Self-guided physical training as a life unfolding activity

A phenomenological approach to lived experiences of cancer patients taking part in physical training programs

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Abstract
Based on the ideas of the impact of architecture on healing and health, the Danish Cancer Society has built buildings of a new kind, called Life Spaces. Our research takes place in one of these houses. In one room, designed as a multi-functional room, cancer patients are invited to do various kinds of physical activities on their own. Several studies have found that physical training programs have a positive impact on cancer patients, in the form of, e.g., well-being, physical capacity, decreased side effects, mental resources, and self-confidence. The aim of this study is to describe what characterizes cancer patients' lived experiences of participating in self-guided physical training. Based on six narrative interviews and, to a minor extent, participant observation and informal conversations, we distinguish three themes, which emerge from the phenomenological analysis: Fitness training, including varied descriptions of exercises; more than illness, recognizing illness as a common experience that does not need to be constantly articulated; and fellowship, exposing the sense of being part of a group of people who take care of each other. The themes are discussed in the light of Medard Boss’ conception of existential traits.

Keywords
cancer patients, life spaces, lived experiences, narrative approach, phenomenological research, self-guided physical training, unfolding life

Introduction
Living with cancer affects many aspects of human life. The way back to a normal life can be a hard path to walk. To support the fight against cancer, the Danish Cancer Society has built so-called Life Spaces for cancer patients. These are buildings in which a homely atmosphere is created, and that have peaceful surroundings (1). In one of these places, cancer patients can participate in self-guided physical training. The positive impact of physical activity on cancer patients is well documented and seems to be related to several different cancer diagnoses (2,3). Patients’ experiences of well-being is related to exercise-based rehabilitation (4). Mental benefits have been identified, e.g., increased self-confidence, distance from illness,
structure in everyday life, and reduced stress symptoms. These factors all seem to improve quality of life (5,6). Moreover, physical benefits are identified, such as increased physical condition and strength, reduced fatigue, increased energy and weight loss (3,7). These physical benefits seem to contribute to the experience by cancer patients of having their body back and to have a positive impact, such as reduced side effects (5,7). Furthermore, social benefits have been identified in cancer patients who participate in group-based training programs. The benefits include not feeling alone, the opportunity to share experiences about cancer, and fellowship (8).

Based on the literature, research has been conducted on group-based physical activities led by an instructor (3,8) as well as individual physical activity at home (9-11). Prominent differences between these types of training seem to be the social aspects and the experience of being a part of something when participating in group-based physical activity. Both group-based and individual physical activity have been the subjects of several studies indicating that physical activity contributes to mental, physical, and social well-being (4,5,8). Most of the studies focus on specific cancer diagnoses (2-3, 7-11). No studies were found that treated cancer patients’ lived experiences related to participating in self-guided physical training. Given the current knowledge about the impact of physical activity, we find it interesting to explore this in the light of self-training activities.

**Aim**
The aim of the study is to describe cancer patients’ lived experiences of participating in self-guided physical training, as it takes place at one of the Danish Cancer Society’s Life Spaces.

**Method**
The study is conducted within a lifeworld phenomenological approach. One session of participant observation, informal conversations, and six narrative interviews form the basis of our data. The German sociologist Harry Hermanns, who describes a five-step model for narrative interviews, has been the inspiration for the interviews (12-14). The first step takes place before the interview and is a phase of preparation, in which participants are selected and introduced to this form of an interview. The second step is an opening phase, where the interviewer makes the participant feel welcome. In these two steps, the interviewer holds the lead role. The roles change in the third step. When asking the opening question: “Could you please tell me how you have experienced doing self-guided physical training in this place from the very first day?” the participant is invited to take the position as a leading narrator. The interviewer sits back and encourages the participant to go on with the story by small comments, such as: “Oh, please go on”, “Please say something more”, or just by being present as an active listener. When the story seems to be finished, the interviewer takes back the lead role and asks for additional descriptions in the fourth phase by asking questions, such as: “You mentioned something about laughing when you tried to sit on the ball. Will you please tell me more about what was going on in this moment?” In the final step, the roles are rebalanced and the interviewer is responsible for ending the conversation in an appropriate manner.

One of the authors was an observer in a one-hour fitness session. During the session, she took photographs with the purpose of later recalling impressions from the session. After the session she wrote fieldnotes about the training and points related to the informal conversations that had occurred.
During a phenomenological analysis, all data are read through to get an overall comprehension. Meaning units are identified and organized into clusters and subclusters (15-16). For each subcluster, variations are created in the form of creative non-fictions, which means that the stories are fictions in form but factual in content (17). These non-fictions are created from the original descriptions, by assembling the participants’ words and phrases into coherent expressions representing the essence of each subcluster. A thematic structure is developed across the clusters and subclusters.

**Ethical considerations**
The study was approved by University College Absalon. As an educational institution University College Absalon made a mutual notification agreement with the Danish Data Protection Agency and this study thereby obtained authorization to initiate this research – which involved sensitive personal data. In addition, the participants gave their consent to participate. They were informed, in writing and verbally, that participation was voluntary and their information kept confidential and anonymous.

**Results**
Three themes seem to be central to a phenomenological description of cancer patients’ lived experiences of participating in self-guided physical training: Fitness training, more than illness, and fellowship – which are presented below. Short narratives, in the form of creative non-fictions (17), are inserted to illustrate the essences of the themes.

**Fitness training**
This theme characterizes the lived experiences of self-guided physical training. The participants themselves are responsible for the training: which exercises to practice, when and how to do it, and so on. However, the participants are not always entirely on their own. Once a month, a physiotherapist provides instructions to newcomers on how to use the fitness machines. She also guides the patients to choose exercises appropriate to their physical disorders. Besides using the machines on their own, the patients are invited to attend group exercises. The group training is run on a voluntary basis. One of the patients who has been involved in the training for a long time is a facilitator for the group training. Her role is similar to a coach. She plans the group exercises and motivates and encourages the participants during training. If she is absent, someone else undertakes the task. Two subthemes embedded in this theme are unfolded below.

**The training session**
In the work-out room, a rowing machine, an exercise bike, and a cross trainer are available. There are balls, skipping ropes, a trampoline, as well as other smaller instruments. In addition to individual use of these equipment, the group training is a great success. The participants enthusiastically tell about a variety of exercises during the group training, as described in this story:

> Many different exercises are going on during a typical session. At first, we just walk around. Fast and slow. Slow and fast. Up on the toes, down on the heels. The insides of the feet. The outside. Swinging our arms backwards and forwards, doing front-crawl like a swimmer, waving the elbows
like a chicken, and other strange moves. We slide on small pieces of wall-to-wall-carpets. Forward, backward and like ice-skating. Quick steps to get the heart rate up. We slide sideways to strengthen the muscles on the insides of the thighs.

Now we are warmed up and ready to go on with the sticks. Since it is easier for me to manage them, with my arms and shoulders, I like the sticks better than the rubber bands. We do all sorts of moves with the sticks. Swinging them one way and the other. Up and down. Behind the neck. Kicking. Bending to the floor. These exercises are like real fitness training.

I will also tell you how we play games. We put nine of the carpet pieces on the floor – a three and three square to play noughts and crosses. One group is equipped with red dumbbells, the other with yellow. One of the team is nominated to decide how to lift the weights and how to run to the carpets and back again. Then it is brain fitness as well, right?

Then it is time for the step platforms. We stand in a row behind the benches. The first in the row decides what to do on the bench. We do the moves one by one, and then the next person is in charge. Before ending the session, we do workout with the balls. Throwing and rolling the balls. Trying to keep the balance while sitting on the balls and at the same time making other moves with the arms and legs. During the session, we have worked all the muscles and joints in the body. You know, we have been diagnosed with different forms of cancer, such as leukemia, breast cancer, lung cancer – you name it. However, no matter what form of cancer, you need to strengthen every single muscle.

As the story shows, the whole body is worked in the fitness training. The patients have different cancer diseases, but the focus is never on just one part of the body. It also shows that some of the training is like playing games. In addition to the story, one of the participants mentioned how they learned their names by throwing balls. A little paradox appears regarding the games. The participants appreciate exercising in a room free of competition. On the other hand, it becomes a sport to go on with an exercise longer than the rest. A room free of competition is a safe place for fitness training, but at the same time, a spontaneous competition can be a motivating force to keep on a little bit longer.

Most of the training takes place indoors, but on fine days, they go outside for a ball game on the lawn or a walk along a special path called the Life Trail, which goes through the forest. The walk on the trail lasts for an hour and gives rise to good conversation.

Benefits of the training
The analysis shows that the participants benefit from the training in different ways. The most specific outcome relates to their physical condition, as represented in this story:

Sure, things happened after I went to the fitness training. Before, it was hard to do everyday things. After a shower, I had to rest a while before breakfast. Shopping was a nightmare. I dragged myself to the car. In the store, I had to rest leaning over the counter. At that time, I was feeling low, very low. The most concrete reward is to be able to do more than before. I go for a long walk almost every day. I am in a much better physical condition. My balance has improved. Now I don’t need to get off the bike to turn around to look for traffic. I can turn my head without feeling dizzy. Furthermore, I recover better after chemotherapy. I am not well after chemo treatment, but now an aspirin and a nap can fix it, and the next day I am fit again.

The participants have experienced a time with disease and onerous treatments, which is described in a before-perspective – meaning before starting the self-guided training program. At that time, they focused on their poor physical conditions and could not imagine finding pleasure in any kind of physical training. In an after-perspective, they describe the
changes they underwent during the self-guided training. They do not mean that the physical torments and discomforts associated with having cancer are erased as if by magic. It means that the participants experience some kinds of benefit. The general outcome is an experience of being in a better physical condition, whether it is in the form of increased endurance, better mobility, more reliable balance or in whatever other changes each person has experienced.

Even though the participants’ experiences of benefits presented above are about improvements, this is not the case for all of them. Some benefits are related to slowing down the process of physical decay. The motivation for patients to go on with the training is to keep themselves as fit as possible in the circumstances, as emphasized in this description:

Someone takes a turn for the better during the training. However, I have reached an age at which the muscles gradually vanish. Therefore, to me it is about keeping myself going. I have not improved but I believe that the training helps to postpone the decay of my body.

The self-guided training has an impact on how the patients experience bodily changes over a period of time as well as day to day changes. The relief of pain, nausea, fatigue and other symptoms associated with cancer makes the patients become absorbed in the moment – like forgetting themselves. While laughing at the strange moves, concentrating on keeping their balance on the ball, or enjoying a slight feeling of competition in the games, they tend to forget that they are cancer patients. In addition to the experiences of bodily changes, the training represents a kind of a motivating power that forces the patient to get out of bed and set off to the training. They get extra energy, so that they can be aware of other people and think about everything other than the cancer – which will be elaborated in the next theme.

**More than illness**

Even though the cancer disease is a frame of reference that is common to all the participants, it is not the central focus during the training. They will not allow cancer – which has various implications that are personal to each individual – to occupy their lives. The training sessions offer them a break from the disease. Of course, cancer is at stake in their time together, but they value conversing about many other topics, such as recipes, cuttings from the herb garden, and a variety of tips and tricks regarding the training. This theme is characterised by the contrasts embedded in the shared experiences of being cancer patients, and a vital force provided by pleasant fellowship and experiences.

**Shared experiences of being a cancer patient**

The participants all have a bodily experience of being a cancer patient. They know the feeling of being tired and recognize low energy levels. They are also familiar with the visible changes of the body, such as being skinny because of severe loss of weight or losing their hair because of chemotherapy, which is at stake in this story:

Lots of us have lost our hair when having the chemo. We don’t worry about that. Some of us wear a scarf to hide the baldness. Others do not hide their head. We have seen it all. We are not scared of that sight. We also know about low energy. Sometimes you have to take it easy. Maybe you just come for the company and a good chat. All of us have been through some tough treatments, so we know better than anybody else does that being in chemo means that your battery is low.
The story provides two examples of shared experiences. It is valuable to the participants to be together with others who are also familiar with the implications of having a cancer disease. They share experiences. They listen to each other. They have time for each other. They can recall the feeling of being too weak to exercise. Furthermore, the awareness of death is a common thought among the participants. They have all known people whose cancer assumed the command in a way that meant that treatment was no longer effective. They know that death is inescapable. While it is positive to share some experiences, they also have to share the bad times. Now and then they have to face the death of one of their group. However, in spite of illness and death, they carry on and try to lighten the atmosphere.

**Vital forces**

The self-guided physical training is associated with fun and cheerfulness. Funny exercises and silly-looking physical moves provoke lots of laughter. There is a light atmosphere that is inextricably bound up with lots of joy, which is highly appreciated. The participants look forward to every training session, and after the session, their faces look like happy smileys – as described in this story:

> Every single time we are filled up with fun and joy. Some of the exercises are quite difficult and when someone can’t keep the balance on the ball, we make fun of it. We laugh. We tease each other. We make a joke of the foolish movements. We all deal with serious illness you know, so black humor is also quite common here. After the training, we sit in the living room for a cup of coffee. When the weather is fine, we can go out into the atrium. Here we continue the joyful atmosphere. We laugh and have a happy time together. Moreover, we talk. We talk about anything and everything, getting to know each other. We like to know the individual human beings. No one wants to discuss illness and cancer all the time. We need to have fun, you know. It is an important part of being a self-trainer. It is nice. I tell you, we have a party here, and we call ourselves “The Happy Self-trainers”.

In addition to the joyful time shared at the training sessions, the participants also have other experiences together. One of these experiences is the event “Run for life”, which is the Danish Cancer Society’s largest voluntary activity. They participate in a 24-hour team walk, which takes place annually in more than 50 cities across Denmark. It is described in this way:

> We participate in the “Run for life”. Wow, it is a fantastic and unique experience. We are together during the weekend, which strengthens our relationship. Since we can’t run so much, we just walk. It is a fantastic event. People cheer on us along the route. Last year tears were streaming down my face. It was a very intense feeling. This event is very high on my priority list. If a birthday or something else comes up, I will do my best to take part in the run anyway. When our families join us, they realize the strong fellowship we have here.

As the story shows, the participants value sharing a good experience together. At the run, the cancer patients get a yellow t-shirt – called the fighter t-shirt – and they are invited to walk the first lap in a group, wearing this t-shirt that shows that they are fighting cancer. By wearing it, they display their struggle, their fight against cancer and they declare themselves as belonging to a special fellowship – not only the “happy self-trainers”, but also the larger group of cancer survivors and fighters. In the evening, there is a so-called “light ceremony”, where every participant in the run event can light a candle in a paper bag and write a message on the bag. The messages can be in the form of “Never give up, dad” or something else to encourage their relatives, or it can be a thought in remembrance of a beloved one who has passed away.
Fellowship – connectedness in a caring atmosphere
This final theme describes how the participants experience a sense of connectedness. It also
describes how these experiences seem to be of vital importance in terms of the reasons why
the participants attend this form of training, as an alternative to fitness centers or sports
clubs.

The friendship, which seems integral to the training activities, is exceptional. The self-
training is characterised by a special form of unity. Everyone is welcome, and everyone is
equal, which is described in this story:

The title printed on your business card is of no importance here. It doesn’t matter if you are doc-
tor-this or director-that. The individual human being is in focus. Nobody is concerned about your
profession, your social status, gender, age or anything unimportant. We don’t have snobbery in the
group. There is no hierarchy, maybe because it is not necessary. We all come here with our different
strengths and weaknesses. As a participant, you are automatically included in the friendship.

The participants pay a lot of attention to each other during the training. If one is sad,
someone takes care of that person. This attentive attitude is a core element of the friend-
ship. When participants are too weak to attend the training, someone pays them a visit. If
they cannot get to the training by themselves, someone offers them a lift. If they turn up but
cannot go through with the training, they just sit down to have a cup of coffee, a talk, and
some company. In that way, everyone has the opportunity to remain a part of the commu-
nity, even if they are too sick to be physically active. Even though someone is too weak to
take part in the training activities, they remain included in the group. This form of caring
appears from the following story:

There is such a caring atmosphere in this place. If someone can’t come here by himself, someone
else will pick him up from home. We are sure that someone will step in to support you if you need
help. We share our phone numbers. If you send a SMS to say that you are not feeling well, someone
calls you to ask what you need, or someone brings a bunch of flowers or just pays a visit to have a
talk. I know for sure that, if I have a relapse, I will get help. There will always be someone to have a
word with, and that is great. That is the spirit here. We care for each other. It means a lot to me.

Friendship is the driving force in the participants’ motivation. During the training, they
courage one another to keep going, to do a bit more. A special characteristic of the train-
ing activities is the warm and welcoming atmosphere as well as the safe environment. They
make newcomers feel welcome, so that, before long, they feel part of the group.

In principle, the training is self-guided. Nevertheless, it seems to be quite important that
one of the patients takes the lead in the group sessions, acting as a kind of a coach. When
the coach is absent, someone else takes over. It seems to be a desirable arrangement, as one
of the participants said: “If we just turn up at the training and start to discuss what to do
today, it will result in complete confusion. Therefore, we are happy that someone takes the
lead and cracks the whip over us.”

The participants go for the self-training as an alternative to a fitness center or a sports
club, which is described in this way:

Everybody here struggles with cancer and is familiar with physical complications as well as fatigue
and sadness. You would not want to start a conversation about your feelings or illness with a com-
plete stranger in the fitness center, would you? In a fitness center you are on your own. Nobody
cares if you are there. In a sports club, of course, the coach and the teammates will notice if you are not there or if you are not well. However, in sport you will be an outsider if you can’t accomplish the training session. Here, as a self-trainer, you are an insider no matter what. In addition, people here have the courage to talk about these things.

The three brief stories above seem to represent the core meaning of the fellowship. The participants experience and value a fellowship characterised by equality, care and concern, and the feeling of being an insider no matter what strengths or weaknesses they bring.

Discussion

Our study shows that cancer patients experience that self-guided physical training has an impact on their physical condition and provides other physical benefits, which is in accordance with existing research (2,8,18). In addition to the physical perspective, social aspects seem to be of great importance, which is also the case in an Australian study (19). As opposed to Spence et al. (2), who find that cancer patients prefer individual training supported by their own supervisor, the participants in our study experience a sense of security and social support by being part of a group. Adamsen et al. (3) found that cancer patients prefer to participate in supervised, structured group training, compared to exercising at home on their own. Our study supports the benefits from group-based training led by a kind of a coach but adds that this leadership role can be adopted on voluntary basis. Our study also supports the findings from Adamsen et al. (3), as regards to the meaning of belonging to a group in which the group members expect the participants to show up. The cancer patients who attend the self-guided training find joy and happiness in being together both during and after the training session. They experience growing social relations, which means that someone cares for them, and recognize the situation when one is feeling down. A Danish study concludes that training-based rehabilitation is a way to achieve physical, mental and social well-being (4). From the holistic perspective, attention can also be paid to the spiritual/existential dimension. A holistic perspective is included in another Danish study, which finds that involvement in daily practical activities creates opportunities for aesthetic enjoyment (20). It enables appreciation of life in spite of living with incurable cancer. La Cour & Hansen (20) find that engagement in daily activities enables aesthetic enjoyment and is essential to create meaning in life. In our study, we recognize the importance of aesthetic enjoyment in the form of a peaceful atmosphere and the social fellowship. Appreciation of life is recognized in the form of joy, happiness, and gratitude for being involved in the self-guided physical training, both as regards the training itself and the social contact.

Taking part in this kind of training provides an opportunity to create meaning in life in spite of a serious disease. To elaborate on the cancer patients’ lived experiences from an existential perspective, we can draw upon the work of the Swiss psychiatrist Medard Boss, who provides an existential foundation for medicine and psychology (21). Boss describes seven fundamental characteristics of human beings – also termed fundamental traits or existentials – as illustrated in Fig. 1. These seven existentials are disrupted or restricted by illness and, according to Boss, affect the existential freedom of the human being.
To the participants in this study, despite their cancer disease and its consequences, in the form of discomfort and adverse effects, participating in self-guided physical training has a positive influence on their body in that they experience tangible improvements. According to Boss, the body can be perceived as a whole, and physical and mental aspects of the body are not separated dualistically (21). This understanding of a whole body can be recognized in the participants’ experiences of training. Both their experiences of physical improvements and of fun and laughter bring vitality to their life situations and contribute to their efforts to unfold life. Even though the existentials are affected by cancer, the patients experience that they can unfold their lives through their bodies. Boss (21) uses the word body as a verb as well as a noun. As a verb bodying forth means that the person, bodily, with all his senses reaches out for the world. Bodying forth is a way of unfolding life in an openness towards the world. The self-guided physical training is a way to get an experience of co-existence. The experiences of fun and laughter are not only connected to physical activity but also to the atmosphere as a possibility to enhance the lived attunement, which is characteristic for the social fellowship among the participants. According to Boss, this atmosphere or the so-called space embraces a relational and sentient being. To use Boss’ terminology, the participants are living in a shared world (21). They experience that the self-guided physical training creates a space that accommodates everyone. No matter how the cancer disease affects the patients’ lives, they experience in different ways that they can unfold their existentials in this room. The room creates a possibility for a shared world where the cancer patients play a role in each other’s lives.

When the cancer patients describe benefits of the training, they compare their present capacity with what they could manage before they attended the training. In terms of Boss’ concept, the cancer created a disruption in the patients’ lives. Concurrently with the treatment, they experienced bodily restrictions, which also affected their social lives. During the self-guided physical training, new opportunities appear. The future embraces different things to hope for as well as realistic expectations of further decay of the body and an ines-
capable forthcoming death. The self-guided training creates the opportunity to unfold life in spite of restrictions to the existentials caused by the cancer.

**Strengths and weaknesses**
The strength of the study is the narrative approach to the interviews, which resulted in a solid body of data in the form of first-hand descriptions of experiences. Furthermore, based on a rigorous analysis, we found the non-fiction stories to be suitable vehicles to extract and describe the characteristics of the patients’ lived experiences. The participant observation and informal conversations conducted represent weaknesses in the study. Informal conversations provide spontaneous descriptions of the immediate experiences of the training sessions – for which reason more conversations could have been desirable. Another weakness relates to gender. All the participants were women. Since the self-guided physical training is for both women and men, it would have been relevant to conduct narrative interviews with men as well, and the lack of their inclusion may have had an impact on the data.

**Conclusion**
The most specific experiences of attending self-guided physical training are characterized by a variety of physical benefits. The participants experience better physical condition, reduced fatigue and more energy for daily activities. The improvements are a motivating factor to keep up with the training. In addition to the physical benefits, the participants experience belonging to a fellowship where they can share their experience of being cancer patients. The fellowship creates a shared world for the participants in which joy, fun and laughter are vital elements, and everyone embraces each other’s input, whether the subject is about cancer or everyday life. The results show how self-guided physical training as conducted at Life Space helps cancer patients to create meaning in life and that it is a way to attain existential freedom. The training has an impact on the participants’ lives as a life-unfolding activity that appears in the way they refer to themselves as “The Happy Self-trainers”.

Since this study apparently is the first to describe cancer patients’ lived experiences of participating in self-guided physical training, further studies are needed to expand on the description of these experiences, and to elaborate on the meaning of the life-unfolding phenomena that emerged in the analysis. We recommend gender perspectives as well as more extensive participant observations to be considered in future studies.

**References**


