

Patients' Expectations of Physiotherapeutic Treatment for Long-Term Side Effects After Cancer

A Qualitative Study

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Patients' Expectations of Physiotherapeutic Treatment for Long-Term Side Effects After Cancer: A Qualitative Study

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Abstract

Objective: This study aims to explore the expectations of physiotherapeutic treatment of long-term side effects (LTSEs) after cancer among patients treated in physiotherapy clinics.

Methods: This a qualitative interview study based on a phenomenological approach. Adult patients with LTSEs after cancer were recruited through The Danish Cancer Society and a private physiotherapy clinic in Denmark. Individual semi-structured interviews were carried out using Microsoft Teams based on an interview guide piloted before the interviews. Interviews were audiotaped and transcribed verbatim. Sampling was conducted with a focus on variation in LTSE. The data were analyzed using Malterud's principles of systematic text condensation and coded in NVivo 12.

Results: 2 males and 8 females with an average age of 55.8 years were interviewed for between 40 and 60 minutes from October to November 2020. Four main themes emerged from the interviews¹: The importance of the physiotherapist's approach,² the benefits of meeting patients with similar symptoms,³ the importance of receiving knowledge, and⁴ patients seeking to maintain their current state more often than aiming to improve their condition.

Conclusions: Patients consulting a physiotherapy clinic with LTSE after cancer prefer the physiotherapist to have knowledge about cancer and to be emphatic. Furthermore, patients prefer to meet like-minded people and expect support to maintain their current condition rather than improve their condition.

Keywords

sequela after cancer, patient expectations, physical therapy, qualitative interviews, primary care

Introduction

The worldwide 5-year prevalence of cancer is almost 5 in 1000 and is slightly more prevalent among women than men.¹ After receiving a cancer diagnosis, the global 5 year net survival rate is estimated at 42.6%, with survival in high-income countries being higher than in low-income countries.² The number of cancer survivors continues to increase because of both advances in early detection and treatment.³

Long-term side effects (LTSEs) can be defined as “a problem that is caused by a disease or treatment of a disease and may continue for months or years.”⁴ Among cancer survivors, about

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86% experience one side effect and fatigue is the most reported side effect in cancer or cancer treatment.⁵ Other common LTSEs are tight surgical scars, lymphedema, pain, reduced function, sexual problems, anxiety, and depression. These often have a significant impact on the quality of life and overall mortality.⁶ In addition, socio-demographic and psychosocial factors are important to consider when identifying people at risk of long-term LTSE.⁷

Patients express needs for healthcare support to cope with LTSEs and almost 30% of all patients express a need for physical rehabilitation to address physical deficits after ending cancer treatment.⁸ Consequently, patients are often referred to physiotherapists for the treatment of pain and other LTSE. Physiotherapeutic treatment is found to be effective,^{6,9} and physical therapy is even reported as most relevant among people with higher numbers of LTSE.¹⁰ However, physiotherapists are often not aware of the relationship between cancer and the symptoms that present. If they are aware, they are unsure of the choice of treatment. This may lead to overestimated goalsetting for rehabilitation and unrewarding results for patients.¹¹ In the literature, most physiotherapy-led interventions include exercise alone or as part of multicomponent intervention programs.¹² Physiotherapy interventions with endurance training, aerobic exercise, and resistance training are found relevant and effective in the treatment of LTSEs in cancer survivors.^{13,14} However, lymphatic drainage interventions after axillary lymph node dissection for breast cancer have not been found to be effective.¹⁵

Previous research has shown that some patients feel isolated and, therefore, benefit from training while others highlight the importance of professional and being involved in exercise like walking and running to tailor physical activity to suit patients with LTSE.¹⁵ Furthermore, qualitative research has shown positive experiences of team training because of the opportunity for social interaction and discussions of common questions and concerns with other cancer survivors.¹⁶ Additionally, qualitative research has found that individually tailored courses addressing individual needs effectively facilitate physical activity among women even though they may suffer from cancer-related fatigue.¹⁷

The body of evidence for treating LTSE is, however, limited, and further knowledge on treating this increasing group of patients in physiotherapy is needed to gain insight and to improve the physiotherapeutic treatment of LTSE. Hence, this study aims to investigate the expectations of physiotherapeutic treatment among patients with LTSE.

Methods

This is a qualitative study of patients with LTSE in physiotherapy practice is reported according to the consolidated criteria for reporting qualitative studies (COREQs).¹⁸

Study Design

This is an interview study focusing on the participants' experienced lifeworld as the specific reality in which they live their lives. The study is thereby inspired by the phenomenological

approach where the preunderstanding was sought to be put aside.¹⁹ RKJ, SJ, and SVG wrote down their preunderstanding and saved these prior to interviewing. They had chosen this subject based on their interest to the field, which had arisen during their clinical practice training.

Research Team and Reflexivity

This interview study has been conducted as part of a larger research project about developing interventions to improve primary care treatment of LTSE in Denmark. The wider research project was conducted in collaboration with the Department of Physiotherapy at University College in Northern Denmark, The Research Unit for General Practice at the Department of Clinical Medicine in Aalborg, the Quality Unit for General Practice in the North Denmark Region, and DEFACTUM (a public research institution in Denmark focusing on increasing social equality in health). RKJ, SJ, and SVG were supervised by MFA (Lecturer at UCN, PT, MSc), MK (Regional consultant for primary care physiotherapy, PT, MPQM), JLT (Professor, GP, PhD), and AR (Lecturer at UCN, Senior researcher, PT, PhD).

RKJ, SJ, and SVG received information about participants agreeing to participate from MK and AR. They repeated study information and scheduled an appointment for interviewing. RKJ, SJ, and SVG had no prior knowledge about the participants. The participants knew this study was part of RKJ's, SJ's, and SVG's thesis and they were informed that the interview study was part of a research project to provide information on the development of interventions to patients and possible educational interventions to clinicians.

SJ conducted all interviews. She did this during her physiotherapy studies where she completed her final thesis in collaboration with RKJ and SVG. She had no prior experience in interviewing. However, she had received training in interview techniques such as open-ended questions, active listening, and probing as part of her theoretical and clinical training as a physiotherapist.

Sampling

Danish-speaking cancer survivors experiencing either lymphedema, pain, fatigue, reduced balance or reduced mobility, aged 18+ years, and treated for LTSE by physiotherapists working in the Danish physiotherapy clinics fulfilled inclusion criteria and participants with some form of cognitive impairment or mental disorder were excluded. Sampling was aimed to achieve a maximum variation on types of LTSE.

Method of Approach

Information about the study was displayed in different relevant groups, an email was sent to 118 physiotherapists in the North Denmark Region and directly to patients via social media. They responded to MFA and MK, who gave contact information to RKJ, SJ, and SVG. RKJ, SJ, and SVG

Table 1. Interview Guide.

Theme	Main question	Follow-up question
Introduction	At first, can you tell me something about yourself?	Age, diagnosis, treatment, cancer-free or not, long-term side effects, and work situation
Start-up at the physiotherapist's practice	Can you describe how you experienced the start-up with the physiotherapist?	*Were you referred by the doctor? *Did you go see the doctor yourself? *How did you experience the first meeting? *Do you have examples of good/bad situations? *What should have been different?
The course at the physiotherapist's practice	What do you think a good physiotherapist is like? Can you describe how you experienced the treatment at the physiotherapist's clinic? Can you describe what a typical consultation with the physiotherapist contains?	*Do you have particularly good or bad experiences with the physiotherapist? *How do you experience the connection between your need for physiotherapy and what you received? *Have you felt involved? *Have you felt heard and seen? If so, what did the physiotherapist do? *How have you experienced the relationship between you and your physiotherapist? *What have you missed in the treatment?
Good advice and possible improvements	What have you gained from your treatment? Do you have any good advice on how physiotherapists could become better at treating people with long-term side effects after cancer?	*Did you feel ready to continue on your own? If so, how? *Did you get the necessary information to continue by yourself? *What would you wish a good neighbor or colleague would experience in a course at a physiotherapist?
Rounding	Further comments Sum up on some of the main points Thanks for your participation	- I do not have further questions. Are you left with something that you want to add or ask about regarding to what we have been talking about?

NOTE: The table shows superior themes, associated main questions, and examples of follow-up questions that were used if necessary.

contacted patients by email or phone to further inform about the study and eventually schedule an appointment for interviewing.

Sample Size

A prior we had decided on a minimum of 8 interviews with an aim to reach saturation. Saturation was discussed between RKJ, SJ, SVG, and MFA.

Non-Participation

Among twelve participants contacted to participate in an interview, one was excluded because the person had not received treatment by a physiotherapist. Another rejected participation: This person was not interested in the subject.

Ethics

All patients gave written informed consent prior to enrollment in the study. This is a non-intervention and interview study and The North Denmark Region Committee on Health Research

Ethics has stated that according to Danish law their approval is not needed.

The Setting for Data Collection

Interviewing was conducted online using Microsoft Teams. We expected all participants were in their own homes. However, we did not systematically plan to ask for this information. Interviews were audiotaped with a dictaphone and on a mobile phone as a back-up. We encouraged participants to be alone. Also, the interviewer (SJ) was alone during interviewing. Transcriptions were not returned to participants.

Data Collection

Interviews were based on an interview guide (Table 1) and were audiotaped and transcribed verbatim. Transcribing was conducted by RKJ, SJ, and SVG, based on a predefined set of rules. Before transcribing and later when the transcribers were in doubt, the transcription technique was discussed between the 3 transcribers.

The interview guide contained 3 topics and a few open-ended questions that the interviewer used as a start, after which follow-up questions were asked if necessary (Table 1). No field notes were made. The interview guide was pilot tested with SJ as an interviewer and MK as a respondent with RKJ, SVG, MFA, and AR present.

Data Analysis

NVivo software (NVivo 12) was used to code the meaningful units. Themes were thereby derived from data by use of Malterud's principles of systematic text condensation were used to analyze data in rounds after 4, 8, and 10 transcriptions.²⁰

Step 1. The total impression—from chaos to themes

First, a data overview was established. RKJ, SJ, SVG individually read all the transcriptions to get a general impression of the content and then come up with preliminary themes. The data were considered with an open mind and an awareness of the participants' own voices. The themes were discussed on multiple occasions until a consensus was reached on common themes.

Step 2. Identifying and sorting meaningful units—from themes to codes

RKJ, SJ, and SVG individually read the transcriptions line by line to identify and code meaningful units. The coding included identifying, classifying, and sorting meaningful units potentially related to the previously negotiated themes. The meaningful units were marked with a code. In this way, the related meaningful units were connected through code groups. The names of the code groups were elaborated from the preliminary themes in step 1.

Step 3. Condensing—from code to meaning

RKJ, SJ, and SVG individually went through one code group at a time to sort the meaningful units of the actual code group into a few subgroups. Afterward, these were discussed, and common subgroups were found for each code group. Then meaningful units were coded into subgroups. The procedure was then repeated with the remaining transcriptions in round 2 and 3. At last, a condensed form and headline for each code group and subgroup were created. For each condensed form, a quotation was picked out. This sought, as far as possible, to maintain the original terminology applied by the participant.

Step 4. Synthesizing—from the condensed form to descriptions and concepts

From the condensates and artificial quotations, analytic texts presenting the most salient content and meaning was written in third-person format, as RKJ, SJ, and SVG were in the roles of re-narrators responsible for interpretations. The analytic text for each of the code groups was reconceptualized, returning to the full transcript, where RKJ, SJ, and SVG

Table 2. Characteristics of the Sample.

Age, Mean (Range)	55.8 (37–71)
Gender, female (%)	8 (80%)
Employed, yes (%)	8 (80%)
Cancer diagnosis	
Breast	6 (60%)
Bone marrow	1 (10%)
Head and neck	2 (20%)
Malignant melanoma	1 (10%)
Long-time side effects	
Tightly surgical scar/connective	4 (40%)
Lymphedema	4 (40%)
Pain	7 (70%)
Fatigue	3 (30%)
Reduced balance	2 (20%)
Reduced mobility	3 (30%)

Note: N = 10. Sampling was aimed for maximum variation on type of long-term side effects.

validated whether the synthesis and the illustrative quotation still reflected the original context appropriately. Finally, a category heading to each analytic text was developed and also reconceptualized according to the full transcription. The category headings show the most significant interpretations and represent the final results of the analysis. In the result paragraph, these category headings are called themes and subthemes listed with the belonging analytic text.

Following the analysis, an external person, not member of the author group, but experienced with qualitative research, read the transcriptions, and validated the result section, including the themes and subthemes.

Results

Interviewing took place between 29 October and 30 November 2020. A total of 10 participants, 2 men and 8 women, were interviewed. Interviews lasted between 30–45 Minutes. There was no repetition of interviews. All participants had undergone cancer treatment, experienced LTSE, and received physiotherapy at the time of interviewing (Table 2).

After the analysis and re-contextualization, 4 themes with 2–3 associated subthemes emerged, an example is tabulated (Table 3). Themes and subthemes are presented sequentially.

Theme 1. The Importance of the Physiotherapist's Approach

Most of the participants experienced having met an empathetic, welcoming, and grateful physiotherapist. One participant expressed the importance of the physiotherapist being honest and direct in their communication. Besides, good collaboration involving the patient in a dialogue about goals and expectations was mentioned to be important. Further, it depends on getting to know each other.

Table 3. Example of Coding.

Step 1	Step 2a	Step 2b	Step 3 (Condensation – from Code to meaning)	Step 4a (Synthesizing – from Condensation to Descriptions and concepts)	Step 4b (Synthesizing – from Condensation to Descriptions and concepts)
The Total Impression – from Chaos to Themes	Identifying and Sorting Meaning units (Examples of Meaning Units)	...from Themes to Codes	Developed Subgroups	Category Headings for Code Groups	Category Headings for Subgroups
The physiotherapist's personality	<p>"I wish for a lovely and warm-hearted physiotherapist [...] Of course, it is fine to keep a distance, but it is also nice to be close to your physiotherapist"</p> <p>"I had probably expected that some massage could help but that was not the case. I got some exercises, and then I could go home and do them. [...] I have heard several acquaintances saying "but, he didn't even touch me"</p> <p>"In general, I might believe that people are taking the easy way. I don't think it is because people don't want to listen, but I believe it is easier to classify people rigidly"</p>	To feel met, heard, and seen	Importance of the physiotherapist's personality Goals and expectations Collaboration and individual adjustment of the course	Importance of the physiotherapist's approach	Empathy and acknowledgment Involvement of patients Individual adjustment
Tilhørsforhold og samhørighed (affiliation and cohesion?)	<p>"Sometimes it is the same people we meet, but not always as someone switch between the teams. There is not the same social cohesion as by the water aerobics where we are always the same people showing up"</p> <p>"I think that it might have given me a relatedness to show up and be with someone who had endured almost the same thing as me. They understand what it is like to have cancer that others who have never tried it do not"</p>	To be with others	The social aspect Belonging and solidarity	Meeting like-minded people and being understood	Social cohesion Being in the same situation

(continued)

Table 3. (continued)

Step 1	Step 2a	Step 2b	Step 3 (Condensation – from Code to meaning)	Step 4a (Synthesizing – from Condensation to Descriptions and concepts)	Step 4b (Synthesizing – from Condensation to Descriptions and concepts)
The Total Impression – from Chaos to Themes	Identifying and Sorting Meaning units (Examples of Meaning Units)	...from Themes to Codes	Developed Subgroups	Category Headings for Code Groups	Category Headings for Subgroups
The physiotherapist's professionalism	"It has been experienced physiotherapists, who have had someone like me in their hands before. It just gives me a feeling of being in safe hands" "I do not think that the physiotherapists are aware that cancer demands something extra. [...] The radiation does something with the body, and I do not think that you have that much experience in that"	The physiotherapist's knowledge	To be in safe and competent hands Lacking experience of long-term side effects	Importance of knowledge	Knowledge as a safety Physiotherapists not being on home ground
Experiences with physiotherapy	"I feel like being kept on track proportional to where I want to go. I also feel exercises as a tool that helps me cope" "Practically, the muscles are loosened. [...] I simply get improved mobility in my arm, when I come for treatment" "I have been at the same [physiotherapist] for 1 year and 7 months, and the last year, I have probably thought that there wouldn't be any change"	Yield/effects of the treatment	Continuing treatment on one's own/ independently When treatment takes effect When treatment does not improve/ no improvement of treatment	Maintenance more important than improvement	Tools for a lifelong project Investment in well- being Chronic pain as a condition of life

Note: Overview of code- and subgroups, meaningful units, themes, and subthemes.

"I hope for a lovely and warm-hearted physiotherapist [...] Of course, it's fine to keep a certain distance, but it's also nice to be close to your physiotherapist" (participant 2)

Subtheme 1a; Empathy and Acknowledgment. Several participants stated the importance of being seen and heard by an empathic physiotherapist with a perfect mix of personal and professional interests. Additionally, mutual respect is important regarding the feeling of being acknowledged and taken care of without being treated as a victim. Some prefer a physiotherapist who dares to address the psychological aspect and several expressed that honesty and direct communication in layman's terms increase the patient's confidence in the therapist.

"Someone who understands what your problems are. I just felt that I was in safe hands with the physiotherapist. They listened and understood the problem" (participant 5)

Subtheme 1b; Involvement of Patients. Some participants did not receive the treatment they had expected. A participant stated that informing the physiotherapist about expectations might have positively changed the situation. Moreover, several expressed a desire of being involved in decisions and receiving information regarding treatment. Getting to know each other was mentioned to give the feeling of collaboration with the physiotherapist while also helping the physiotherapist to understand the individual. In connection with an experience of having to ask for new exercises, one of the participants considered it fair to take the initiative.

“I’d probably expected that some massage might help but that wasn’t the case. I got some exercises, then, I was able to go home and do them. [...] I’ve heard several acquaintances saying ‘but, he didn’t even touch me’” (participant 4)

Subtheme 1c; Individual Adjustment. For the participants, the ideal course is individually tailored. One participant had a physiotherapist who was able to vary the training, while others were annoyed by the idea of “one size fits all” and feeling incorrectly assigned to a team. Another participant had experienced that very few physiotherapists were giving a diagnosis and starting treatment based on a thorough examination.

“In general, I might think that people are taking the easiest path. I don’t think it’s because people don’t want to listen, but I believe it’s easier to classify people more rigidly” (participant 6)

Theme 2. Meeting Like-Minded People and Being Understood

The participants described the social and enjoyable aspects of exercising with others, especially if the patient was feeling alone or having a hard time training alone. Several participants felt connected to other patients. Furthermore, they felt it was possible to share experiences and be understood when they were with other cancer patients.

“We didn’t talk that much, but just a little. It was actually fine having a subconscious connection to a group that you know are going through the same as you” (participant 6)

Subtheme 2a; Social Cohesion. Several participants described the social aspects of being with others. A participant considered it particularly rewarding for people who spend a lot of time alone. Furthermore, social cohesion was stated as achieving higher success when a consistent group of people participated. Another participant considered that team training was an opportunity for completing exercise and that this had more value than the social aspect. A participant attending a social cycling team experienced it as a legitimate opportunity for getting into a little conversation.

“Sometimes, we meet the same people, but not always as someone will switch between teams. There is not the same social cohesion as with aqua aerobics where the same people always show up” (participant 3)

Subtheme 2b; Being in the Same Situation. More participants described the feeling of synergy and a subconscious connection when being with others in the same situation who truly understand them. People had the experience of attending a team where you could contribute to anything relating to LTSE. This was elaborated by another who felt it rewarding to hear relatable experiences and identify with others.

“I think that it might have given me a sense of connection by showing up and being with someone who had endured almost the same thing as me. They understand what it’s like to have cancer that others who’ve never had it don’t always understand” (participant 6)

Theme 3. The Importance of Knowledge

Several participants experienced a lack of knowledge with LTSE. However, some had good experiences where physiotherapists made an honest attempt to treat them despite having a lack of knowledge.

“I probably know more about long-term side effects than many of the people I meet in the system. [...] Some of the physiotherapists where I go don’t know about long-term side effects and they are not specialised” (participant 3)

Subtheme 3a; Knowledge as a Safety. Some participants described a feeling of being in safe and competent hands when the physiotherapist has knowledge of working with LTSE and watches to make sure everything is going well. A participant considered it rewarding and calming to receive extra information about her specific situation. Most expressed the importance of being perceived as a whole person. Furthermore, a participant had experienced a more relaxed atmosphere at the physiotherapist’s compared to at the doctor’s. Also, this participant felt a respect for the fact that patients can also have important knowledge about their health condition.

“Experienced physiotherapists have had someone like me in their hands before. It just gives me a feeling of being in safe hands” (participant 1)

Subtheme 3b; Physiotherapists Not Being Familiar With LTSE. Several participants expressed that many physiotherapists are not familiar with LTSE. A participant expressed a wish to know more about LTSE from personal experience, which many healthcare professionals do not have. However, the importance of trying and being honest when not having qualifications was mentioned, as it is fair that not everyone will know everything. A participant considered it was desirable that physiotherapists should seek more information and specialize in LTSE.

“I don’t think that physiotherapists are aware that cancer demands something extra. [...] Radiation does something with the body and I don’t think they have much experience in that” (participant 7)

Theme 4. Maintenance Is More Important Than Improvement

Several participants experienced the effects of attending different treatment activities. A few had experienced

treatments that were insufficient, but several agreed that their current treatment is predominantly maintenance. Several participants mentioned that treating LTSE is a lifelong project, which is why they request different tools to improve this lifelong treatment.

“I experience the treatment as some kind of maintenance. I’m not quite sure things will get much better than they are now because of the body’s decay” (participant 2)

Subtheme 4a; Tools for a Lifelong Project. Several participants mentioned the importance of receiving tools to use at home as the damage from the radiation treatment never disappears. Moreover, one had obtained knowledge about exercises and techniques for massaging their surgical scar, and one participant experienced that more focus on the exercises resulted in a noticeable improvement. Furthermore, a couple of the participants described the value of receiving continuous supervision from a physiotherapist.

“I feel like I’m being kept on track in relation to where I want to go. I also feel exercises are a tool that helps me cope” (participant 10)

Subtheme 4b; Investment in Well-Being. Most of the participants have experienced the effects of treatment. One woman talked about a great and surprising experience in loosening up a tight surgical scar, while another experienced that the physiotherapist was able to move the lymphatic fluid away. Some participants have experienced improved mobility, physical well-being, or softening of the muscles in the axilla. One woman described the feeling of being in a slightly small wetsuit that fits better after treatment. Furthermore, one described her body getting better when doing her exercises, while another mentioned the need to remind herself that treatment and exercising are good investments.

“In practical terms, the muscles are loosened. [...] when I come for treatment, I simply get improved mobility in my arm,” (participant 6)

Subtheme 4c; Chronic Pain as a Condition of Life. One man has concluded that massage does not help him. Several participants perceived massage more as a symptomatic treatment than a holistic treatment when experiencing LTSE. They expressed a perception that LTSE never disappears, regardless of the amount of massage received. One woman said that if she were a millionaire, she would visit a physiotherapist once a week because it would be more effective. However, another questioned whether physiotherapy made a difference. One man considered it important in trying to resign himself to the conditions of life that chronic pain inflicts, as otherwise, this might lead to psychological problems.

“I’ve been seeing the same [physiotherapist] for one year and seven months and over the last year, I’ve probably thought that there wouldn’t be any change” (participant 2)

Discussion

Principal Findings

The aim of the study was to investigate what patients expect from physiotherapeutic treatment of LTSE in physiotherapeutic clinics. Throughout the analysis the following themes emerged: (1) The importance of the physiotherapist’s approach, (2) the importance of meeting like-minded people and being understood, (3) the importance of knowledge, and (4) maintenance is more important than improvement.

Strengths and Limitations

We used a data-driven step-by-step procedure that promotes transparency and supports the identification of the participants’ experienced lifeworld, putting our preunderstanding aside.²¹ The interviewers’ position as a graduating student without any relation to the participants fostered an adequate distance between the interviewer and the participants. Hence, they did not need fear insulting a trained physiotherapist or someone they knew. A study limitation might be the limited diversity of the participants’ characteristics. Only 2 men were included and most of the female participants were diagnosed with breast cancer, which limits the gender diversity in the study and is a weakness in the study. Furthermore, being a qualitative study with 10 participants, findings from this study need to be supported by quantitative research into the external validity of the findings.

Transcripts were not sent to participants for feedback, which may have improved internal validity. However, to address this limitation, an external person was used to validate the results. This led to minor adjustments to the text. However, themes and subthemes were not changed. We believe this to strengthen the study and reduce the risk of bias. Before interviewing, RKJ, SJ, and SVG stated their preunderstanding. Even though some findings are in line with their stated preunderstanding, new knowledge did arise during this study. Quotations are translated from Danish to English, however, cautions were taken in keeping the participants’ meanings. However, interviewing in one language and reporting in another is a limitation of the study.

Comparison With Previous Studies and Theories

Importance of the physiotherapist’s approach. This theme can be related to the Calgary–Cambridge Guide, an evidence-based communication model that provides the framework for professional health communication.²² Several informants mentioned the importance of meeting a physiotherapist who is empathic, generous, and appreciative, showing personal and professional interest, which are keywords in the first phase of the Calgary–Cambridge Guide and are in line with patients’ preferences for their physician.^{22,23} Furthermore, the Calgary–Cambridge Guide focuses on dialogue regarding goals and expectations and delivering information that allows the patient

to be involved in shared decision-making.²⁴ Others have also found that patients with cancer prefer involvement in medical decisions.²⁵ This involvement in physiotherapy includes using an individualized treatment approach, offering education during all aspects of treatment and working with patient-defined goals by a physiotherapist with sufficient social skills in addition to showing specific knowledge about cancer.²⁶

Meeting like-minded people and being understood. Some of the participants describe team training as a way for social cohesion to arise. Furthermore, they find it essential to discuss questions and thoughts with someone in similar life situations. These findings are supported by a study where women experienced social interaction with other cancer survivors as positive and having the opportunity to discuss common issues and concerns.¹⁶ According to the Self Determination Theory, the 3 basic psychological needs underlying intrinsic motivation are: autonomy, competencies, and relatedness. These are considered important for this patient group.²⁷ In this case, the feeling of relatedness is met by being able to relate to others, feeling safe, and being connected with the surroundings. This promotes an intrinsic motivation to continue training and obtain long-term exercise adherence.²⁸ The importance of being treated with others can also be found in a hospital setting²⁹ where support from other participants was a key facilitator in overcoming challenges such as fatigue and mental issues.²⁹

The importance of knowledge. Varied perspectives on physiotherapists' knowledge about LTSE appeared in this study. Obtaining greater knowledge and insight could meet the participants' basic psychological needs, autonomy, and competencies, which are described as important in the Self-Determination Theory.²⁷ Receiving relevant information can improve the participants' competences for attending their treatment and making decisions that could give them the feeling of ownership of the situation and believing in their abilities. The participants' statements regarding the importance and feeling safe with physiotherapists delivering information are supported by a qualitative study of women with breast cancer,¹⁶ concluding that it felt safe and calming to receive relevant knowledge about the intervention. A recent review found that internet-based programs are effective in reducing LTSE.³⁰ Maybe physiotherapist should be more aware of advising patients to seek information online in combination with their treatment. However, it is important to recommend specific homepages, otherwise patient's lack trust in information from the Internet.³¹

Maintenance is more important than improvement. Not all participants had experienced an improvement in the treatment they received. However, it was more important for them to maintain their level of health and for symptoms not to increase. Several of the participants who did not experience an

improvement mentioned an awareness of things not being much better. This is in line with findings from a previous study where even patients who were highly motivated to exercise did not hold strong beliefs that exercise would decrease LTSE.³²

This highlights the importance of the recommendations in the Calgary–Cambridge Guide, emphasizing that physiotherapists need to match expectations and involve the patient to ensure common thoughts about the choice of treatment and treatment goals.²²

Implications for Practice

The findings of this study highlight various factors that could improve the experience of physiotherapeutic treatment of LTSE. First, physiotherapists should meet patients with a holistic and biopsychosocial approach. Second, patients could benefit from being involved in decisions about their treatment and treatment goals by an emphatic physiotherapist. Third, special attention is needed for the participants concerning their feelings about being abandoned by the health care system with LTSE. The participants' experiences of the physiotherapist's knowledge was varied. Even when physiotherapists had insufficient knowledge, several participants accepted this if the physiotherapist was honest about it. Still, most of them expressed a desire for physiotherapists specializing in LTSE. Patients' expectations for maintaining their functional levels rather than improving their condition was not included in our preunderstanding and was a surprising finding. However, findings from this qualitative phenomenological study need to be supported in future research and call for quantitative research to quantify this belief/expectation. This is a widely spread belief that actions are needed since exercise decreases the risk of mortality and recurrence while also being associated with less severe LTSE.³³ In addition, intervention studies are generally small and rarely have long follow-up periods^{34,35}; consequently, future studies on effects need to be large scale and report long-term follow-up.

Conclusion

Patients consulting a physiotherapy clinic with long-term side effects after cancer prefer the physiotherapist to have knowledge about cancer and to be emphatic. Furthermore, patients prefer to meet like-minded and expect support to maintain their current condition rather than necessarily improve it.

Clinical Messages

1. Patients seek information about LTSE after cancer from physiotherapists.
2. Patients aim to maintain their level of function and symptoms rather than improve these.

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Author Contributions

RKJ participated in the conception of the study, transcription, analyses, and interpretation of data. RKJ participated in drafting the first version of the paper and took a lead in co-ordinating rounds of corrections. RKJ drafted the last version of the manuscript and read and approved the last version of the manuscript. SJ participated in the conception of the study. SJ conducted all interviews and participated in transcription, analyses, and interpretation of data. SJ participated in drafting the first version of the paper and read and approved the last version of the manuscript. SVG participated in the conception of the study. SVG participated in the transcription, analyses, and interpretation of data. SVG participated in drafting the first version of the paper and read and approved the last version of the manuscript. MFA participated in the conception of the study. MFA participated in the interpretation of data. MFA participated in commenting on the manuscript in rounds of corrections for the paper and read and approved the last version of the manuscript. MK participated in the conception of the study. MK assisted in recruiting participants and acted as a respondent in the pilot interview. MK participated in commenting on the manuscript in rounds of corrections for the paper and read and approved the last version of the manuscript. JLT participated in the conception of the study. JLT participated in commenting on the manuscript and in rounds of corrections of the paper and read and approved the last version of the manuscript. AR participated in the conception of the study. AR participated in the interpretation of data and commenting on the manuscript in rounds of corrections for the paper. AR supervised RKJ in drafting the final version of the manuscript and reading and approving the last version of the manuscript.

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References

1. Pisani P, Bray F, Parkin DM. Estimates of the world-wide prevalence of cancer for 25 sites in the adult population. *Int J Canc.* 2002;97(1):72-81 doi:10.1002/ijc.1571.
2. Ward ZJ, Scott AM, Hricak H, et al. Estimating the impact of treatment and imaging modalities on 5-year net survival of 11 cancers in 200 countries: a simulation-based analysis. *Lancet Oncol.* 2020;21(8):1077-1088. doi:10.1016/S1470-2045(20)30317-X.
3. Miller KD, Siegel RL, Lin CC, et al. Cancer treatment and survivorship statistics, 2016. *CA A Cancer J Clin.* 2016;66(4):271-289. doi:10.3322/caac.21349.
4. National Cancer Institute at the National Institutes of Health. Available at <https://www.cancer.gov/about-cancer> accessed May 6, 2021.
5. Pearce A, Haas M, Viney R, et al. Incidence and severity of self-reported chemotherapy side effects in routine care: A prospective cohort study. *PloS One.* 2017;12:e0184360. doi: 10.1371/journal.pone.0184360
6. Gegechkori N, Haines L, Lin JJ. Long-term and latent side effects of specific cancer types. *Med Clin.* 2017;101(6):1053-1073. doi:10.1016/j.mcna.2017.06.003
7. Brandão T, Schulz MS, Matos PM. Psychological adjustment after breast cancer: a systematic review of longitudinal studies. *Psycho Oncol.* 2017;26(7):917-926. doi:10.1002/pon.4230
8. Ohlsson-Nevo E, Alkebro I, Ahlgren J. Cancer patients' interest in participating in cancer rehabilitation. *Acta Oncologica.* 2019;58(12):1676-1683. doi:10.1080/0284186X.2019.1633017.
9. Pyszora A, Budzyński J, Wójcik A, Prokop A, Krajnik M. Physiotherapy programme reduces fatigue in patients with advanced cancer receiving palliative care: randomized controlled trial. *Support Care Canc.* 2017;25(9):2899-2908. doi:10.1007/s00520-017-3742-4
10. Rangel J, Tomás MT, Fernandes B. Physical activity and physiotherapy: Perception of women breast cancer survivors. *Breast Cancer.* 2019;26(3):333-338. doi:10.1007/s12282-018-0928-7
11. Gupta E, Ng AH, Fu JB, et al. Cancer rehabilitation providers and oncology patient expectations for functional outcomes after inpatient rehabilitation. *PMR.* 2020;13:729-736. doi: 10.1002/pmrj.12473
12. Lin K-Y, Frawley HC, Denehy L, Feil D, Granger CL. Exercise interventions for patients with gynaecological cancer: a systematic review and meta-analysis. *Physiotherapy.* 2016;102(4):309-319. doi:10.1016/j.physio.2016.02.006
13. Hilfiker R, Meichtry A, Eicher M, et al. Exercise and other non-pharmaceutical interventions for cancer-related fatigue in patients during or after cancer treatment: A systematic review incorporating an indirect-comparisons meta-analysis. *Br J Sports Med.* 2018;52(10):651-658. doi:10.1136/bjsports-2016-096422
14. Cataldi S, Greco G, Mauro M, Fischetti F. Effect of exercise on cancer-related fatigue: a systematic review. *Journal of Human Sport and Exercise.* 2021;16(3):476-492 doi:10.14198/jhse.2021.163.01.

15. Devoogdt N, Van Kampen M, Geraerts I, Coremans T, Christiaens M-R. Different physical treatment modalities for lymphoedema developing after axillary lymph node dissection for breast cancer: a review. *Eur J Obstet Gynecol Reprod Biol.* 2010;149(1):3-9. doi:[10.1016/j.ejogrb.2009.11.016](https://doi.org/10.1016/j.ejogrb.2009.11.016)
16. Brunet J, Saunders S, Gifford W, Thomas R, Hamilton R. An exploratory qualitative study of the meaning and value of a running/walking program for women after a diagnosis of breast cancer. *Disabil Rehabil.* 2017;40(1):1041-1048. doi:[10.1080/09638288.2017.1283714](https://doi.org/10.1080/09638288.2017.1283714)
17. Enblom A, Lindquist H, Bergmark K. Participation in water-exercising long-term after breast cancer surgery: Experiences of significant factors for continuing exercising as a part of cancer rehabilitation. *Eur J Canc Care.* 2018;27(1):e12736. doi:[10.1111/ecc.12736](https://doi.org/10.1111/ecc.12736)
18. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care.* 2007;19(6):349-357.
19. Giorgi A. The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. *J Phenomenol Psychol.* 1997;28(2):235-260. doi:[10.1163/156916297X00103](https://doi.org/10.1163/156916297X00103)
20. Malterud K. Systematic text condensation: a strategy for qualitative analysis. *Scand J Publ Health.* 2012;40(1):795-805. doi:[10.1177/1403494812465030](https://doi.org/10.1177/1403494812465030).
21. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006;3(2):77-101.
22. Iversen ED, Wolderslund MO, Kofoed P-E, et al. Codebook for rating clinical communication skills based on the Calgary-Cambridge guide. *BMC Med Educ.* 2020;20:140. doi:[10.1186/s12909-020-02050-3](https://doi.org/10.1186/s12909-020-02050-3)
23. Lelorain S, Cattan S, Lordick F, et al. In which context is physician empathy associated with cancer patient quality of life? *Patient Educ Counsel.* 2018;101(7):1216-1222. doi:[10.1016/j.pec.2018.01.023](https://doi.org/10.1016/j.pec.2018.01.023)
24. Burt J, Abel G, Elmore N, et al. Assessing communication quality of consultations in primary care: initial reliability of the Global Consultation Rating Scale, based on the Calgary-Cambridge Guide to the Medical Interview. *BMJ Open.* 2014;4(3):e004339. doi:[10.1136/bmjopen-2013-004339](https://doi.org/10.1136/bmjopen-2013-004339)
25. Hahlweg P, Kriston L, Scholl I, et al. Cancer patients' preferred and perceived level of involvement in treatment decision-making: an epidemiological study. *Acta Oncologica.* 2020; 59(8):967-974. doi:[10.1080/0284186X.2020.1762926](https://doi.org/10.1080/0284186X.2020.1762926)
26. Wijma AJ, Bletterman AN, Clark JR, et al. Patient-centeredness in physiotherapy: what does it entail? a systematic review of qualitative studies. *Physiother Theory Pract.* 2017;33(11): 825-840. doi:[10.1080/09593985.2017.1357151](https://doi.org/10.1080/09593985.2017.1357151)
27. Flannery M. Maps. *Change Management for Organizations.* 2017;44(2):155-156. doi:[10.1188/17.ONF.155-156](https://doi.org/10.1188/17.ONF.155-156).
28. Teixeira PJ, Silva MN, Mata J, Palmeira AL, Markland D. Motivation, self-determination, and long-term weight control. *Int J Behav Nutr Phys Activ.* 2012;9:22. doi:[10.1186/1479-58689-22](https://doi.org/10.1186/1479-58689-22).
29. Ferri A, Gane EM, Smith MD, Pinkham EP, Gomersall SR, Johnston V. Experiences of people with cancer who have participated in a hospital-based exercise program: A qualitative study. *Support Care Canc.* 2021;29(3):1575-1583. doi:[10.1007/s00520-020-05647-y](https://doi.org/10.1007/s00520-020-05647-y)
30. Huang J, Han Y, Wei J, et al. The effectiveness of the Internet-based self-management program for cancer-related fatigue patients: a systematic review and meta-analysis. *Clin Rehabil.* 2020;34(3):287-298. doi:[10.1177/0269215519889394](https://doi.org/10.1177/0269215519889394)
31. Riis A, Hjelmager DM, Vinther LD, Rathleff MS, Hartvigsen J, Jensen MB. Preferences for web-based information material for low back pain: qualitative interview study on people consulting a general practitioner. *JMIR Rehabilitation and Assistive Technologies.* 2018;5:e7. doi:[10.2196/rehab.8841](https://doi.org/10.2196/rehab.8841)
32. Hirschey R, Docherty SL, Pan W, Lipkus I. Exploration of exercise outcome expectations among breast cancer survivors. *Canc Nurs.* 2017;40:E39-E46. doi:[10.1097/NCC.0000000000000362](https://doi.org/10.1097/NCC.0000000000000362)
33. Cormie P, Zopf EM, Zhang X, Schmitz KH. The impact of exercise on cancer mortality, recurrence, and treatment-related adverse effects. *Epidemiol Rev.* 2017;39(1):71-92. doi:[10.1093/epirev/mxx007](https://doi.org/10.1093/epirev/mxx007)
34. Kamel FH, Basha MA, Alsharidah AS, Salama AB. Resistance training impact on mobility, muscle strength and lean mass in pancreatic cancer cachexia: a randomized controlled trial. *Clinical Rehabilitation.* 2020;34(11):1391-1399. doi:[10.1177/0269215520941912](https://doi.org/10.1177/0269215520941912).
35. Granger CL. Physiotherapy management of lung cancer. *J Physiother.* 2016;62(2)60-7. doi:[10.1016/j.jphys.2016.02.010](https://doi.org/10.1016/j.jphys.2016.02.010)