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Experiences of cancer rehabilitation among patients in rural areas in northern Iceland: physical and psychosocial well-being, coping, quality of life, and satisfaction with care. A qualitative study

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ABSTRACT

Physical rehabilitation and psychosocial support are a part of cancer patients well-being and their ability to cope. Physical geography and healthcare provider barriers may have negative influences on patients' health outcomes. To explore the perceptions and experiences of cancer rehabilitation in a rural area in northern Iceland. A further aim was to explore patients' physical and psychosocial well-being, coping and satisfaction with care. A qualitative study using semi-structured interviews and thematic analysis was completed with a purposive sample of 21 patients at a tertiary hospital in northern Iceland. Three main themes emerged: 1) Rehabilitation – the need for improved access support and continuity; 2) Coping and quality of life – balancing life as it was before cancer against the present situation in order to achieve normality; 3) Satisfaction – encountering caring behaviours enhances satisfaction and well-being. Specifically targeted rehabilitation programmes need to be included in the treatment options for cancer patients. Survival instinct, coping mechanisms and a strong urge to maintain general functionality are of paramount importance intertwined with patients' ability to cope with the disease and treatment, and their satisfaction with care.

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Arctic circumpolar; rehabilitation; support; physical activity; caring; coping; rural areas; satisfaction with care

Introduction

Rehabilitation is a process meant to enable people with disabilities to obtain and preserve optimal physical, psychological, and social functions [1]. Cancer rehabilitation is meant to decrease patients' physical and psychological suffering and to reduce symptom burden from cancer or cancer treatment [2–4]. Furthermore, Nordic, and European perspectives on cancer and rehabilitation emphasise that the long-term implications of cancer and its effects on the daily life of the patients and their families should always be considered [5]. Consistently, incorporation of evidence-based cancer rehabilitation into the curricula of a higher education system has also been addressed and advised [6].

Iceland is one of the eight member states of the Circumpolar North and one of the world's economically most developed countries [7]. Icelandic landscapes are shaped by the forces of nature, characterised by its widespread mountainous lava desert with a little over 10% of the country being covered by glaciers [8] (Figure 1). Climatic conditions are largely unpredictable during winter and may become extremely difficult at times [9]. The distinction between urban and rural,

which is most useful in this study, means in the Icelandic context distinguishing between, on the one hand, the capital region in the southwestern part of the island, and on the other hand, the remaining parts of the country. The population in Iceland reached 356,991 in January 2019: 228,231 lived in the capital region, or 64% of the whole population, while 36% lived in rural settlements [10].

Looking at the incidence of cancer from a global perspective, in the year 2008 an estimated 12.7 million individuals were diagnosed with cancer and according to the available evidence this number is bound to rise substantially by 2030 [11]. Furthermore, the incidence rate of cancer among the Icelandic population has quadrupled since registration on cancer diagnosis began in 1954, around 1,500 individuals are diagnosed on a yearly basis [12]. Studies conducted in the Circumpolar North have addressed the diverse and unique healthcare delivery in that part of the world [13–15] showing that cancer is becoming a significant public health problem. Findings indicate an urgent need for improvement in both access to and delivery of the relevant services [11,13,14,16]. Physical

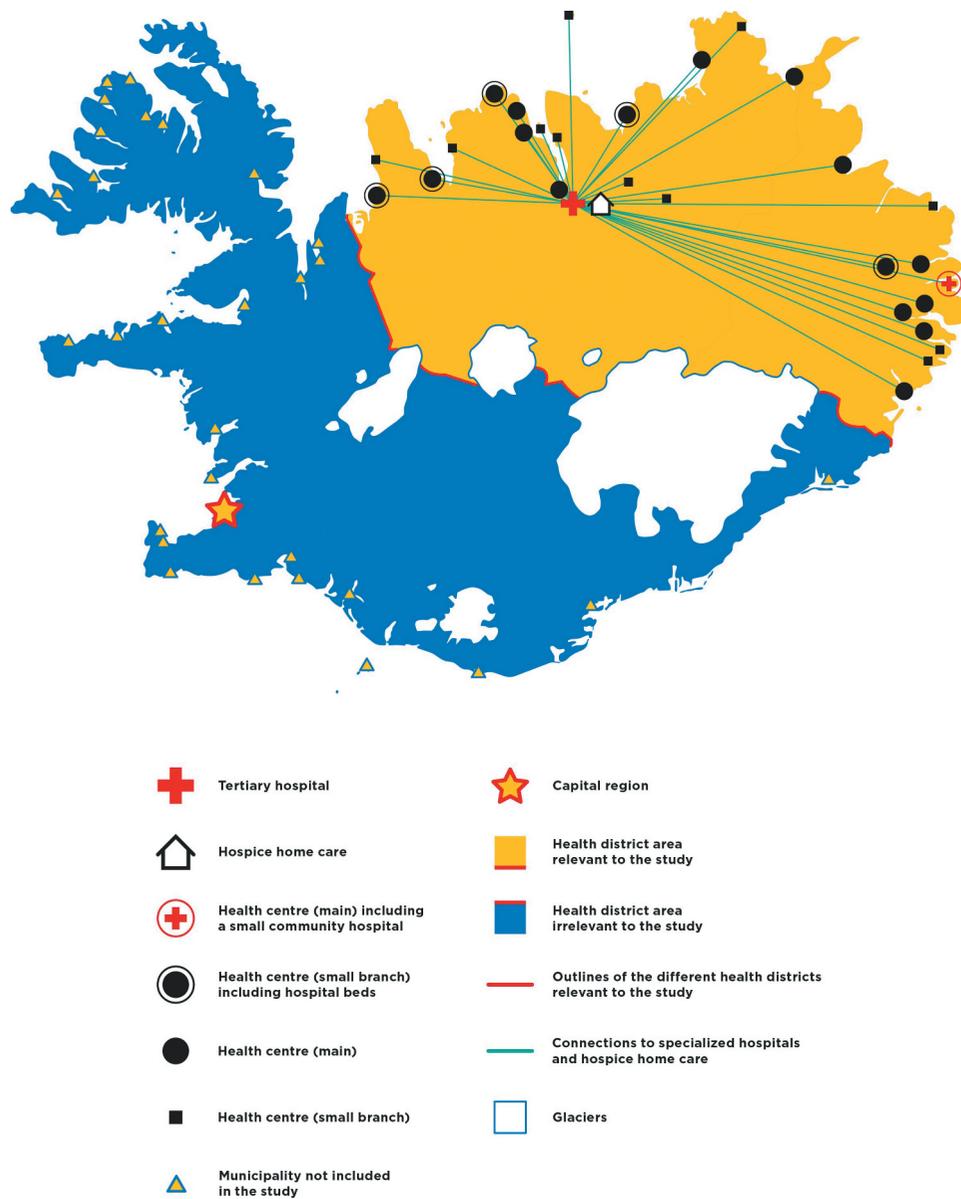


Figure 1. Map of study area.

geography, healthcare provider-related barriers, and lack of continuity in care provision are known to have negative influences on patients' health outcomes [17,18]. Studies have found that rehabilitation is not routinely offered to patients with cancer, the main reasons being lack of patients' referral for physiotherapy and limited exercise resources [19,20].

To date, there is still little direct evidence from reliable clinical studies conducted in the Circumpolar North on physical and psychosocial benefits of rehabilitation [21]. Nevertheless, important data are emerging elsewhere indicating that both patients who have survived cancer and those who have a far advanced cancer prefer a supervised rehabilitation programmes [22–24]. Moreover, the same need for

physical and psychological rehabilitation has also been reported in other parts of the world [22,25].

It is worth noting that rehabilitation is still underutilised in the delivery of high-quality oncology services [23,26]. Studies conducted in multiple countries have found similar trends in underreferrals to cancer rehabilitation services, this occurs in spite of its association with significant improvement in physical and psychological well-being, increase in quality of life, and improved survival [2,27–29]. The use of technology has been addressed as one example that might support virtual cancer exercise and increase the possibility of cancer rehabilitation in rural and low-resource settings [30]. However, more research is needed to investigate how technology can be used to improve the care

provided for patients with cancer throughout the whole disease process [26].

The need for better understanding patients' physical and psychosocial rehabilitation needs, their ability to cope with cancer and their satisfaction with care, have been repeatedly highlighted [19,23,24,31,32]. To some extent, rehabilitation services for patients with cancer are available in Iceland within some hospitals and specific institutions, although it is rather haphazard with the respect to who gets rehabilitation and where [32]. Lack of research on these issues in the specific context of rural areas, Icelandic ones in particular, and the high incidence rate of cancer among the Icelandic population, prompted this study. The aim of this study is, therefore, to explore patients' perceptions and experiences of cancer rehabilitation in rural areas in northern Iceland (Figure 1). A further aim was to explore these patients' physical and psychosocial well-being, coping and satisfaction with care. In this manner, we can provide an important integration, in the first place to the existing Icelandic research, and in the second place to Circumpolar and Arctic studies, and as well globally. We, therefore, set out to answer the following research questions:

- (1) What are the patients' perceptions and experiences of cancer rehabilitation service in rural areas of northern Iceland?
- (2) How do these patients cope with their illness and treatment?
- (3) How does cancer and its treatment affect these patients' quality of life?
- (4) How do interpersonal aspects of care influence patients' satisfaction with care and service?

Materials and methods

Theoretical approach

The key conceptual framework for this study is Lazarus and Folkman's model of stress and coping [33], which is theorised to consist in the individual's cognitive and behavioural efforts to reduce, minimise, master, and/or tolerate internal and external demands of the person-environment transactions [34]. Within this theoretical framework, coping with external demands is seen as serving two major functions: (1) problem-focused coping, i. e. trying to change the stressor by dealing constructively with the problem that is causing the distress, and (2) emotional- focused coping, i. e. the effort to manage a stressful situation by trying to regulate the emotions via changes in the perceived meaning of the stressor itself [33–35].

Design

A descriptive qualitative approach was consciously selected for this study which attempts to make sense of, or to interpret, phenomena in terms of the meaning that people attribute to them [36]. Ethical approval was obtained from the Ethics Committee of Akureyri Regional Hospital in Iceland (nr. 9/2016), according to Icelandic regulations on scientific studies of patients, and in accordance with the Declaration of Helsinki [37]. To secure the quality and trustworthiness of this study the authors followed the three main steps and each sub-item presented in the checklist: Consolidated criteria for reporting qualitative research (COREQ) [38] (Appendix 1). Participants gave their informed consent in writing for participation in the study prior to their interview. The study was conducted over a three-month period in the year 2017 in an outpatient clinic providing cancer treatment for individuals living in a small town of approximately 19.000 inhabitants in northern Iceland. The clinic also provides treatment for patients from surrounding rural areas characterised by small village societies and farms.

Participants

For the recruitment of participants, a purposive sampling method was implemented. Patients were eligible for the study if they possessed cognitive and communicative abilities to understand and express themselves in Icelandic and were 18 years of age or older. The oncology nurses in the outpatient clinic judged if patients should be excluded, based on their evaluation of patients' ability to communicate effectively, and/or of any severe physical or psychological impairments that could be significant with regard to our study. Those patients who met the inclusion criteria (n = 55) were given a written description of the study, including an explanation of their rights as participants and of the methods that would be used to obtain data and ensure anonymity. They were also informed about how they could contact the researchers if interested in participating.

Semi-structured interviews

The method used for collecting data consisted in in-depth individual interviews using a semi-structured interview framework [39]. The framework included a list of four main concepts that should be brought up for discussion: rehabilitation, coping, quality of life and satisfaction with care (Figure 2).

Twenty-one patients were interviewed, without anyone else present, by three different researchers (EBB, PS, EH) who were unknown to the participants, and most

Box 1. *Interview guide used by the interviewers*

- **Q1. Could you describe your experience of rehabilitation service provided to you during your time of illness, what matters most and what should be prioritised in rehabilitation?**
Further probes:
 1. Who informed you about possibilities regarding rehabilitation?
 2. Did you receive specific rehabilitation from health care professionals?
 3. Were there any specific aims regarding the rehabilitation provided to you?

- **Q2. Can you tell me how you have dealt with life during your time of illness? How have you coped with the situation?**
Further probes:
 1. What has been going well?
 2. What has been going badly?
 3. Have you had enough support from health care professionals when problems arise?
 4. What have you done, generally, to maintain physical and psychological health in your situation?

- **Q3. Are there some issues that have affected your quality of life during your time of illness - and now particularly while receiving chemotherapy?**
Further probes:
 1. Is there anything in particular that has changed in your life?
 2. How do you manage to perform tasks that you need to do?
 3. Do you feel any changes in your ability or skills?
 - a. If so, in what way?
 4. What is it that you feel as most disturbing – anything that may affect your quality of life?

- **Q4. Are you satisfied with the care and service you receive when you come here for your treatment?**
Further probes:
 1. What is it that you consider as most important in the care and service?
 2. Are there any specific issues that matter most and that you would like to emphasize regarding rehabilitation?

Figure 2. Interview guide used by the interviewer.

importantly, who were all trained interviewers with experience in qualitative study design. The duration of each interview ranged from 25 to 60 minutes. Eleven patients were interviewed, at the outpatient clinic, eight preferred to be in their own home, while two were interviewed in the home of one of the interviewers, as explicitly requested by those participants. Recruitment continued until data saturation was reached in the interviews number 15–21; since no new information or codes emerged in the last six interviews, recruitment was ceased at 21 participants [40].

Data analysis

Interviews were audio-recorded and transcribed verbatim. Each transcript was given a number to ensure anonymity [41]. Bengtsson's [41] four stages of content analysis guided the process of coding of the text: decontextualization, recontextualization, categorisation

and compilation (Figure 3). First, the transcripts were read line by line independently by two researchers who are also authors of the present article (EBB, EH), to get a clear and cogent understanding of the overall contents [41,42]. Codes were found and grouped into coherent categories, each of which was given a name or a code, to prepare for a thorough examination and understanding of the underlying meanings of the text thus obtained [41]. Then, the quality and trustworthiness of the analysis was secured by all the authors (EBB, EH, PS, GB, FRP) who met on several occasions to discuss the codes and categories, until a final consensus was reached. Lastly, descriptions with similar meanings or related topics were agreed upon by the researchers. A formulation of main themes and sub-themes was then completed, reflecting the relationships and interaction between the codes related to the participants' descriptions of their experiences [41] (Figure 4).

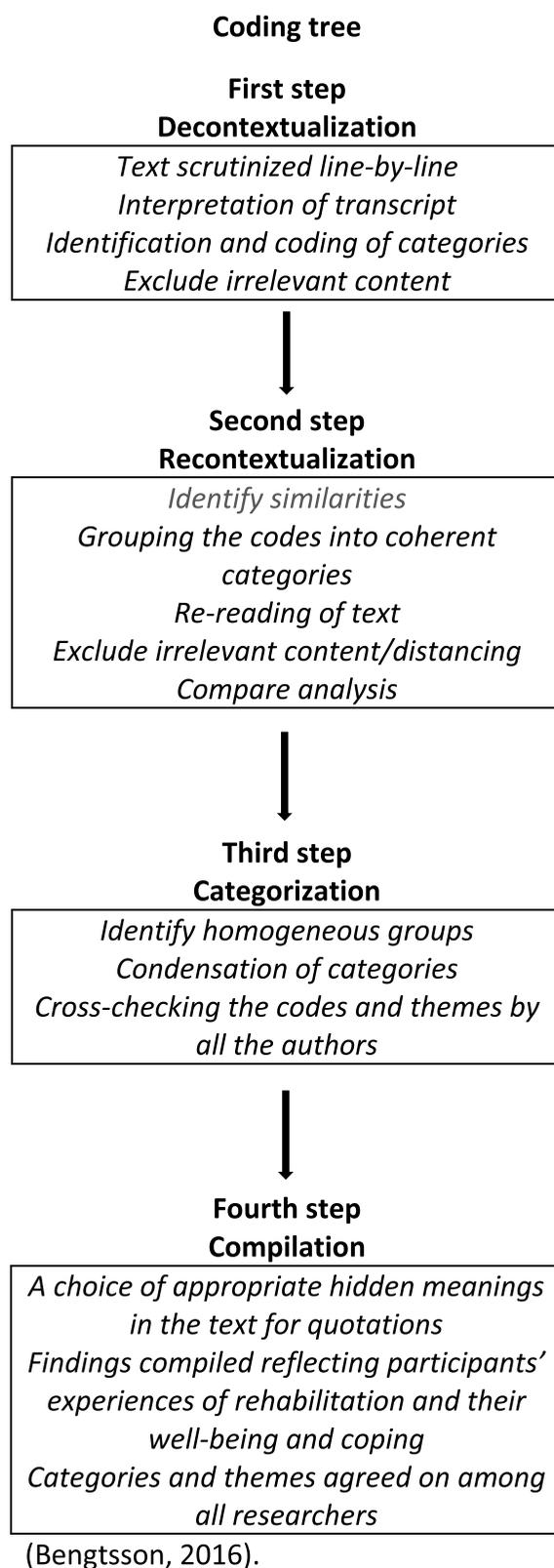


Figure 3. Coding tree.

Results

Of those 55 patients who met the inclusion criteria and were invited to participate in the study 21 accepted. As

stated, the research sample consisted of 14 women and seven men, age range 30–82. The time since diagnosis was from six months to 13 years (Table 1). The participants with a permanent residence in the 19,000-

Core theme: Rehabilitation provided to patients with cancer depends on patient's survival instinct, well-being and luck rather than being an organized part of treatment			
Meaning unit	Sub-themes	Upper themes	Main theme
<p>When my therapy was finished - I was admitted to the rehabilitation ward - that was amazing - I would have liked to be there earlier in the process</p> <p><i>One needs to be guided forward and assisted in figuring out what is best suited - one should not have to fight for this and that</i></p> <p>No matter how I felt I got up in the morning, took a shower and got dressed - I had to maintain a normal routine</p> <p><i>...a physical therapist came in and told me to twist my shoulders... said that I should start doing that... I did not get anything else</i></p>	<p>Importance of rehabilitation early in the treatment process</p> <p>Finding out 'by chance' about rehabilitation resources</p> <p>Survival instinct to prevent more damage – believing in the power of normal routine</p> <p>Feelings of abandonment</p>	<p>Security in rehabilitation service</p> <p>Survival instinct, general functionality, and continuity</p>	<p>Rehabilitation: The need for improved access, support, and continuity</p>
<p>... we just decided to go on, either you just sit down and cry and give up or you just make an effort to try to live your life, as you had never been diagnosed with cancer</p> <p>I think I am more balanced - it is strange to say it, but in many ways, I am happier than I was</p> <p>I prefer to suffer from pain than to be in a stupor because of morphine</p>	<p>A strong urge to prevent the disease taking over</p> <p>New perspectives on life – acceptance and gratitude for what is left to live for</p> <p>The perseverance in a life of pain – the importance of being alert</p>	<p>A task to complete – acceptance and hope</p> <p>Living in the present and valuing life</p> <p>The impact of disease and treatment on patient's well-being</p>	<p>Coping and quality of life: Balancing life as it was before cancer against present situation to achieve normality</p>
<p>... the role of a partner is very important - she sleeps beside me, wakes up beside me and goes to sleep beside a sick individual, there is a serious need for help there</p> <p>The service provided is superb, we appreciate it so much... this safety net all around us</p> <p>I can always phone the clinic - you are always connected to the same person - you just feel that you have a friend</p>	<p>The value of support from spouse - importance of meeting the needs of the patient and his loved ones in a caring and sensitive manner -</p> <p>Importance of trust an essential part – can lead to a feeling of friendship</p>	<p>Fulfilment of psychological needs</p> <p>Support for family</p> <p>The interaction of caring encounters - establishment of a good relationship</p>	<p>Satisfaction: The interaction of caring encounters positive relationship and support for a loved one enhances satisfaction and well-being in patients</p>

Figure 4. Meaning units, condensed meaning units (sub-themes) and codes (main themes) extracted from participants descriptions about rehabilitation, satisfaction with care, coping and quality of life.

inhabitant town (T) were 11, while those living in the sparsely populated areas of the study, consisting of small villages (V) or farms (F) were 10. All participants were receiving chemotherapy treatment at the time of their interview; most (11) were receiving treatment for breast cancer (Table 1). One participant had, at his own initiative, requested to be referred by an oncologist to a rehabilitation ward as an inpatient. Four had been referred by their physicians to a rehabilitation day centre. Seven attended rehabilitation at their own initiative. The remaining nine participants had not been informed

of any kind of rehabilitation, nor of any possible benefits from such a treatment, neither did they take the initiative to seek it.

Three main themes were extracted from the interviews: 1) Rehabilitation – the need for improved access, support and continuity; 2) Coping and quality of life – balancing life as it was before cancer against the present situation, in order to achieve normality; 3) Satisfaction – encountering caring behaviours enhances satisfaction and well-being. Each of these themes encompassed a variation of sub-themes relating to the

Table 1. Demographic characteristics, place of residence, diagnosis, time since diagnosis, stage of cancer, treatment.

	N = 21	%
Gender		
Women	14	67
Men	7	33
Age range	30–82	
Marital status		
Married	16	76
Single	5	24
Place of residence		
Town –19.000 inhabitants	11	52
Villages or farms	10	48
Diagnosis		
Breast	11	52
Pancreas	1	5
Colon	2	9
Lung	1	5
Lymphoma	1	5
Prostate	3	14
Ovarian	1	5
Did not know	1	5
Stage of cancer		
Non-metastatic disease	8	38
Metastatic disease	13	62
Treatment		
Chemotherapy	21	100
Time since diagnosis (6 months-13 years)		

patients' own perceptions and experiences of rehabilitation, coping strategies and the impact of cancer and treatment on their quality of life, and satisfaction with the provided care.

1. Main-theme: Rehabilitation-the need for improved access, support, and continuity

All participants regarded rehabilitation as a vital part of the whole cancer treatment. Participants negatively described the lack of opportunity to approach any kind of rehabilitation. In fact, there was no specific rehabilitation available to them, nor a designated process that was put into motion. The absence of standard instructions on how rehabilitation services might be accessed was reported as a missing essential component of their treatment plan:

One needs to be guided forward and assisted in figuring out what is best suited, it [rehabilitation] should maybe be a bit more automatic, it is important that the system takes care of us, one should not have to fight for this and that (P5-T).

Sub-theme: Security in rehabilitation service

Participants discussed how they found out "by chance" that they might benefit from a rehabilitation programme. This happened mostly in daily conversations with family and friends. It appeared that most participants' ideas about rehabilitation had to do with going to the gym, at their own initiative, or joining cancer support groups. However, despite the often inaccurate or limited information that they had typically received in such conversations, all the participants expressed

a strong opinion about the importance of receiving rehabilitation services early in their treatment. It was also frequently emphasised that their physical capabilities at the time of rehabilitation commencement should be considered. Three participants had been offered rehabilitation by their general practitioner (GP) and one had been referred by his oncologist to an inpatient rehabilitation ward in the local hospital:

When my radiotherapy was finished and I had gathered some strength, I was admitted to the rehabilitation ward, I think that was amazing, and when I come to think about it, I would have liked to be there earlier in the process (P-5-T).

Sub-theme: Survival instinct, general functionality, and continuity in rehabilitation service

The gradual decline in physical and mental strength causing enormous tiredness was the most common obstacle preventing the participants' own initiative to seek physical support. For most participants, it was important to maintain daily routines, to have some sort of a schedule, regardless of the situation:

No matter how I felt, I got up in the morning, took a shower and got dressed, that was number one, two and three, even though I didn't do anything else during the day but this, I had to do it, I had to maintain a normal routine (P1-V).

Individual efforts to exercise regularly were reported as another essential element in their perceptions and experiences. Those who had tried to attend physical exercise by going to a fitness centre explained how

difficult it was to exercise in a room where there had been a class earlier (e.g. the room was airless, people had been sweating and there was a bad smell):

It is not possible to equate a person that is in treatment and a person that was in treatment one or two years ago, I felt so sick in there, so I stopped going to that class (P4-T).

Furthermore, negative experiences were reported regarding the information provided to them about physical therapy while the participants were having treatment for their cancer. Often it was inadequate, involving an interview and instructions on how to correctly use their own body. Sometimes, only a single interview took place:

When my surgery was done, a physical therapist came in and told me to twist my shoulders and other things, said that I should start doing that, and then I did not get anything else (P7-V).

2. Main-theme: Coping, and quality of life, balancing life as it was before cancer against the present situation to achieve normality

Some participants, particularly those who had been diagnosed with a recurrence of cancer, reported that they felt insecure and uncertain about the future. Some of those participants elaborated on how difficult it was for them to have to face their own mortality. Quite simply, it was too much for them to cope with, which reduced their resistance against the disease.

Sub-theme: a task to complete, acceptance and hope

It was apparent that the effort to maintain normality in life and keep the usual routine going became stronger as time passed. Initially at least, the situation was handled as any other task in life before being diagnosed with the disease, this was just an additional task that needed to be dealt with. Most participants spoke about how they had made up their own mind to face the situation in a positive way. Those who were 73 and older explained that having reached that age helped them to accept their inevitable death:

... you see, we just decided to go on, either you just sit down and cry and give up, or you just make an effort to try to live your life, as if you had never been diagnosed with cancer, as much as you can (P4-F).

I am going to enjoy my life with my spouse, I am content, being at my age I accept the inevitable (P18-V).

Sub-theme: living in the present and valuing life

Most participants expressed the importance of being positive, being mindful and not thinking too much about the time when death would eventually occur.

Some found comfort and strength in religion and prayer, which contributed to a better outcome, while being negative meant resisting things that could help. It was for some a surprise to discover that it was possible to be as positive as was indeed the case, even in these difficult circumstances. A certain type of perseverance set in, along with a determination to never give up and continue to find ways to make life easier and meaningful:

... just tackle all this with a positive way of thinking, to live a healthy life as I have always done, with my wife, take this as it comes, that is the only thing I can do (P21-F).

I think I am more balanced than I was before, just these little things which irritated me they do not matter today. I made the decision that I was going to live my life happily while I had it, and do my best for myself and others. It is strange to say it, but in many ways, I am happier now than I was before (P2-T).

Sub-theme: the impact of disease and treatment on patient's well-being

Pain and feeling nauseated were the most severe factors affecting the participants' quality of life. This constant suffering did not only cause impaired physical activity and hinder any participation in physical rehabilitation, but it was also seen to lead to increased withdrawal from other family members and friends. Despite the benefits arising from taking drugs for pain relief, some participants chose to suffer rather than having to deal with the side-effects of the drugs:

I have pain going down my leg, I can hardly walk. Yet, I prefer to suffer from pain than to be in a stupor because of morphine (P4-F).

Some had help from drugs preventing nausea and vomiting, but those who did not benefit from anti-nausea medication described the "horrible feeling" of constantly feeling nauseated, leaving them unable to do anything. Furthermore, all the participants spoke of the difficult experiences of feeling nauseated during treatment:

Then it was the nausea, it really disturbed me. I was not able to do anything, just staying home and feeling awful. Nothing could make me feel better because of the constant disturbance from the nausea. I had sometimes pain, but that was nothing compared to the nausea. I did what I had to do despite the pain, but the nausea just took everything from me (P5-T).

Despite this constant awful feeling of nausea, the participants spoke of their longing to be able to manage the situation and go back to normality in life. Hoping for a better life was evident in the participants'

descriptions, who also spoke of their need for more support and encouragement and emphasised that it should be an indispensable part of the chemotherapy treatment.

3. Main-theme: Satisfaction, encountering caring behaviours enhances satisfaction and well-being

Being satisfied as patients in an outpatient clinic depended on the care and service, including the delivery of drugs, psychological support, and being provided with caring attitudes by health care professionals. Terms that were frequently used, relating to the participants' perception of care, included: "being taken care of", "sensitivity", "understanding", "good listening" and "trust".

Sub-theme: fulfilment of psychological needs

The participants described how access to psychological support from the very beginning, even from the moment of diagnosis, was important to them. A holistic sense that someone was taking care of them, and that there was continuity in this care, was clearly expressed as most meaningful concerning their security and well-being:

The service provided is superb, we appreciate it so much to have this safety net all around us, the nurses in the hospice home care are wonderful, always here on time, we can call any time and they come at once (P20-T).

Also, a notable finding in this study was apparent in the participants' descriptions, indicating gender differences in seeking and using psychological support:

We [men] need the service just as much. We just consider ourselves so tough and think that we can do this, then you cry just like everyone else, in the corner. We hide our feelings because we are men (P9-F).

Sub-theme: support for family

Most participants spoke of the need for support for their family. This support was regularly described as vital for the well-being of the patients and their closest family members. The participants described how they experienced enormous emotional difficulties when they had to deal with the insecurity, distress and fear they sensed in their close family members. This concerned especially patients who were married and those who had children. Support from spouses was frequently reported as most helpful, and highly valued, implying a sense of security throughout the cancer trajectory. It was even described as being more valuable than support from health care professionals:

I have a wonderful partner that has stood by me during this disease. The role of a partner is very important. One cannot forget that she sleeps beside me, stands beside me, wakes up beside me and goes to sleep beside me, a sick individual. There is a serious need for help there and, I would have liked to see better support with that (P9-F).

Sub-theme: the interaction of caring encounters, establishment of a good relationship

The participants' satisfaction with the care provided was dependent on the compassionate attitudes shown by health care professionals, how sensitive and understanding they were to the patients' problems, and how patients perceived doctors' and nurses' professional skills. The terms most frequently seen in the participants' descriptions (being taken care of, sensitivity, understanding, good listening and trust) related to the establishment and continuity of a good relationship between them and the nurses. This aspect appeared in the findings as being an essential part of the service provided to them, capable of enhancing the patients' satisfaction. All participants spoke of how the service in the outpatient clinic, including the possibility to have access to the clinic any time they needed it, gave them a sense of security. This sense of security was intertwined with the importance of positive relationships, which in some cases developed into a feeling of friendship:

The outpatient clinic here is lovely, it is just great, it is a big bonus in my life to have this clinic here, to be able to go there and get my medication administered, to have my own nurse here, this is great (P1-T).

I can always phone the clinic, whenever I need to, I do that often. You are always connected to the same person, you just feel that you have a friend (P8-F).

Discussion

In this study we were interested in different aspects of how physical rehabilitation and psychosocial support are intertwined with the patients' well-being, their ability to cope with the situation, and their satisfaction with the received care in rural areas in northern Iceland. This study also highlights the importance of being sensitive to the patients' situation and the establishment of a positive relationship when meeting the patients' concerns regarding his or her situation and/or the worries of significant others [43].

Patients' experiences of rehabilitation

A key finding in this study is the negative experience of rehabilitation service provision portrayed by low

entrance rate into organised rehabilitation, resembling findings in previous studies on this issue [24,25,44]. The participants frequently expressed that in a casual conversation with family members or friends, they realised that rehabilitation might be a helpful option for obtaining desired strength and normality in life. This indicates that pure luck may in some cases be the decisive factor for providing rehabilitation for patients with cancer [19,20], rather than well-established institutional practice. This calls for urgent attention and consideration of the benefits of physical rehabilitation for patients with cancer and disparities in meeting those needs [2,28,45]. In this study, only one participant had, at his own request, been referred to a supervised rehabilitation service by an oncologist, and another four had been referred to a rehabilitation ward by their physician. This coincides with earlier findings showing patients' poor awareness of cancer rehabilitation in the community and a need for the promotion of rehabilitation, particularly by oncologists [19].

Rehabilitation has been repeatedly highlighted as an essential aspect of oncology [23–25] and suggestions concerning how new virtual technologies could be used to increase the possibility of cancer rehabilitation in rural and low-resource settings have already been made [30]. These suggestions are worth considering in relation to the Icelandic context of this study, insofar as only one inpatient rehabilitation unit exists in the rural areas that took part in the study with a long waiting list to boot [32].

Supervised rehabilitation offered to patients with cancer has been shown to be significantly beneficial [2,27–29]. Despite that knowledge, the findings in this study are, nevertheless, still in accordance with the results of previous studies, showing that one of the main barriers continues to be the lack of patients' referral to physiotherapy [20,24]. One could speculate whether this is related to divergences in the most common treatment of physical and psychosocial symptoms in different countries, institutions, or environments. However, such a broader comparative context falls outside the scope of our Icelandic-based study.

There is also a reason to believe that patients in this situation need more information on the treatment options, including rehabilitation, which might increase their well-being and quality of life, possibly even more than can be seen in this study [4]. It has also been pointed out that nurses lack knowledge and practice to design exercise programmes for patients with cancer [20]. Unfortunately, little attention has been paid to cancer rehabilitation for patients in rural areas, preventing any suggestions on that aspect of care in such an environment [15].

This study shows that it is fundamental that there should be stronger cancer rehabilitation pathways. Physical therapy, interviews with psychologists, and other forms of psychosocial support were also clearly stated as important factors [19]. Findings indicate that the patients' needs for cancer rehabilitation are characterised by complex challenges of various problems that need continuous monitoring [31]. However, our study shows that the insufficient instructions about physical rehabilitation can cause feelings of abandonment. Tellingly, and importantly for the Circumpolar context, these findings coincide with findings in a study conducted in Greenland, reporting a lack of adequate attention to patients' self-motivation and to the efforts in coping with a new ordinary life demanded by severe pathologies, cancer included [14].

Coping and valuing life

In our study, sheer survival instinct, a strong urge to maintain general functionality, and the personal willingness to make efforts to prevent the disease from taking over and controlling one's life, were dominant issues in the participants' descriptions. Getting cancer and going through treatment were seen as any other task in life: they had to be dealt with and completed. Therefore, it was essential to make an effort so as to balance life as it was before cancer against the present situation, in order to achieve normality. The participants' determination was clearly seen in their descriptions, in which they voiced their intention to live in the present and value life despite the severe impact that the cancer and its treatments had on their quality of life and well-being. These findings, characterised by positive thinking and new attitudes towards life, indicate that the patients' acceptance of the situation and their ability to put worries into perspective may reduce anxiety and depression [46]. Further, there is a resemblance between our findings and an earlier study, suggesting how everyday activities can help patients to distance themselves from their diagnosis and prognosis, and enjoy life, even when they are constrained by generally lower energy levels [47].

At a more general level, the participants' descriptions in our study further reflect and corroborate Lazarus' and Folkman's [33] conceptual framework of stress and coping, hence the validity of this framework for qualitative research such as our own. Furthermore, our findings echo their suggestion that the use of problem-solving, emotional support and acceptance-coping strategies, especially by dealing actively with the problem and avoiding negative thoughts, can significantly promote quality of life and mood [48,49].

The interaction of caring encounters, and patients' well-being

Our study clearly demonstrates the significant power of caring encounters in healthcare. The importance of meeting in a caring and sensitive manner the complex needs of the patients and their loved ones during their disease and treatment process was a fundamental issue, which nearly all participants remarked upon [19]. These findings are also supported by numerous studies on patients with cancer showing the importance of having a good relationship between patients and healthcare professionals, and its impact on the patients' ability to cope with cancer and their satisfaction with care [50–52]. Our study also indicates that the physical proximity of the nurse, while administering treatment, offers opportunities to establish a good relationship during repeated treatments [51,53].

The findings in this study give reason to believe that systematic cooperation between healthcare practitioners and specific rehabilitation institutions in rural areas are essential [13–15]. As seen in this study the participants were not given adequate information on rehabilitation resources, nor were they referred to a specific rehabilitation centre or institution, unless they had asked for it themselves. Previous studies conducted in the Circumpolar North have elaborated on the lack of access to healthcare services and the consequences it may have for health and well-being [17]. These are great challenges facing healthcare professionals today, due to the growing burden of cancer in some of the inhabited Arctic regions [13–15]. In the light of results in this study future research should focus on patients' awareness of cancer rehabilitation and resources in his community. Recent studies indicate a need for continuous studies of the benefit of telemedicine with focus on improved function and pain management, patient's satisfaction with such visits and a possible decrease in hospital length of stay [54,55]. Studies of telemedicine initiatives are highly appropriate in rural and low-resource settings. Furthermore, patients' descriptions of their experiences should be highlighted in continuing studies on communication and establishment of a therapeutic interpersonal relationship as perceived by cancer patients in their stressful period of treatment. Finally, it would be interesting to conduct intervention studies on these issues always aiming for increased quality of care in clinical practice.

Strengths and limitations

The main strengths of this study are twofold: First, the accuracy of the data was secured by following the four

steps of reliability in qualitative research, as presented by Lincoln and Guba (1985): credibility, dependability, conformability and trustworthiness [56]. Also, to reduce bias and to ensure reliable data, three trained interviewers experienced in qualitative-study design, and unknown to the participants, conducted the interviews and all the authors reviewed codes and categories until a final consensus was reached. Second, this study is, to our best knowledge, the first study of its kind in Iceland. It, therefore, generates unique data on patients' perceptions and experiences of cancer rehabilitation service in rural areas in Iceland, and the impact of cancer and its treatment on these patients' well-being and coping abilities, and satisfaction with care. The results can only be representative for those patients who took part in the study. Nevertheless, this should be considered as a strength, in as much as the sample is statistically representative of the people diagnosed with various types of cancer in Iceland and the rural communities of the Circumpolar North at large [12,14]. The use of a qualitative method allowed the researchers to obtain a deeper understanding of the phenomena under study. Further, strength is to be found in the resemblance of its results with the findings of previous studies in analogous settings [19,23,29,51].

There are some limitations in this study which warrant deliberation. Those who were judged to be unable to participate, because of some physical or psychological impairment prior to the study, might have provided some valuable information about specific needs regarding rehabilitation and psychosocial support. Consequently, what was lost by not being able to include these individuals in our study remains a gnawing hypothetical mystery. Also, the fact that participation was voluntary, points to a possible self-selection bias in the sample, this was inevitable under the extant ethical and methodological circumstances. The design of our study makes it impossible to obtain detailed information about those who did not respond to the invitation to participate. In addition, the different ages of the participants and the variation in the stage of the disease might have had an influence on the participants' expectations and experiences [57]. Contacting participants for member checking some months after interviewing them, was not an option, we wanted to show respect for those who could now be in a more advanced stage of the disease, or had died, and their families. Finally, the lack of similar studies on patients with cancer in rural areas of Iceland impedes the comparison of our results with those of others dealing with the same subject.

Conclusions

Results clearly indicated the current inadequacy of full cooperation between health care practitioners, institutions, and other competent sources capable of providing rehabilitation services for patients with cancer in rural areas of northern Iceland. This gap needs to be monitored closely in future research, bearing in mind that the need for rehabilitation will continue to grow along with the increased number of people with cancer in this environment. Findings in this study also indicate the significant importance of organised and supervised rehabilitation for these patients, while the opposite can be both physically and emotionally devastating. The strong will and determination to handle the situation and maintain normality in life as this was before cancer, were mixed with the patients' coping strategies and the way care was being provided to them. Finally, findings in our study highlight the importance of caring in a sensitive manner, an establishment of positive patient–professional relationships, and an understanding of multiple personal and environmental problems.

Geolocation of the study area

Latitude: 65° 41' 02" N

Longitude: 018° 06' 38" W

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No potential conflict of interest was reported by the author(s).

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Ethical approval

Ethics approval was obtained from the Ethics Committee of Akureyri regional hospital in Iceland, according to Icelandic regulations on the scientific study of patients and in accordance with the Declaration of Helsinki.

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