

# Homeworld/Alienworld: a qualitative study about existential experiences after cancer treatment

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**Background:** As a group, cancer survivors experience significant vulnerability and existential challenges. The biomedical approach dominating health care is insufficient to meet such existential challenges in an individualistic, holistic way.

**Objective:** This study aimed to explore the existential experiences of those treated for different cancers.

**Methods:** An exploratory phenomenological–hermeneutical design was used to obtain an understanding of existential experiences after cancer treatment. Data were collected through in-depth interviews with 21 individuals who represented a purposive sample and were recruited from a cancer organisation.

**Results:** Three overriding themes emerged from the phenomenological–hermeneutical analysis are as follows:

Experiencing an unfamiliar tiredness; Experiencing not being fully oneself; and Experiencing a feeling of being alone.

**Conclusions:** Existential suffering after cancer treatment involves living on the edge of the old homeworld and the experience of a new alienworld. Individuals undergoing such suffering need a transformational process, from the alienworld to the homeworld, which must be supported by the healthcare system.

**Implications for practice:** To facilitate the transformational process, healthcare professionals should communicate with patients throughout their cancer journey about how their existential experiences have been integrated into their lifeworld, allowing them to tell their own story from the perspective of lifeworld brokenness.

**Keywords:** cancer survivors, existential experiences, lifeworld, lived experience, phenomenological hermeneutics.

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## Background

In 2016, an estimated 15.5 million cancer survivors were living in the United States, a number that is expected to increase to 20.3 million by 2026 (1). In Europe, more than 3 million new cancer cases are diagnosed annually (2). Early diagnosis and improved treatments have led to higher cancer survival rates. To date, approximately half of patients diagnosed with cancer will survive for 10 or more years (2).

With survival rates increasing, it is important to understand how individuals who have undergone cancer treatment live with the consequences of their cancer journey (3). Most individuals treated for cancer face a new reality, with dramatic changes in their life being shaped by

chronic late effects of treatments or enduring damage caused by chemotherapy, radiation, surgery, medications and other treatments (4–6). Side and late effects include physical, cognitive and emotional distress, including depression, anxiety, sleep problems, fatigue, impaired quality of life, and sexual and social struggles (4–6). Patients undergo transformational processes, experiencing changes that may negatively restrict their capacity in everyday life and greatly influence their perceptions of self (3–7).

The current approach to rehabilitation of individuals treated for cancer is predominantly grounded in biomedical discourse, rather than a lifeworld perspective (8). A biomedical understanding of the patient's situation is insufficient to meet their rehabilitation needs, because this approach cannot remove or remedy existential suffering and a sense of homelessness (8).

Culture and society typically refer to individuals living postcancer as 'survivors', pointing to a heroic journey. These cultural norms for illness narratives project the

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cancer journey as a dramatic struggle, which ends in either a biotechnological triumph over cancer or a tragic death (4, 9). Further realities of living after cancer treatment are also absent or treated superficially in extant research, reflecting a general lack of attention to lived embodiment in health communication (4, 10).

Many individuals treated for cancer lack long-term plans for their life. Undergoing cancer treatment involves a long recovery process, and those who experience late effects after cancer treatment report needing a complex rehabilitation programme (11). Hvidt (3) claims that living postcancer involves a liminal experience of having to navigate in a borderless and unfamiliar territory between a homeworld and an alienworld. According to Ellingson (9), there is a need to voice lived experiences after cancer treatment by sharing true stories and lived realities of late effects.

Previous research has described the cancer journey as bringing about a sense of lifeworld disruption. However, after cancer treatment, there seem to be existential difficulties in finding a firm footing in the sense of self, with individuals questioning their self-understanding considering who they were before the cancer and who they really are now; this is an area that should be further investigated. Based on previous research, we suggest that a lifeworld perspective might be fruitful for exploring the lived experience of life after cancer treatment and allow a better understanding of the existential journey individuals undergo and the unique challenges they face.

As such, this study aimed to gain an in-depth understanding of individuals' existential experiences of life after cancer treatment. This study was an attempt to move beyond psychological, psychosocial and pathological approaches, and instead visit existential concerns, which form the core of lived experiences.

## Theoretical perspective

The homeworld concept, described by the phenomenologist Anthony J. Steinbock to extend our understanding of lived experiences, is used herein to explore life post-cancer treatment. The homeworld is understood as an intersubjectively familiar territory in which we are 'at home'. The homeworld is always co-constituted through a so-called 'liminal' experience in which an alienworld is delimited (12).

Steinbock (12) explains how the two lifeworlds – homeworld/alienworld – relate to each other within an intersubjective structure that makes one constitutively dependent upon the other. The homeworld is taken for granted, while the alienworld is abnormal and unfamiliar. Steinbock emphasises that individuals constantly undergo a homeworld/alienworld transformative journey. This process of transformation relates to two modes of liminal experiences: 'appropriation' and 'transgression'

(13). Appropriation involves realising qualities of the homeworld by recognising particular alienworld qualities as different from those of the homeworld. By contrast, transgressive experiences involve encounters with the alienworld through which individuals recognise, and perhaps accept, the homeworld qualities of that alienworld. This can happen through two types of breaks or ruptures in the homeworld: a light break or a heavy break. Steinbock described such shifts in homeworld as a critical comportment that may entail the renewal of a homeworld where revitalising and renewing are attempts to realise the homeworld more fully. The liminal encounter is when the homeworld and alienworld meet, merging without losing the former. When the normal structure of our experience is challenged and restructured, resulting from a heavy break, it gives rise to a profound sense of incomprehensibility (12).

## Methods

An exploratory design was chosen based on a phenomenological–hermeneutical approach. A lifeworld approach is advisable when the field of research is complex and requires an in-depth understanding (14, 15). This approach attempts to be open to the lived experiences, by investigating the first-person perspective on the phenomenon (14). Dahlberg et al. (14) note that the lifeworld is the world of lived experiences, and lifeworld theory can help describe the existential world in which all humans live our daily lives. Lived experiences should be examined as the participants describe them, returning to the phenomena themselves (14). Kvale and Brinckmann (15) outlined an open lifeworld approach to qualitative research interviews. Based on this, we sought to introduce a lifeworld perspective focusing on how individuals who had been treated for cancer experience their lives. Our goal was to move beyond labels (e.g. depression, fatigue) and gain a better understanding of the existential situation experienced by the individual.

### Data collection

The analysis is based on a purposive sample, which was used to select information-rich cases through the best available resources. Participants were recruited from a Cancer Association, an organisation that provides support through conversation, counselling and guidance to those affected by cancer. The inclusion criteria were individuals who had completed cancer treatment, were in good current health and agreed to participate in an in-depth interview.

Potential interviewees were invited to participate in the study by the leader of the Cancer Association and were provided with written study information. Those who decided to participate contacted the first author by

**Table 1** Background information of the participants (N = 21).

Sex	Age (Years)	Occupation	Year of treatment completion
Male	28	Working	2016
Female	35	Working	2016
Female	38	Sick leave	2019
Female	40	Working	2015
Female	42	Working	2018
Male	42	Working	2010
Female	48	Working	2015
Female	50	Disability benefit	2017
Female	50	Working	2018
Female	52	Working	2015
Male	53	Working	2012
Male	53	Working	2016
Female	56	Sick leave	2016
Female	57	Working	2017
Female	57	Working	2009
Male	58	Disability benefit	2018
Female	60	Working	2017
Male	64	Retired	2018
Female	65	Disability benefit	2016
Female	72	Retired	2015
Female	72	Retired	2017

telephone, text message or e-mail to arrange an interview.

A total of 21 individuals – six men and 15 women, aged 28–72 years (Table 1) – who had undergone cancer treatment, participated in the study. The participants had different cancers and had undergone different treatments; on average, they had completed cancer treatment 4–5 years previously. One participant had completed their treatment during the previous year, and another 10 years prior. Though one participant had recently been informed that he had cancer metastases, he was included because he had experiences of life postcancer treatment.

A semi-structured interview guide, with questions that were neither too narrow nor fully open-ended, was developed to facilitate free reflection on the interviewee's own situation (15). The same interview guide was used for all interviews, and nuances were sought through follow-up questions.

Each interview began with a statement such as: 'Please talk about how you experience your life situation after cancer treatment'. Follow-up questions were aimed at uncovering thoughts and feelings in relation to what is most important/essential for living life now, according to the participant's actual situation, and how they handled life now to make it bearable. Each interview lasted 60–90 minutes and was carried out at the Cancer Association office. The empirical data material consisted of the interviews, carried out by the first author, which were recorded and transcribed verbatim.

### Data analysis

Text interpretation and analyses occurred at three levels: self-understanding, common sense and theoretical interpretation (15) (Table 2). The process of moving from understanding to interpretation occurs as a hermeneutical movement between the particular, the universal and the whole, wherein the interpreter cannot be fully aware of his/her own prejudices and preunderstanding (16). The researchers' preunderstanding involves the belief that existential phenomenon is important when struggling with health-related issues.

*Self-understanding.* The interviewer read the complete interview transcripts to grasp an intuitive initial holistic understanding, wherein fragments of significance emerged. The co-authors then participated in further readings, analyses and discussions to reach a common understanding. The first stage of interpretation was to identify the participants' self-understanding. Thereafter,

**Table 2** Examples of three contexts of interpretations

<i>Three contexts of interpretations</i>		
<i>Self-understanding</i>	<i>Common sense</i>	<i>Theoretical interpretation</i>
It is not like being tired in a normal way.	Experiencing an	Brokenness in a lifeworld perspective (Steinbock)
I never feel really rested, no matter how my night has been. It is a kind of powerlessness.	unfamiliar tiredness	
You have been kind of chewed on for a period in the health system, and then you get out, feeling entirely different, and everything is changed, physically and mentally.	Experiencing not	fully being oneself
I have not felt quite like myself ... I accept it, but I think it is annoying and unfair. Life is a challenge even when things are normal.	fully being oneself	
All my friends are acting as if nothing has happened, expecting me to be the same as before. They see me as the same, but I do not feel quite the same as before.	Experiencing a	feeling of being alone
'You are looking radiant'. But I notice that if I say 'Oh, it is so hard', it is as if people do not want to hear that, they do not want to believe it, because I do not appear to be suffering.	alone	

units of meaning were collected and parts that belonged together were arranged under preliminary headings.

*Common sense.* When identifying common sense, the participant's self-understanding was reinterpreted and restated based on their intended meaning within the context of a reasonable, universal understanding. All authors discussed the thematising of data as a circular process, moving back and forth between parts of the text and the text as a whole, until the whole and parts were unified (16). The units were systematised into intricately connected topics, and a new level of abstraction revealed three themes: *Experiencing an unfamiliar tiredness*, *Experiencing not fully being oneself* and *Experiencing a feeling of being alone*. All authors were involved in the discussion to enhance the interpretation. The abstraction process was performed as a collaboration among all authors, who searched for themes that covered the empirical materials. The first two levels of interpretation (self-understanding and common sense) are presented in the Results section.

*Theoretical interpretation.* The third level, theoretical interpretation, is based on relevant research and theories that may deepen understanding of the findings, and is presented in the Discussion section (15).

### *Ethical approval*

The project was evaluated by the Regional Ethical Committee and approved by the Norwegian Social Science Data Services (No. 2018/2278). Confidentiality was guaranteed, and the participants provided consent after receiving written information from the researchers. All participants were informed that they could withdraw from the study at any time without providing any reason. Steps were taken to anonymise the interviewees. All participants had access to professional support at the clinic, if needed.

## **Results**

The study findings represent an interpretation, based on the participants' descriptions of their existential experiences following cancer treatment. The thematised findings indicated *Experiencing an unfamiliar tiredness*, which was illustrated by descriptions such as 'exhausted and depleted' and 'impaired concentration and memory'; *Experiencing not fully being oneself*, which was illustrated by descriptions such as 'a palpable condition' and 'the challenge of accepting the situation'; and *Experiencing a feeling of being alone*, which was illustrated by descriptions such as 'being outside' and 'not being confirmed'.

The thematised findings illustrate the two levels of interpretation: self-understanding (quotation) and common sense (our understanding and interpretation of the

quotation). The third level of interpretation follows in the Theoretical Interpretation section.

### *Experiencing an unfamiliar tiredness*

All participants described a condition of 'tiredness' after completing their treatment. This tiredness appeared to be independent of the type of cancer, treatment or time since completing the treatment. Tiredness was a constant part of life, could sometimes strengthen and could occur as attacks.

*Exhausted and depleted.* A common characteristic of the tiredness condition was that it was difficult to explain how it felt. The participants struggled to find words to describe their own experiences. Several mentioned 'fatigue', but they found that the concept did not accurately describe their experience:

[14] I do not like to use the word 'fatigue', I do not want to use that label. I do suffer a lot from tiredness ... It is not like being tired in a normal way. It feels more as if your body – down to my little toes – only works 20%. It is as if my body is entirely depleted.

The participants experienced a condition of tiredness that the concept of 'fatigue' did not sufficiently describe. It was hard to find words for what they felt to be so taxing. They typically started by saying what it was not, because it was difficult to define. The respondents described the condition as comprehensive and challenging:

[8] I never feel really rested, no matter how my night has been. [11] It is a kind of powerlessness. [3] After my treatment was over, I felt I never got into a flow state. [15] There is only a vacuum. I am not functioning ... It is like old car batteries – If they were fully discharged, it was impossible to recharge them.

The participants stated that they lacked the strength to persevere, as they had in the past. With their energy and strength depleted, the only option was to isolate themselves and attempt to relax. The tiredness that they experienced after cancer treatment compelled them to slow down:

[3] On my day off, I wake up feeling so tired, empty, and unwell, as if I have been to a party ... I just want to be left alone on my own.

This state of tiredness is real and stressful to the highest degree. Feelings of exhaustion, a lack of energy and being depleted best described their experiences. The participants were never entirely rested, and repose did not help. To describe how they perceived their lives, they used exploratory language, saying that they struggled to find adequate words. They found the concept of 'fatigue' to be inadequate. The tiredness they were experiencing felt much more extensive. To describe it, the participants typically used metaphors such as 'a discharged car battery' and

'being in a vacuum'. Parts of the descriptions involved explaining what they were unable to manage. The condition they experienced appeared impossible to define.

*Impaired concentration and memory.* Most interviewees stated that their mental capacity had changed. Their mental processes were slower and life itself proceeded at a slow pace. They described this condition in various ways:

[8] It feels a bit like having cotton in my head or a kind of fog. It is as if I have spent all the words ... I need a break, to slow down and find a way back to where I was. [4] My brain has simply become burnt out. I feel a pressure against my head, it tightens and presses as if someone has filled cement up there. [15] There is just a vacuum. I am here, but I am not functioning.

The participants resorted to multiple metaphors to describe the mental and intellectual changes they sensed. Their heads felt empty and disconnected. The mental changes had consequences on their lives:

[15] If there are too many impressions, I fall over ... Because I forget that my knees must hold me. [8] I spend a lot of energy on simply being present. The brain must throw in the towel. [7] I was unable to cope in my job; I was teaching, and suddenly, it was if my whole brain became disconnected.

Social life may have been affected the most. The participants' social lives had changed irreversibly. They felt a need to be alone and had less interest in being with others. Their lives moved at a slower pace, and their mental processes were slacker. They perceived that their memory and concentration had deteriorated.

### *Experiencing not fully being oneself*

All interviewees expressed that they found themselves in a challenging situation after completing their cancer treatment. They struggled to become comfortable with themselves and to understand and accept their situations, as well as their experiences of their selves.

*A palpable condition.* Many interviewees expressed that they lived in a different state after their cancer treatment. The words they used expressed astonishment, frustration and a life that felt transformed and unreal:

[4] You have been kind of chewed on for a period in the health system, and then you get out, feeling entirely different, and everything is changed physically and mentally. [8] It is a subjective experience. The body feels different, but it is not imaginary. [4] I struggle a bit to accept that life actually has become more boring ... You gear down from the fifth to the third gear. I am there and the others are outside. It is as if I live in a different world. [4] I see myself as very dull. You become tired of being tired.

I live in a bubble, my own little bubble. [14] Somehow, it is impossible to understand, which is a bit frustrating.

The participants needed to relate to themselves in a different way. They attempted to understand themselves, but constantly became astounded. They became uncertain about themselves and about what they were really experiencing.

Many also said that they were not feeling depressed and that their condition was not related to mental processes:

[6] I get easily moved and tend to feel anxiety if there is too much pressure on me. I am mentally vulnerable ... it turns around very fast. [8] A kind of gloominess is often part of it ... and often a kind of emptiness. [4] I do not feel depressed but feel enveloped in a grey cloud. [3] I am quite sure about that. I do not feel depressed at all. ... When I am pushed too far, I get nasty and ugly in a way.

The participants searched for the right words to describe their experiences. It was as if they needed to distance themselves from the general public's idea that individuals treated for cancer are depressed or struggle mentally. They did not attach their own experiences to the general explanations. What they felt was something different, which did not lend itself to classification. Some participants tentatively considered whether what they were sensing was anxiety or depression, only to find that it did not adequately cover their plight.

*The challenge of accepting the situation.* Several of the interviewees expressed that it was a challenge to accept the changes that the cancer treatment had entailed:

[17] The thing is, I have not felt quite like myself ... I accept it, but I think it is annoying and unfair. Life is a challenge even when things are normal. [14] After all, I have come to accept now that things are not going to be the same as before. Maybe this tiredness will stick to me for the rest of my life. I do not know. [8] There is also a feeling of grief and loss, because when I try to do the things I did before, it feels entirely different. [16] So, in certain areas, I feel I am still in a vacuum where I ask myself 'Can anything more be done here?'

Multiple emotions, such as fear, grief, loss, irritation and resignation, were mentioned by the participants. Reconciling with their condition was tough for them. They felt that when one does not feel like oneself, adopting a conscious relationship with life and oneself is called for.

### *Experiencing a feeling of being alone*

All participants struggled to find themselves and to define who they were in relation to others. It was painful for



them that others were unable to see the changes that they were going through. Being unable to evoke a response during encounters with others was a strain for them.

*Being Outside.* All participants struggled with themselves and their encounters with the outside world. They elaborated on this in different ways, such as describing how others could not see the struggle in them, or that they appeared normal to others:

[17] All my friends are acting as if nothing has happened, expecting me to be the same as before. They see me as the same, but I do not feel quite the same as before. No one sees it, that is so frustrating. [4] They all say: 'You are looking so good'. Ha! They should only have known. So, I become a bit like: 'For God's sake, am I supposed to walk around in dirty clothes and with no makeup ... in order to show what I really feel inside?'

The participants described the condition as follows: encountering the outside world after undergoing cancer treatment may feel exacting. Others cannot see it on you, and you do not quite understand it yourself. Changes are invisible to the surroundings, which in itself may lead to additional suffering. Others do not appear to really understand individuals who are postcancer treatment.

*Not being confirmed.* Most participants deplored the lack of understanding for their unmanageable life situation after being declared healthy. They missed recognition and confirmation, sensing that the comments they received were well meant but still exacting:

[17] Maybe I am bitter? No, I am not bitter! However, when people say 'How lucky you are! They (doctors) are so skilled today', and they mean well and say, 'You are looking radiant'. But I notice that if I say 'Oh, it is so hard', it is as if people do not want to hear that, they do not want to believe it, because I do not appear to be suffering. And then there is the myth that 'everyone' has cancer. Really, tell me, who are they? I feel they are trivialising it. I wish my friends and surroundings would give me attention that would last beyond the completion of radiation therapy. Because I feel ill longer. But they would rather say 'You are looking so good', or 'It is good, it is over'. But it is not over. It is only over for them. [8] You are mirrored by your relations, are you not? And you feel so different. So, you feel extremely vulnerable since others cannot see the internal changes that have taken place, and vulnerable for not being understood or misunderstood. How are people to understand if we do not dare explain or put our condition into words? You place yourself in a very vulnerable situation by doing it.

Not being understood, or seeing that their condition was not being recognised, created vulnerability in the participants. Some experienced that people around them cared less when their convalescence was over, sending signals that the individual now needed to move on. The participants stated that admitting to tiredness in meetings with others felt awkward; the way they perceived it, the reactions of others could easily become awkward. Many of them stated that they wished to be listened to and understood. Visiting a Cancer Association for a talk was a good experience and helped reduce some of the burden. They all wished for a place where they could talk about what felt incomprehensible.

## Theoretical interpretation and discussion

This study aimed to obtain an in-depth understanding about individuals' existential experiences of life after cancer treatment. In the following discussion, we further interpret the meaning of the existential experiences and elucidate these according to a theoretical understanding. The overall interpretation relies on Steinbock's theoretical thinking of disruption in the lifeworld, and the brokenness experienced while living one's life in a homeworld versus an alienworld (12, 13). Our findings show that individuals experience major challenges in their lives after completing cancer treatment. They struggle to express their experiences of themselves when dealing with a different life, which feels like unfamiliar terrain, because the postcancer individual experiences life as a tangible condition that is 'not as before' and 'different from former life'. This may be understood within Steinbock's extrapolation of work by Husserl, using descriptions of the homeworld/alienworld. Steinbock (12) explained how the two lifeworlds—homeworld/alienworld—relate to each other within an intersubjective structure, which makes one world constitutively dependent upon the other (12). In the context of our study, the participants feel unable to live fully in the alienworld/homeworld, as a unit. These participants described their experiences with this lack of unity as an unfamiliar condition according to tiredness, concentration, memory or being outside oneself and the surroundings. However, the homeworld appears to be fundamentally changed by the limits of the existential 'cancer journey', or by what Steinbock calls an alienworld (12). The homeworld is always co-constituted through so-called 'liminal' experiences in which an alienworld is delimited, as navigating a borderless and unfamiliar territory (3). The participants described such liminal experiences as no longer being at home as they had once been, seldom entering the normal life flow, and a brokenness in the lifeworld from cancer treatment changes. They experience being in a world distinct from their precancer one because they are unable to objectify fully how they experience their

present life. The taken-for-granted, home-like homeworld seems to be disrupted by all the brokenness after cancer treatment. This is described as vague experiences using metaphors such as 'a discharged car battery', 'being in a vacuum', 'cotton in head' and 'living in a bubble'. It appears that experiences of brokenness are embodied, but to some extent, the changes are also alien, as the interviewees live in a challenging tension between the homeworld/alienworld. Although the alienworld is not explicitly present to them, the unfamiliar alienworld marks the homeworld experiences.

The liminal experiences are represented in the interviews by the participants being at risk of losing the homeworld. Steinboch (13) describes such a challenging shift in the homeworld as a 'critical compartment'. However, this critical space might allow potential for homeworld renewal, in which one might attempt to realise the homeworld more fully. The vulnerable space is where the unknown meets the familiar, safe space. The participants are challenged by the liminal encounters, striving to bring the two lifeworlds together. If the alienworld is excluded from the homeworld, they may lose their experience of a safe homeworld.

The participants described many serious changes, such as 'a sudden fatigue seizure', 'missing the mental state of the situation', 'flips quickly into anxiety' or 'the body fails' in some way. With an interruption/break in ordinary life, the alienworld becomes visible to the individual experiencing it. According to Steinbock (13), becoming an 'alien of the home' can occur via two types of breaks in the homeworld: light or heavy (13). A light break is a slight disruption to the normal experience, whereas a heavy break upsets an individual's entire communal homeworld and calls into question their ability to appropriate the homeworld through a 'limiting off' of the alienworld (3, 12). This liminal experience, caused by significant brokenness, is obvious in our study and experienced as an alienworld that is delimited and manifests after a brokenness in the lifeworld. Moreover, cancer appears to create a heavy break in the lifeworld, a brokenness which may cause the most significantly experienced burden for individuals who have undergone a cancer journey. We always carry both a homeworld and an alienworld in our lived bodies and practices (12, 13). The homeworld is a well-known territory, providing individuals with a sense of belonging by which they understand themselves. A shift in the homeworld is thus a critical space for the participants in which they experience themselves through both appropriation and transgression in a meeting with themselves, with what is unfamiliar, alienworld (13). Another study confirmed that after a traumatic event that alters an individual's perceptions of self, the world and their possible future, they do not recognise themselves as fully themselves (17). Similarly, the cancer survivorship journey involves

not only managing the ongoing and physical late effects of disease or treatment, but also a period of negotiating the 'same' world with an altered perspective. This incorporates the lived experiences as disruptions and irrevocable change (10).

The participants revealed that they felt burdened from the lack of confirmation from the outside world, the culture and healthcare system, and not being understood. They expressed that the outside world cannot see their burden because it is not visible. Ellingson (9) claimed that the cultural norms for illness cannot provide individuals with intelligible cultural narrative models to understand themselves. Furthermore, the prevailing discourses in the culture, which are strongly dichotomic and do not include nuances of the lived experiences, might create an additional burden. According to Steinbock (13), there is potential for incorporating the alienworld into the homeworld, rather than losing the homeworld in the encounter with suffering; however, cultural and historical discourses play a significant role in reinforcing the alien state (13). The known, which is formed by the cultural message, is taken for granted. Incorporating the liminal experiences into a new understanding might be hindered by culture and tradition.

Neither the homeworld nor the alienworld can be regarded as the 'original sphere', because they are in a continual historical becoming (12). Following cancer treatment, the individual must incorporate both the homeworld and the alienworld before ultimately arriving at a sense of transformation, in which meaning is derived from both (3). Moreover, the biomedical discourse is so dominant in the history of cancer survivors that it is challenging to find one's own deeper understanding of a changed self.

The cultural context, norms for cancer survivors and dominant descriptions encourage cancer survivors to feel as if they are in a battle in which they should fight to 'look good, feel better' or maintain a positive attitude (4). Our study reveals a variety of illness expressions that touch upon serious existential postcancer challenges. Cancer might disrupt the lifeworld experienced in the form of a disconnect with the self, alienation with the self and bewilderment (18). The term 'cancer survivor' ineffectively captures the different phases of the cancer journey and fails to serve well those it is meant to describe (19). Studies have shown that many do not feel that the term describes them adequately because it does not reflect their lived experiences (19). In our study, participants attempted to refine expressions such as 'fatigue' and 'depression' and several stated directly that such concepts do not describe their actual experience. Existential suffering is a much deeper concept and differs from conditions such as anxiety, depression and posttraumatic stress (5).

These interviewees experienced living in a different world, one that was impossible to understand when their

bodies were depleted, and were not fully functional. Experiences after cancer treatment therefore appear to disrupt the inner equilibrium (18), and these individuals appear to live life in a state of liminality (i.e. a space between two living spaces) (20).

The participants struggled with the fact that those around them did not see or understand their burden with living life postcancer or really want to hear stories about their experiences. After cancer treatment, individuals need to be allowed to tell their stories to allow transformational processes (i.e. owning one's truth) (18). Ellingson claimed that the truth of what remains in the wake of active treatment, such as chemotherapy, radiation, invasive procedures and toxic medication regimes, is the dark side of the medical sciences. What remains is more than can be expressed by a dichotomy of triumphant and tragic story endings (9). Mikkelsen et al. (8) drew on Habermas' theoretical framework to suggest that the lifeworld of individuals treated for cancer can be partly colonised by the system during hospitalisation, which can often lead cancer survivors to feel left in limbo after treatment. Brokenness in the lifeworld remains significant beyond the initial triumph of becoming cancer-free (9). Through liminal encounters with the alienworld, the typicality of the homeworld itself is transformed. As such, healthcare services should not be based solely on an objective, biomedical foundation.

The participants may have struggled to acknowledge their foreign world, considering their homeworld. There is really only one world people live in, but implicit to this world is both an alienworld and a homeworld (12). When the normal structure of our experiences is challenged and restricted, as a result of a heavy break, it gives rise to a profound sense of incomprehensibility (12). The constantly transformative journey, which extends greater comprehensibility, might unite the two 'liminal experience' modes of appropriation and transgression. The unusual and the known homeworlds must come into contact for the transformative processes that allow life to begin flowing again. This means that the process of transformation facilitates the uniting of the unfamiliar alienworld with the homeworld. In this study, we found that our participants were on a vague journey towards recognising their alienworld, which was foreign and different from their homeworld, and striving to interweave these experiences. In achieving this, they might renew their homeworld.

### Implications for practice

It is our opinion that the dominant biomedical discourse embedded in the cancer treatment system does not expedite positive health practices postcancer. This system, as a sole standard, fails to capture the disruption that cancer survivors experience in their embodied lived lifeworld.

We believe that healthcare professionals need to communicate more effectively with patients throughout their cancer journey about whether and how the illness experiences have been integrated into their lifeworld and whether help is needed to achieve existential rehabilitation. The healthcare system needs to turn towards a lifeworld perspective during the rehabilitation of individuals who have undergone a cancer journey to transform their alienworld to their homeworld. We think it is important to understand the individual's existential experiences during one-to-one counselling to share the existential burden.

### Methodological considerations

This study used a purposive sample, meaning that the participants were proficient with, and well informed about, the phenomenon of interest in the study. Our diverse sample of 21 participants included both men and women of different ages who had experienced different cancers and treatments. Recruitment was administered by a Cancer Association, which received an overwhelming and far higher than anticipated number of responses. Sample size was based on an information power analysis and appears strong, given that the sample specificity contained adequate information, leading to data material with rich, detailed descriptions that allowed us to develop new knowledge based on the study's aim and established theory (21). We found Steinbock's theoretical homeworld/alienworld perspective of great value for examining the phenomenon of life after cancer treatment. This theoretical perspective serves to both synthesise existing knowledge and extend the sources of knowledge beyond the empirical interview data (21). We judge our study to be an important contribution to the understanding of the lifeworld of survivors from cancer treatment. As such, the pragmatic validity seems to be strong as the result is fundamentally necessary to developing support for the target group of people.

The participants' openness to describing their lived experiences, regardless of the course of their cancer treatment and diagnosis, was another study strength. However, it might be considered a limitation that we did not explain their existential experiences in relation to these background data. Nevertheless, the study purpose was not to explain the relationships among cancer type, treatment, late effects or enduring damage, but rather, to go beyond the biomedical perspective to achieve a lifeworld approach. We suggest that our findings are applicable to cancer patients in similar contexts.

### Conclusions

Our findings may help explain the gap in the dominant approach, which has provided a limited understanding of



the experiences caused by a disruption to the lifeworld and lived existential experiences. As a group, individuals surviving cancer treatment have needs that are inadequately met by the current healthcare system. The biomedical perspective does not appear to reduce individuals' burden following cancer treatment. This study provides an in-depth understanding of the extent to which survivors are unfamiliar with themselves after treatment. The findings reveal that they have lost the ground beneath themselves, their homeworlds seem unclear, and the alienworld dominates. As such, rehabilitation programmes targeting this group need to incorporate this understanding to help such patients unify their home and

alien worlds. We suggest that new approaches are needed to confirm and support transformational processes that incorporate the alienworld into the homeworld.

## Author contributions

VU, BF, ED, and KR planned the study design. VU was responsible for drafting the manuscript. All authors contributed to the writing process.

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