances to seek treatment away from home requires targeted attention from nurses. It is important to help patients create better synchrony throughout the turbulent changes they face. Disruptions in temporality and changed intersubjective relations should be negotiated by nurses in a comprehensive way *vis a vis* incorporating support sensitive to patients' distinctive experiences and needs. Findings underscore a need to build up specialized service that enhances continuity of treatment and specialized care. For example, enhancing the use of technology to create better continuity in the support and maximizing feelings of agency. The findings can also be used to develop semi-structured questionnaires that help people express needs that they tend to not overtly express while living through recurrent waves of cancer treatment.

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