The Recovery Process When Participating in Cancer Support and Rehabilitation Programs in Sweden

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Abstract
The aim was to illuminate the meaning of participating in support and rehabilitation programs described by people diagnosed with cancer. Nineteen persons were interviewed in focus groups and face-to-face. Data were analyzed with a qualitative phenomenological hermeneutical method for researching lived experiences. Interpretation proceeded through three phases: naive reading, structural analysis, and comprehensive understanding. Three themes were disclosed: receiving support for recovery when being most vulnerable, recapturing capabilities through supportive activities, and searching to find stability and well-being in a changed life situation. Participating in the programs was an existential transition from living in an unpredictable situation that was turned into something meaningful. Recovery did not mean the return to a state of normality; rather, it meant a continuing recovery from cancer treatments and symptoms involving recapturing capabilities and searching for a balance in a forever changed life. This study provides new insights about the experiences of participating in cancer support and rehabilitation programs.

Keywords
cancer, lived experience, rehabilitation, resilience, research qualitative, suffering

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Introduction
Overall survival in European countries has improved for all people diagnosed with cancers and for the major cancer sites. Survival increases might be attributed to the development of prevention in the form of screening programs, cancer-service infrastructure, and increased access to innovative treatment (Verdecchia et al., 2007). However, once treatment is completed and the disease is cured, the consequences of cancer disease continue to be substantial for patients and families, and the need for rehabilitation may be extensive (Hellbom et al., 2011). Participating in rehabilitation and support programs may reduce anxiety (Granström Björnekelett et al., 2012), but psychosocial interventions seem to have short-term benefits to well-being (Parahoo, Norman, McCaughan, Humphris, & Mills, 2013). The effectiveness of psychosocial support is strengthened in improving cancer symptoms and emotional well-being (Matsuda, Yamaoka, Tango, Matsuda, & Nishimoto, 2014). In many cases, a person’s rehabilitation needs are not met by the health care system or fully utilized by themselves or their relatives (Cheville, Kornblith, & Basford, 2011). It is important to identify and understand how people diagnosed with cancer experiences the consequences for that person of participating in rehabilitation and support programs.

Background
A multidisciplinary support and rehabilitation care team comprising different members may address the innumerable impairments affecting cancer survivors’ function (Silver, Baima, Newman, Galantano, & Shockney, 2013). To fulfill the patient’s and indeed the family’s needs, continuing...
rehabilitation is suggested to be an integral and continuous part of cancer care (Baili et al., 2013; Hellbom et al., 2011). From a global as well as a national perspective, there is a large difference in people's access to rehabilitation. If rehabilitation is offered, it is provided by many different actors, for example, hospitals, cancer societies, and private rehabilitation organizations, or at community level, informally in families and networks (Baili et al., 2013; Berg et al., 2014). Based on nine support and rehabilitation programs in Sweden supported by non-profit organizations, three types of programs were identified: multimodal rehabilitation (programs providing a broad range of combined therapies), comprehensive cancer support programs (providing a combination of a few therapies including single body-based therapies), and single therapy programs (offering support by means of one specific therapy). The multimodal and comprehensive programs offer a variety of activities and therapies such as baths and physiotherapy, as well as psychosocial interventions such as health education, which were highly valuable and relevant for participants (Berg et al., 2014).

Psychosocial rehabilitation may involve cognitive behavioral, psychoeducational, supportive, and counseling interventions, and should be facilitated by trained or lay personnel to improve quality of life, self-efficacy, and knowledge, and reduce distress, uncertainty, and depression (Parahoo et al., 2013). For patients diagnosed with cancer participating in support groups, there were significant improvements in their emotional state, illness adaptation, as well as marital relationships (Zabalegui, Sanchez, Sanchez, & Juando, 2005). Exercise may have beneficial effects on health-related quality of life domains including cancer-specific concerns (e.g., breast cancer), body image/self-esteem, emotional well-being, sexuality, sleep disturbance, social functioning, anxiety, fatigue, and pain at varying follow-up periods (Mishra et al., 2012). Pain, musculoskeletal issues, deconditioning, fatigue, balance, psychosocial issues, and lymphedema are most amenable to rehabilitation (Silver et al., 2013). Programs that comprised participants with different types of cancer compared with cancer site-specific programs were more likely to show positive improvements in bodily outcomes (Scott et al., 2013).

Along with health professionals, families and friends often play a central role in providing support (Chambers et al., 2013). Sharing cancer experiences and strategies in a rehabilitation program are experienced as useful for people diagnosed with cancer and their relatives (La Cour, Ledderer, & Hansen, 2014). In general, cancer survivors benefit from support group participation, but few patients attend such groups. However, younger women who attended used more active, adaptive coping strategies and felt more control over their cancer, and at the same time, they were more distressed and anxious (G. E. Grande, Myers, & Sutton, 2006). Patients with diverse diagnoses of cancer associated participation with low level of support and negative feelings about the benefit to themselves. They wanted more attention and encouragement from health care professionals, and more appreciation of their strength and capabilities (G. Grande, Arnott, Brundle, & Pilling, 2014; Rotegård, Fagermoen, & Ruland, 2012).

There are only a few studies describing experiences of participating in support and rehabilitation programs. One qualitative study found that a sense of spirituality was perceived as related to a transpersonal entity that transcends the self and extends beyond spatial-temporal boundaries. This was experienced as an empowering and supportive resource and perceived as significant for the person’s healing and survival (Assing Hvidt, Raun Iversen, & Ploug Hansen, 2013). The meaning of persons diagnosed with cancer experiences when attending support and rehabilitation programs needs to be further explored and not limited to cancer survivor’s experiences. Furthermore, the current body of knowledge is also limited concerning persons with cancer and their experiences in the transition between medical care and how the community supports their rehabilitation process and support needs after attending a support and rehabilitation program. To gain more knowledge in this area, the present study focuses on experiential outcomes of cancer support and rehabilitation programs.

Aim

The aim was to illuminate the meaning of participating in support and rehabilitation programs described by people diagnosed with cancer.

Method

This study used a phenomenological hermeneutic approach, and interviews were conducted with the purpose of generating rich descriptions of participants’ lived experiences, which we have little knowledge about. The authors of the study have comprehensive experience of generating and analyzing qualitative data. All the authors are registered or specialist nurses with a PhD and have cared for patients with cancer and their families, in different phases of the disease in different contexts. None of the researchers has experience of working in support and rehabilitation programs.

The study was approved by the Regional Ethics Review Board in Gothenburg (Ref. 228-13). Ethical considerations were guided by and adhere to the World Medical Association Declaration of Helsinki (1964).

Setting and Sample

To constitute a purposeful sample of participants, managers responsible for non-profit support and rehabilitation programs were contacted by letter. The managers then asked participants who had completed a program whether the research group could contact them. Twenty-three participants gave informed consent to be approached by email and
Table 1. Background Data of Participants.

| Characteristics                  | Number of Participants (N = 19) |
|----------------------------------|---------------------------------|
| Gender                           |                                |
| Male/female                      | 4/15                            |
| Cancer diagnosis                 |                                |
| Breast/prostate/gastrointestinal | 10/2/3                          |
| Others (lung/sarcoma/brain)      | 4                               |
| Metastases                       | 2                               |
| Other health problems            |                                |
| Arthritis/angina/relapse new cancer |                            |
| Fatigue/depression/short memory | 10                              |
| Median age in years (range)     | 55 (41–74)                      |
| Married/not married              | 13/6                            |
| Children living at home ≥18 years of age | 13                          |
| Education                        |                                |
| Senior high school/university    | 6/13                            |
| Having someone to talk within the family/outside the family | 16/18                          |
| Gainfully employed               | 11                              |
| On full sick-leave, old age pension, unemployed, or working part time | 13                             |

telephone, and 19 women and men accepted participation. Those who did not take part (n = 4) had planned a vacation at the time of the interviews, or their email addresses and telephone numbers did not work. Those included had undergone cancer treatment, some had a metastasized cancer, and others were survivors and participated for at least 1 week in two different structures of support and rehabilitation programs. One program was classified as multimodal, and the other as comprehensive (Berg et al., 2014). Four focus groups with a median of four (3–6) participants and two individual interviews were completed in rural and urban regions in the south and north of Sweden. The focus group interviews were completed in different settings: at a university, at a conference hotel, and at a hospital. Individual interviews were performed as this was most convenient for these participants. Background data of participants are described in Table 1.

Interviews

The focus groups (Krueger & Casey, 2009) and individual interviews were completed in 2013. Two researchers were present and carried out each focus group as moderators. The main interview question was as follows: Please describe your most significant experiences of participating in the rehabilitation and support programs. The participants related to the meaning of participating during the interviews, and they talked, listened, and triggered each other when reflecting on demanding experiences during illness and rehabilitation. Before the key question, opening and introductory questions were asked to provide the participants with an opportunity to tell the others about themselves. After the key question, transition and concluding questions were asked, for example, what the participants thought had been the most important issue during the discussions. While interacting in the focus groups, the participants created their personal narratives and the conversations not only emotionally affected them but also touched the interviewers. The focus groups lasted about 90 minutes and the individual interviews about 20 minutes. All interviews were audio recorded and transcribed verbatim.

Analysis

Applying the phenomenological hermeneutical method for researching lived experiences, the data were analyzed in a movement between the parts and the whole, explanations and understanding. The process followed three interrelated phases: naïve reading, structural analyses, and comprehensive understanding (Lindseth & Norberg, 2004; Ricoeur, 1991). The individual interviews were analyzed separately from the focus groups. The narratives from these individual interviews were compared with the narratives from the group interviews about the meaning of lived experiences and were included in the analyses if they confirmed or brought another meaning to the text as a whole.

Naïve reading. To attain an immediate understanding of the meaning in the focus groups, the transcriptions were read several times, while simultaneously listening to the audiotaped recordings. This was performed with an open commitment to obtaining a general holistic sense of how participants experienced participating in support and rehabilitation programs. The naïve readings gave a first impression of what the text was about with the intention of capturing the meaning of participation.

Structural analyses. The transcribed text was extracted into meaning units that described the meaning of participating in the programs. The units were condensed and reflected upon. Subthemes were grouped together into themes and abstracted with the aim of revealing the meaning of participation. Questions raised during the naïve reading about the meaning of participation, about different activities, and about participants’ learning processes were explored throughout the structural analysis. These questions were a support when explaining the meaning structure of the text (Sander Dreyer & Pedersen, 2009) by means of moving from surface and simplicity of the text to its depth and complexity.

Comprehensive understanding. To reach an interpreted whole, the naïve reading and the structural analysis of the phenomenon under study were taken together. The meaning of the studied phenomenon as narrated by individuals of different ages and genders living in rural and urban regions of Sweden was explained by subthemes and themes...
revealed. The themes were interpreted and reflected on in discussions with all authors, resulting in interpretations of possible meanings of participating in support and rehabilitation programs. Finally, as an aid to broadening and deepening our understanding, a critical interpretation and discussion of the text was completed related to pre-understanding, the aim of the study and research questions, as well as related literature.

Findings

Naïve Understanding

To understand the meaning of participating in support and rehabilitation programs, it was important in the naïve reading to interpret the text in relation to the participants’ narrations of earlier experiences of cancer illness. To be diagnosed and being treated for cancer involved a need to reflect on a changed life situation, on being a cured person as a whole and the transitions this involved. Despite having finished treatment, symptoms such as fatigue and anxiety were present, and there was a struggle to find stability in everyday life. The participants emphasized a sense of being bodily, emotionally, and existentially different. The participants argued that the cancer care regimens had failed to respond to their needs of rehabilitation, and the support and rehabilitation programs became a lifeline. Participants expressed a need to reflect and make sense of the situation before attending the programs, to be given enough care and time to recover from the disease and treatment, and to find ways of redirecting their lives.

Structural Analysis

The structural analyses were disclosed by three interlinked themes and seven subthemes (Table 2). These themes are illustrated by quotations describing the focus group (F1–4), individual interviews (I), or the participants (P1–6).

Receiving Support for Recovery When Being Most Vulnerable

Overcoming life-threatening illness. The participants described that undergoing treatment for cancer for a longer period of time had been difficult, and strains such as mental and physical fatigue had been a barrier to a normal functioning life. A feeling evolved that existential attitudes toward life had changed and that it could never be the same again. Participants also admitted that they had thoughts of death and asked themselves serious questions such as, “How long have I got left?” Some participants envisioned reprimands that their cancer was caused by improper lifestyle, a stressful life, and that long-term problem in relationships influenced the development of the disease. Although still motivated to overcome their cancer, participants did ponder questions such as, “What happens next?” The hope of getting well strengthened the desire to continue living, and some participants described that when the news came that they had overcome the disease, it was an indescribable feeling: “I was walking on my lit track as I had loads of times and I just shouted, YES! I did it” (F4P2).

The return to work was a challenge in relation to social insurance regulations and requirements of work that could not be fulfilled. In addition, participants perceived that the cancer care failed to adequately respond to their actual needs of care, and post-treatment assistance with other forms of support was perceived as limited. The participants described a need to be left alone in silence and tranquility, needing “time to land and find strength,” which they hoped participation in the support and rehabilitation program would offer.

Breaking up and getting oneself together. Bringing new nuances to life and having a break from routine procedures was described as an opportunity supported by the rehabilitation programs:

Before you can recharge with something new, positive you have to break up with the old shit. In the beginning there were a lot of opportunities to talk about what had been difficult and the disappointments. (IP1)

Participants described that to leave difficult illness experiences behind, they needed support from the rehabilitation programs. They had decided and were willing to actively influence their life situations and to set aside time for recovery. This involved taking care of themselves and being in the moment in a process that was possible to influence, and when attending the program, having time to consider the question, “What should I do with the rest of my life?”

Having an open approach and striving to be involved, listening, and being curious about other people’s experiences of cancer was described as a necessity and a support in the

| Table 2. Subthemes and Themes Disclosed in the Structural Analysis. |
|-----------------------------|-----------------------------|
| Themes                      | Subthemes                  |
| Receiving support for recovery when being most vulnerable | Overcoming life-threatening illness |
| Recapturing capabilities through supportive activities | Breaking up and getting oneself together |
| Seeking stability and well-being in a changed life situation | Reconsidering the body to regain autonomy |
|                             | Sharing and letting go of suppressed emotions |
|                             | Balancing self-care advices in daily life |
|                             | Re-evaluating family relations |
|                             | Exploring alternative supportive platforms |
attempts to get oneself together. Participants felt it was important to meet with other people with cancer who looked healthy, leading to an increased interest in these people who were so deeply talented at dealing with life. There was a willingness to learn new things, get help to break old habits, and discover new things about oneself as a person to experience well-being and security. In their encounters with other people, participants felt strength and knowledge were conveyed through the conversations.

We were ordinary bodies wearing our own clothes and we were outside; it was spring so there was fresh air and it was so amazing to see how quickly, if we are talking rehabilitation, how fast it actually affects a kind of healing in that I personally see myself among others who have a lot of cancer inside, but we all look like we are pretty healthy. We get together and see what we can make of our lives while we have cancer. Relate ourselves to everything and relate to ourselves. (F2P6)

In a restorative environment, where the starting point was health, it was possible for participants to invest in themselves and in life, which contributed to joy and inspiration. They were also able to calmly probe their limitations and opportunities, cry, harbor negative feelings, and show weaknesses.

**Recapturing Capabilities Through Supportive Activities**

**Reconsidering the body to regain autonomy.** Taking part in rehabilitation activities was perceived by participants as a means of receiving support, guidance, and tools at a time when their bodies lacked energy, and they had limited ability to take their own initiative. There was a need to re-create the approach to oneself and to see oneself as a healthy person. To meet these requirements, the tools that the rehabilitation programs offered were healthy food, physical activity, one-to-one or group conversations, and an exploration of what promotes well-being and recovery of control of the body.

The participants stated that trying new activities contributed to a sense of freedom, enhancing a sense of their own ability and exploration of limits in terms of what the body could handle. Having dedicated time to do physical activities or other things like a relaxing massage or an unhurried morning swim was perceived by participants as almost a spiritual experience. Having a choice of several activities gave the participants the feeling of having a buffet table of experiences:

But I, I thought it was super. I’m very happy with all the stuff in principle, apart from that annoying laughing session (laughs out loud). (F3P3)

I didn’t have anything like that. (F3P1)

No, yours was a little different. While I was there, there was a group doing mindfulness so that was going on at the same time, and then there were this kind of laughter therapy. (F3P3)

Yes, but didn’t you like it? (F3P2)

No. (F3P3)

**Sharing and letting go of suppressed emotions.** The therapeutic dimension of the programs gave participants a straightforward way of opening up, not only in terms of how they were living but also in awareness that there was a life beyond the cancer experience. Sharing one’s story with like-minded people and listening to the others’ stories could be a powerful experience, which was sometimes difficult to process. “We sat there and listened, and my goodness, the pain everyone had gone through and so on. And then it somehow released and then it was wide open these last few days and very responsive” (F1P1).

Talking to others who were in the same situation and understood what it meant to have cancer was emphasized by the participants as a real benefit. Through dialogue, they exchanged perceptions about the meaning of living through cancer and, in this context, explored experiences that helped them listen to themselves. “And I have to say, I’ve learned so much about life after I got sick, so I am grateful indeed” (F1P4).

Yes that you have the need, not to become so trapped with all of your experiences and thoughts and such. Because . . . at work or among friends, it’s not that popular if you talk about it, or it’s almost impossible. So I think it’s great that I found it [the program] and that I could both meet and listen to others and be close and talk myself. (F1P5)

The participants described that they did not need to cry about themselves but to cry with others, letting go of all their stored up feelings, making them stronger and giving meaning for participation. The activities in the rehabilitation programs mediated affection, confidence, and hope, and were a support for the participants, providing strategies for living a healthy life after they were completed.

**Seeking to Find Stability and Well-Being in a Changed Life Situation**

**Balancing self-care advices in daily life.** The participants stated that when they returned home after completing the program, it was difficult to achieve a life balance, and some said that it was difficult to follow advices on self-care regarding diet and exercise. Seeking to maintain balance was described as a struggle involving emotional suffering relieved from the time of cancer diagnosis. It was difficult to integrate a balance into everyday life, and it was a personal responsibility, which involved changing daily routines concerning diet and exercise, combined with managing a full-time job. Some participants said they perceived the situation as “serious” because the risk of relapse was present. This was offset by living as healthy and active as possible, which involved strictly following self-care
advices and, for example, just eating vegetables and excluding red meat and exercising regularly to build up the immune system. Despite a positive attitude toward changes of lifestyle, participants sometimes had feelings of anxiety as to whether they could cope with the challenge of changing their habits, as the food sometimes tasted different from the food they were used to.

You eat vegetarian food and yes, all possible combinations of food and all those little white juices and shots. (F3P1)

It’s so extreme, right. Extreme. (F3P3)

Potato water. (F3P1)

Yeah, exactly. (F3P3)

Yes, I have . . . (F3P2)

It is very extreme. (F3P3)

Having reassessed their lifestyles, participants described it as a failure if they did not reach the targets they had set, and feelings of guilt were created in the presence of a burdensome fatigue that contributed to increased stress. Participants emphasized going to work every day but then admitted that the strength and desire to accomplish other activities diminished due to the struggle in overcoming fatigue. They described an uncertainty about how long their bodily strength would last and had to strike a balance and act appropriately.

My thinking is this: I’ll probably just go for it. So it’s got this way again unfortunately. I push at it at work as usual, although I’m really tired and it’s like I can’t do anything other than just work and just . . . I can just work. Now I do have time to for a little exercise and that, but everything else I just have to de-prioritize but you might as well feel that you don’t know like, I feel a lot like this, how long you have left and I, but I don’t know if I’ll come out of it like. I can’t say . . . my daughter said, but you could resign? Yes, it’s easy to say that you should resign, but you can’t quite do that either. (F3P3)

What to do instead then? (F3P2)

Yes, then there will be other problems instead. So I mean no, it’s not that simple. I haven’t worked for this many years to then quit at the end, no I won’t do that. No, I would never do that. But it’s really hard to strike a balance, it’s very difficult. (F3P3)

Re-evaluating relations with family. The home and family were described by the participants as providing security, and the support of relatives and friends gave meaning to life during the recovering phase. It was a comfort to talk and cry with loved ones, but the participants found it difficult and sad when they did not have patience with their children or relatives. One of the participants’ big concerns was that the family would collapse if a relapse occurred and that small children in particular needed them at home. Couples who had participated together in the rehabilitation programs described how this changed the understanding of their partners and that they saw them in a new light strengthening the relationship.

Now I was there on a course for couples and I thought it was so great to hear, now it was just the women who had cancer, who were there then, but the men talked about their . . . So it became very . . . I got a completely different understanding of my husband, but then God . . . how they . . . they really love their partners, and really do everything and it became very clear. You become very open and all that. (F1P1)

Yes, and I also think it’s very important that it’s not just them here, instead you have to go there as a couple. I mean how you become in a relationship when . . . It was great. My husband also thought it was great. (F1P4)

The participants said bringing knowledge about self-care practices and inspiring the family to live a healthier life became integral to their new lifestyles. They wanted to share their stories of participation in the rehabilitation program with the entire family, revisiting the place where it was held and showing the family the beautiful restorative environment, thus encouraging the family to change their own self-care habits.

Exploring alternative supportive platforms. The participants described a desire for continued contact with other individuals who had lived through cancer. They searched for organized support outside of health care, creating opportunity for more frequent face-to-face meetings with others in the same situation. It was likened to having an extra family who knew about and understood the complex situation entailed by having lived through cancer. Sharing thoughts about life and death and other spiritual and existential issues was perceived by participants as natural and positive.

Telephone and email was described as a support in maintaining contact and was especially valuable in case anyone was re-diagnosed with cancer. Exchanging experiences with persons with cancer also led to participants searching for different groups on social medias (e.g., Facebook) or developing their own blogs or websites, where the effects of therapy, life, and death could be discussed.

On Facebook, I got a lot of people interested in what I had done and I got a lot of support through Facebook. They asked me to define the feel of cancer, they examined themselves and found their own cancers, so three people have discovered their cancer through my site. (F2P3)

The participants felt it was significant that after some time, the number of such groups decreased as members died. This was a reminder of one’s own death and mortality. During illness, existential, spiritual, and religious issues
arose, and for some, the church congregation became a life-line in the various adaptations of losses and grief.

**Comprehensive Understanding**

Participating in a support and rehabilitation programs for people diagnosed with cancer provides opportunities of receiving personal support for the recovery when being most fragile. The support increased the participants’ sense of well-being and meaning, bringing renewed nuances to life and providing a break from ordinary routine procedures. In this way, the participation paved the way for recapturing capabilities through supportive activities through reconsidering the body to regain autonomy and sharing and letting go of suppressed emotions with like-minded people. Furthermore, recapturing capabilities involved searching to find stability and well-being in everyday life through balancing challenging self-care advises, re-evaluating relations with family, and exploring alternative supportive platforms. We interpreted that participating in support and rehabilitation programs was an existential transition (Meleis, 2010) from being in an unpredictable and incomprehensible illness situation to creating meaning (Frankl, 1986) in a forever changed life situation. It was interpreted as a willingness among participants to leave difficult illness experiences behind transforming unpredictability into something meaningful using new strategies to live a different life. That is, recovery did not mean the return to a state of normality as life could not be the same as before participants were diagnosed with cancer. Rather, it meant a continued recovery from long-term cancer treatments and burdensome symptoms involving recapturing capabilities and reassessing a former lifestyle as well as a struggle to find bodily, emotional, existential, and social well-being in everyday life.

**Discussion**

The participants described that receiving support when being most fragile involved loss of function and values, which hindered their ability to handle their existence, which has also been found by Ferrell and Coyle (2008). The participants described an existential transition that could be explained as being in an unpredictable or meaningless situation to finding meaning in life. According to Yalom (1980), meaninglessness forces humans to create meaning when life is transformed. Frankl (1986) states that there is no meaning in life while suffering unendurably, but it can be both endured and transformed if the person experiences a possible meaning of change in the future. Meleis (2010) describes transition as involving critical turning points and personal response patterns that may facilitate or inhibit the transitional experience. In this study, participants described a transition involving suffering, and joining a program may have been the turning point that facilitated this transition in the recovery process.

The participants in our study described breaking up with the past and getting themselves together in the sense of rebuilding life. This process was supported by the individual and group activities in the rehabilitation programs by exploring bodily functions, capabilities, and affirming emotional needs. According to Slade (2009), supportive interventions involve developing relationships, promoting well-being, providing treatment, and coordinating social networks.

Being together and connecting with like-minded people became a frame of reference for sharing suppressed feelings and strengthened the participants’ trust in personal abilities and resources. Communicating on a one-to-one and group basis and listening to others, as well as exchanging, confirming, and affirming experiences, provided strategies for how to go on and live a meaningful life. Personal strength is a crucial factor in making sense of the cancer experience and having a sense of control, and becoming an active partner in care and recovery has been described by Rotegård et al. (2012). Becoming visible as a person through one’s life story, being exposed to other people’s attitudes to cancer, putting words to cancer, and talking about the disease brought a sense of freshness. It supported the picture that self-value was under recovery and progress, and helped the participants feel as though they were people with a current existence. Another study has found that group-based cognitive rehabilitation intervention in cancer survivors was effective for improving attention abilities and overall quality of life related to cognition (Cherrier et al., 2013). Peteet (1982) argues that support includes sharing emotional burdens, strengthening and caring about others, maintaining independence, and putting other people’s interests in focus.

Seeking stability and balance in a changed life situation was necessary while and especially after participating in rehabilitation programs because responsibility for self-care in daily life had changed. The participants described that it was about finding your identity and being conscious about your personal qualities, overcoming cancer diagnosis, and instead focusing on life as a healthy person. Being conscious about your personal qualities was described in a study as empowering and supportive during rehabilitation, and perceived as responsible for survival (Assing Hvidt et al., 2013). This may also mean that even if it was a struggle to find stability in daily life, this suffering was alleviated, and discovering new personal qualities gave life meaning. Here, alleviation of suffering encompasses bodily, cognitive, social, and existential dimensions (Öhlén, Bengtsson, Skott, & Segesten, 2002; Öhlén, Wallengren Gustafsson, & Friberg, 2013).

The participants in our study stated that following advice about self-care practices and work at the same time could be a full-time job and that they simultaneously struggled with fatigue, and a fear of failure is a kind of suffering according to Svenaeus (2014). The participants described their routine as a template on which they were forced to live their lives to keep relapse of cancer at bay. Yalom (1980) describes this as
the conflict between freedom and responsibility. To avoid failure, participants lived by the template, which became a responsibility. Alone in their situation, they worried about failure increasing the risks of relapse. Not succeeding was a burden for some of the participants and increased stress levels. Living with the fear that the family would collapse if a relapse occurred was also a burden, particularly when thinking about their children. This may also be described as liminality, a concept describing the experience and insecurity involved in living with the risk of cancer recurrence that disrupts future plans and affects social interactions (Blows, Bird, Seymour, & Cox, 2012). Negative feelings and increased stress may also slow down the recovery process, although this may be balanced by support from family and other cancer survivors, for example, by joining online groups. Even if our participants felt this was a lifeline, they lived with the insecurity of their own mortality, coming to terms as they did with the deaths of other cancer survivors in these groups. According to Goldner-Vukov, Moore, and Cupina (2007), the recovery process seems to involve both setbacks and successes, and to handle this, persons diagnosed with cancer need coaching and consolation. The recovery process may be facilitated if existential issues are addressed by professionals, and the individuals themselves make changes for success.

The participants described attending support and rehabilitation programs as part of a process of change involving earlier illness experiences. They not only lived with the threat of relapse and struggled to maintain a balance in daily life but also experienced alleviation from the suffering. Morse and O’Brien (1995) consider it necessary for people to have the emotional strength to acknowledge suffering, including pain, helplessness, and insecurity on a bodily and existential level. Ricoeur (1992) describe that the person is recognized as an acting, as well as a suffering, and vulnerable person, and the question is if support and rehabilitation interventions encounter the person’s capability; strengthen the bodily, cognitive, and existential dimensions. Accordingly, support and rehabilitation interventions could be presented to persons diagnosed with cancer as recovery programs, indicating that they will be recognized as capable persons rather than individuals who need full rehabilitation. It is of importance to avoid applying the perspectives of those who rehabilitate and instead to proceed from the perspective of those who recover. In our study, recovery did not mean the return to a state of normality. According to Collier (2010), the medical model of recovery is to cure, and Whitley and Drake (2010) describe that recovery aims in reducing symptoms and returning to former levels of functioning. In our study, recovery for people diagnosed with cancer meant recapturing capabilities and reassessing a former lifestyle involving a suffering that was transformed into something meaningful using new strategies to live a different life. This is more in line with what Collier (2010) describes as “life recovery” that focuses on personal development and change. The meaning of recovery in cancer rehabilitation, specifically the transition of recovery for persons participating in support and rehabilitation programs needs to be further investigated.

Methodological Reflections

A limitation of the present study is that the managers responsible for the different programs selected the participants, and we do not know how this was actually done. All the participants included were satisfied with their participation in the support programs. We do not know if managers invited unsatisfied participants or if those unsatisfied did not give their consent.

In the discussions, all participants emphasized how they had struggled and continued to struggle to recover from the cancer illness. Despite this, they were quite relaxed in sharing and dialoguing about challenging experiences, which may be a consequence of being used to discussing these issues with other people who are diagnosed with cancer. Using an interpretative approach to the analysis was also a strength of this study and gave another understanding of the participants’ narratives, even if it was challenging to balance the interpretation and not under- or over-interpret the concealed meaning.

Conclusion

Participating in cancer support and rehabilitation programs involved a transition, that is, a continued process of recovery from long-term treatments and burdensome symptoms receiving support in a restorative environment with like-minded people, at the same time, being at one’s most vulnerable. The participants were ready to leave difficult illness experiences behind, transforming an unpredictable situation into something meaningful using new strategies in everyday life. Recovery involved recapturing capabilities and reassessing a former lifestyle as well as a struggle to find bodily, emotional, existential, and social well-being. Recovery did not mean a return to a state of normalcy as before the cancer rather, participants had to deal with an ever changed life situation. This must be recognized early by nurses and doctors in communication with patients during cancer treatment to facilitate the transition from medical care to support and rehabilitation programs. Future research may explore the effects of different support and rehabilitation programs measuring factors as quality of life, recovery, work ability, and self-esteem, which may become essential for guidelines concerning rehabilitation activities. Cancer support and rehabilitation interventions should perhaps be presented as recovery programs, and information about these programs should be provided by health care professionals.

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