

Navigating severe chronic cancer-related fatigue: an interpretative phenomenological analysis

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ABSTRACT

Objective: This article presents a phenomenological study on the embodied experiences of patients with Chronic Cancer-Related Fatigue (CCRF), aiming to better understand this complex phenomenon.

Design: Data collection consisted of individual interviews with 25 participants who suffered from severe CCRF for at least three months after cancer treatment was finished.

Main outcome measures: Against the theoretical background of philosophical phenomenology, we explored embodied experiences, incorporated temporal and spatial aspects of living with CCRF. We applied interpretative phenomenological analysis (IPA) to analyze the transcripts of the interviews.

Results: Using IPA, we identified four themes on how chronic fatigue is experienced post-cancer: (1) Worn out; (2) Diminishment of one's 'I can'; (3) Invisibility; and (4) Regaining one's 'I can'.

Conclusion: For clinical practice, these results imply that professionals could focus more on the role of the body and limitations of one's 'I can' when treating CCRF. By studying these embodied CCRF experiences in individual patients, future research could help personalize and optimize treatment.

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Introduction

Cancer-Related Fatigue is one of the most prevalent and disruptive symptoms experienced by cancer patients before, during and after treatment (Ebede et al., 2017; Wang et al., 2014). In the National Comprehensive Cancer Network (NCCN) guidelines Cancer-Related Fatigue is defined as: '*a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning*' (National

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Comprehensive Cancer Center, 2020). In at least one-quarter of all cancer patients, this fatigue becomes a chronic problem. When fatigue persists for at least three to six months after treatment, it often becomes chronic (Goedendorp et al., 2013; Jones et al., 2016; Servaes et al., 2007). To make a clear distinction between fatigue during and after treatment, we use Chronic Cancer-Related Fatigue (CCRF) for fatigue post-treatment (Bruggeman-Everts, 2019). CCRF is an important public health issue due to the negative impact on patients' lives, and incurring medical and social costs (Hofmarcher et al., 2020). In clinical practice, it is strongly recommended to screen quickly for severe fatigue in newly diagnosed cancer patients to prevent it from being overlooked and become an under-reported, under-diagnosed and under-treated chronic problem (Abrahams et al., 2017; National Comprehensive Cancer Center, 2020). In order to properly screen for CCRF we first need to know more about patients' experience with CCRF.

Suffering from CCRF is often accompanied with distress, impacts daily life and reduces the quality of life (Curt et al., 2000; Ploos van Amstel et al., 2013; Schmidt et al., 2012). A recent study, applying network analysis to study symptoms among cancer patients seeking psychological care, showed evidence for the interrelatedness of CCRF with both risk factors (helplessness and physical symptoms) and protective (acceptance of illness) factors on a group level (Schellekens et al., 2020). The complexity and interrelatedness of CCRF with other symptoms require a better understanding and response to both the long-lasting physical cognitive, and emotional needs of these patients (Richardson et al., 2011).

Different psychological and exercise interventions are effective in reducing CCRF (Bennett et al., 2016; Corbett et al., 2019; Mustian et al., 2017; Pearson et al., 2018). To date, there are also effective equivalents of these therapies available for patients with CCRF in an online form (Seiler et al., 2017). Despite this range of evidence-based treatments, it is not clear which type or combination of treatment works best for which patient (Mustian et al., 2017; Seiler et al., 2017). Insight in how to tailor therapy to patients' needs and characteristics will help to improve symptoms, reduce dropout, and can potentially reduce costs and improve implementation (Couper et al., 2010; Mol et al., 2010; Morrison et al., 2012; Noar et al., 2007; Twomey et al., 2018; Van Beugen et al., 2014).

A vital first step in the development of personalized therapy for CCRF is understanding this experience from the patient perspective (Bennion & Molassiotis, 2013). The understanding of lived experiences entails the patients' illness story, what the disorder means to the patient and goes beyond any objective, quantifiable and clinical data (Toombs, 1987). In addition, it reveals how patients feel, explain, interpret and understand their illness (Mishler, 1984; Toombs, 1987). More insight into the subjective, lived experiences of CCRF could improve recognition and understanding of the severity of the problem in the communication between patients and professionals (Mishler, 1984; Toombs, 1987). These insights could support professionals to be more empathic in their communication, provide useful information about future expectations at the right time and formulate their questions in a correct way (Fernandez, 2020).

The richness and depth of qualitative research could help to understand patients' lived experiences (Given & Sammure, 2008). A research method that could assist in

tailoring treatment for CCRF is to ask for a more detailed description of experiences in the patients' own words. This method could help unravel if the interrelated problems a patient suffers from belong to one phenomenon or differentiate into distinctly different phenomena with different etiologies, and investigate the preferred word choice to determine possible targets for treatment (Laisaar-Powell et al., 2019). For example, Dolgoy et al. (2019) identified new intervention targets by studying how people affected by cancer spontaneously described the nature and impact of fatigue. Besides the physical, emotional and functional consequences of CCRF, people also described how this fatigue impacted the sense of self and created feelings of uncertainty related to the onset, duration, impact and management of the fatigue. Based on these findings, the authors concluded that interventions addressing uncertainty and altered sense of self may be helpful to them (Dolgoy et al., 2019).

Previous studies emphasized the role of the body and bodily awareness in patients' experiences with CCRF (Levkovich et al., 2019; Pearce & Richardson, 1996; Penner et al., 2020; Ream & Richardson, 1997). A meta-ethnography, a review based on an interpretative analysis of sixteen qualitative studies showed that embodiment is a central phenomenon in experiencing and responding to CCRF (Bootsma et al., 2020). The included qualitative studies showed limitations, such as small sample sizes, the inclusion of patients not only after but also during treatment that did not meet the duration criterion for chronic fatigue, and an overrepresentation of breast cancer patients. A detailed and comprehensive analysis of embodied experiences of CCRF in a mixed, larger sample after cancer treatment is lacking.

The present qualitative study explores the lived experiences of patients with severe CCRF. The lived experiences of CCRF could help to describe how the bodily disruption presents itself in the patients' life (Mishler, 1984; Toombs, 1987). It starts with the question how patients experience these bodily disruptions of CCRF. The exploration is theoretically guided by the philosophical phenomenological account of disruptions in the experience of embodiment, time and space, and how these are related in patients that suffer from CCRF (Grünfelde, 2018; Husserl, 1989; Merleau-Ponty, 1962). In our analysis CCRF is approached as a 'chronic illness of its own rights' (Pertl et al., 2014; Rosman, 2009), within the context of the post-cancer experience (Ellingson & Borofka, 2020; Glaus et al., 1996; Hubbard & Forbat, 2012; Kelly, 2009; Pearce & Richardson, 1996).

Theoretical framework

Phenomenology of the body, time, and space

A phenomenological approach enables us to describe the essence of CCRF by exploring it from the perspective of those who have experienced it (Teherani et al., 2015). It focuses on what we perceive rather than on the reality of things. This exploration of the meaning of experiences, consists of both what is experienced, and how it is experienced (Carel, 2012; Teherani et al., 2015). Perception is a basic element in using phenomenology to understand human experience, and an embodied activity itself (Merleau-Ponty, 1962). According to the philosophical phenomenology of Merleau-Ponty, embodiment can be defined as 'how we live in and experience the world through our bodies, especially through perception, emotion, language, movement in space,

time and sexuality' (Merleau-Ponty, 1962; Wilde, 1999). A phenomenological view of the body allows us to explore different dimensions of how CCRF disrupts a person's embodied being in the world, their experience of time, space, self, and relations to others (Bury, 1982; Charmaz, 1983; Corbin, 2003; Grinfelde, 2018; Husserl, 1989; Merleau-Ponty, 1962; Toombs, 1990). The identification of all dimensions from different perspectives provides the opportunity for a comprehensive analysis of the lived experiences to gain a more complete insight into the disruption of this mind-body-world unity, which started with the cancer diagnosis (Ellingson & Borofka, 2020; Glaus et al., 1996; Hubbard & Forbat, 2012; Kelly, 2009; Pearce & Richardson, 1996). This approach rejects mind-body dualism or other binaries because dualism is not helpful when exploring patients' experiences. The main goal is to use the framework to broaden the perspective of the patient's experience.

One's body can be experienced as the physical, objective body (*Körper*) (Husserl, 1989; Merleau-Ponty, 1962). The material and social dimension of embodiment represent ways of experiencing this objective body from an 'outside' or third-person perspective (Grinfelde, 2018). The material dimension expresses the body as a material thing in a causal relationship with the world. This bodily experience is often affected by the so-called gaze of the other (Sartre, 2001). Whenever one feels that one's body becomes subject of the gaze, one's focus may change from being engaged in projects in the world towards awareness of one's own body. Leder (1990) calls the thematization of one's body apart from itself as a material object: 'dys-appearance'. The social dimension illustrates that the material body is embedded in a social context. The other could treat the patient as an object instead of subject, which causes a split between the subjective, lived body and objective body. When patients adopt the perspective of the objectification of their body by the gaze of the other and become aware of themselves as 'an alien thing', this can be described as 'social dys-appearance' (Leder, 1990). Adjacent to the experience of the objective body, an objective way of experiencing time exists: the linear or outer time that refers to the time that can be measured by clocks, calendars etc. (Husserl, 1964; Toombs, 1990).

A second form of how one's body can be experienced, is as a lived, subjective body (*Leib*) (Husserl, 1989; Merleau-Ponty, 1962). The representation of the affective and functional dimensions are ways of experiencing the subjective body from a 'within' or a first-person perspective (Grinfelde, 2018). The affective dimension represents the chronically ill body as a bearer of (new) sensations. The functional dimension refers to the body as a seat of free movement, the possibility to act in the world, or put differently the 'motor intentionality' or one's 'I can' (Husserl, 1989; Merleau-Ponty, 1962). Additionally, the subjective way of time-experience is the lived or inner time, defined as the ongoing stream of consciousness in which duration and temporality are experienced (Husserl, 1964; Toombs, 1990). For example, waiting for a doctor's appointment could feel like hours even when the clock time is merely 30 minutes.

A chronic illness disrupts the possibility of action and changes the experience of both spatiality and temporality. First, in health one can move in and through space easily, while in illness space can seem restricted (Corbin, 2003). The lived space of the body is the situational spatiality in health. The body appears to oneself as a posture towards a certain task without a need to measure the geometrical distance surrounding a body, that is the positional spatiality (Merleau-Ponty, 2012). The

disruption of the lived body in case of chronic illness transforms the experience of the body as an orientational and intentional locus (Toombs, 1995). Because the situational spatiality is disturbed, the positional spatiality remains and a patient has to think before he or she acts (Merleau-Ponty, 2012). This is reflected in the heightened sense of distance between oneself and surrounding things, because a loss of mobility. The same location previously considered as 'near' is now seen as 'far' (Toombs, 1995). To overcome this loss of mobility and heightened sense of distance, patients with a chronic illness experience changes in the spatial arrangement of how to reach, open, or place things (Corbin, 2003). For example, chronically ill patients consider putting things within reach and strategically on the ground floor in their home to avoid taking the stairs because of their disabilities. Second, the introduction of a chronic illness, such as the persistence of CCRF after cancer (Hubbard & Forbat, 2012), into someone's life results in a disturbance of another time component, the biographical time, a disruption of previous lived experience (Corbin, 2003). Biographical time comprises all experiences, memories and emotions derived over a life-time and carried within the self (Corbin, 2003). When life is disrupted by a chronic illness, patients could experience feelings of alienation (Zeiler, 2010) because their body of the present and the future is compared to the body of the past and appears as 'other' and 'strange' to them, which could result in a loss of self (Charmaz, 1983; Corbin, 2003).

Material and methods

In this qualitative study, part of the REFINE project for personalizing treatment for CCRF, initiated at the Helen Dowling Institute, Mental Health Center for Psycho-Oncology in the Netherlands, 25 patients with severe CCRF participated. The guidelines of standards for reporting qualitative research (SRQR) were followed (O'Brien et al., 2014). First, we re-analyzed semi-structured interviews with nineteen CCRF patients, who completed one of two web-based interventions in the randomized-controlled More Fit after Cancer trial (Fitter Na Kanker (FNK) trial) (Bruggeman-Everts, 2019; Bruggeman-Everts et al., 2017). Participants of the FNK trial reported their lived experiences with CCRF. However, this exploration of lived experiences was less in-depth, because the open-ended interview questions focused on evaluating the interventions (Table S1 Topic guide FNK trial). After re-analysis, the data provided insufficient answer to our research question: how do patients experience bodily disruptions of CCRF? Therefore, additional semi-structured interviews were required for a more in-depth exploration of the embodied experiences of CCRF. The first author developed a new topic guide with open-ended questions based on clinical expertise, literature and piloted it with a therapist experienced in treating patients with CCRF at the mental health center for psycho-oncology. Topics of this interview guide were experiences (descriptions, sensations, cognitions, patterns, attributions), consequences (daily life, body, self), actions (self, others, helping and hindering factors), and other important factors (Table S2 Topic guide REFINE project). Subsequently, six new patients were interviewed on their experiences with CCRF. Initially, the first interview was considered a pilot interview. As the questioning was positively evaluated, we included this interview in the analysis. We published a separate paper that focused on what helps patients in responding to CCRF (Bootsma et al., 2021).

This study was approved by the Twente Medical Ethical Committee (P12-26) and the Research Ethics Committee of Tilburg School of Humanities and Digital Sciences (REC#2018/24) and was performed in accordance with the Declaration of Helsinki. Patients received an information letter and provided written informed consent. In some cases, the partner was present during (a part of) the interview. Field notes were taken during and after each interview. All interviews were audio-recorded and transcribed verbatim immediately after the interview by research assistants of the projects.

Interview data from FNK trial

To evaluate the web-based interventions of the FNK trial, 19 out of 22 selected patients were interviewed (December 2015–March 2016) about their experiences with the programs: nine (partially) completed the physiotherapist-guided Ambulant Activity Feedback (AAF) and ten (partially) completed the psychologist-guided Mindfulness-Based Cognitive Therapy (eMBCT) (Bruggeman-Everts, 2019). For the present qualitative analysis on lived embodied experiences, we particularly focused on patients' perception of interrelated symptoms, limitations, and impact on their daily life. For the FNK trial, participants were recruited via online and offline channels. Eligibility criteria were: (1) finished curative treatment at least three months ago (except hormonal treatment); (2) severely chronic fatigue score ≥ 35 on Checklist Individual Strength (CIS)—fatigue severity subscale (FS) (Vercoulen et al., 1994); (3) >19 years old and 18 years old at disease onset; (4) no current or former severe psychiatric comorbidity (i.e. suicidal ideation, psychosis or schizophrenia). The interviews took place at the patient's home and lasted on average 40 minutes. The two researchers who conducted the interviews had experience in the field psycho-oncology and/or qualitative research (see **Acknowledgments**).

Additional interviews REFINE project

The first author who conducted (August 2018–January 2019) the additional interviews had prior experience in conducting qualitative research in the field of psycho-oncology. Interviews were held at the patients' preferred location: mental health center specialized in Psycho-Oncology, the patient's home, or online with a video-connection. The average duration of these interviews was 64 minutes. These patients were recruited by their health care professionals in a mental health center specialized in Psycho-Oncology, a general practice, physiotherapy centers situated in urban and non-urban areas of a central part of the Netherlands, and via patient websites. In total 28 patients responded and we selected six participants that were all severely fatigued after completing cancer treatment and met the same eligibility criteria as used in the FNK trial. Recruitment of participants stopped when sufficient rich and thick personal accounts were collected to answer the research question.

Because almost half of the interviewees ($n=8$) of the FNK trial were middle-aged women with a history of breast cancer, purposive sampling (on age, gender, partner status, cancer type, and treatment) was applied to gain a broad scope of the lived

experiences of CCRF patients. This resulted in a more diverse sample of in total 25 severely fatigued participants (Table 1). Eleven patients (44%) scored above the cut-off for depression screening (≥ 15) on the Hospital Anxiety and Depression Scale (HADS) (Mitchell et al., 2010; Vodermaier & Millman, 2011).

Data-analysis

The interpretative phenomenological analysis (IPA) (Smith et al., 2009) started with the analysis of the interviews of the FNK trial. The first and third authors started with reading and re-reading the interviews. In the next step, they inductively coded the first five interviews with descriptive codes (MaxQDA software, version 18.2.0), while being supervised by the second and last author. This supervision included responding to questions and coaching during the coding process. The two researchers constantly compared and discussed the codes until they reached consensus. Increasingly less differences were found between the independent coding of the two authors. Therefore, after the first five interviews, the first author continued coding the remaining (20) interviews in the same way. All questions and inconsistencies during the coding process were discussed and decisions were recorded. Member checks were utilized for the six additional interviews of the REFINE project by sending a summary of findings to participants. All participants responded that they agreed with the content of the summary.

The code list was organized in seven main categories (i.e. experiences, metaphors, comparisons, beliefs, responses, helpful and unhelpful response) based on the interview data. We created six individual 'CCRF experience profiles' based on codes of the patients that participated in the REFINE project. We discussed these individual 'CCRF experience profiles' and the code list with the multi-disciplinary team of authors, who have clinical and qualitative research expertise in psycho-oncology. We excluded data from analysis that was related to partners who sometimes participated in the interview and data concerning the online therapy of the FNK trial.

The analytical process was case-by-case, inductive and iterative. Some examples of descriptive codes from the first part of the analysis included: 'battery is low, need to recharge' [metaphor] and 'what I could I cannot do anymore' [comparison]. The next phases of analysis consisted of seven team discussions about the individual 'CCRF experience profiles' and code list. Together the authors extracted general patterns and themes from the code list. The results of the analysis were continuously checked with the underlying data (interviews). In the next group meetings, the theoretical framework was elaborated upon and applied to the code list to search for different patterns in the data.

In the latter phase of analysis, the authors searched for cross-case themes emerging from the different patterns. Four themes were identified about how chronic fatigue is experienced, what kind of functional limitations result from this fatigue, how the invisibility causes problems in social context and how patients adapt to the fatigue and its limitations. The analysis was completed by discovering dynamics and relations between the different themes within an individual patient.

Table 1. Participants' characteristics (N = 25).

Characteristic	Value
Female/male gender (n)	16/9
Age at interview (years; mean \pm SD, range)	52.64 \pm 12.86 (21–80)
In a relationship (n)	23
Children at home (n)	11
Education level (n) ^a	
Low	3
Intermediate	13
High	9
Currently employed (n)	
Job	10
(Partial) disabled	8
No job/household	4
Retired	2
Scholar or student	1
Type of cancer(s) (n) ^b :	
Breast ^c	10
Haematological ^d	8
Digestive system	5
Head or neck	2
Male genitalia	2
Urinary tract	2
Bone or soft tissue	1
Brain and central nervous system	1
Skin	1
Gynaecological	1
Treatment(s) (n) ^b :	
Surgery	20
Chemotherapy	18
Radiotherapy	15
Hormonal therapy	6
Immunotherapy	2
Bone marrow transplantation	1
Metastasis (n)	7
Comorbidities (n) ^e	12
Months since first diagnosis-interview, (M \pm SD, range)	56.88 \pm 45.11 (11–169)
Months since last treatment-interview, (M \pm SD, range)	43.72 \pm 35.96 (6–152)
Checklist Individual Strength (CIS) score ^f , (M \pm SD, range)	43.0 \pm 5.02 (35–52)
Subscale: Fatigue Severity (FS)	
Hospital Anxiety Depression Scale (HADS) score ^f , (M \pm SD, range)	13.84 \pm 5.39 (4–23)
Duration of severe fatigue (n)	
3–5 months	1
6–12 months	6
1 year–2 years	6
2–5 years	7
>5 years	5
Prior professional support for cancer (n) ^g	18

^aLow = primary/lower secondary education; intermediate = upper secondary education; high = higher vocational training/university.

^bNumbers do not add up to 25 because multiple options are possible.

^cOne participant had another type of breast cancer for the second time and was counted twice.

^dOne participant had two different hematological diseases and was counted twice.

^eComorbidities: diabetes, spine condition, pelvic disease, lung disease (asthma, bronchitis or COPD), thyroid disease, liver disease, ulcerative colitis, graft versus host disease, sleep apnea, neuropathic sensations, vertigo, tinnitus, PTSD, neurological disease, migraine and inflammatory bowel disease.

^fBaseline data T0a FNK trial.

^gProfessional support: revalidation, general practitioner, spiritual counsellor, social worker, psychologist, institute for mental health care, institute for psycho-oncology, psychosomatic exercise therapy, physiotherapy and lifestyle program.

Results

Embodiment in CCRF: four different dimensions

In their descriptions of CCRF, the participants in our sample referred many times to their feelings of fatigue in their lives before cancer and reported differences in severity, timing, causality, and recovery between their pre- and post-cancer experiences of fatigue. Their experience of cancer and its treatment marked a change in their feelings of fatigue, functioning, and identity. Participants longed for their pre-cancer situation, which they experienced as a much better situation, in terms of how they felt and their level of functioning. Regarding their future, participants wondered whether they would keep suffering from CCRF and its limitations.

The process of experiencing CCRF is dynamic. That is, despite the chronic nature of CCRF, the fatigue experience changes over time and across social situations, with differing sensations and limitations. We identified four themes of patients' experiences related to navigating CCRF. In this report, we explicitly quote twenty participants using pseudonyms (i.e. Amy, Brian, Britt, Christian, Daisy, Daniel, Finley, George, Isabelle, Jasmine, June, Kyra, Logan, Lynn, Oliver, Quinty, Rose, Samuel, Sebastian, and Zoe). Of course, our results are based upon the analysis of the interviews with all twenty-five participants. In all four themes different dimensions of experiencing embodiment, time and space were incorporated. **(1) Worn out** is an affective dimension that entails different descriptions of sensations (i.e. physical, emotional, sensory, and cognitive) of fatigue experienced over time in the patient's body (e.g. limbs and/or mind), which could result in a loss of self. **(2) Diminishment of one's 'I can'** is a functional dimension that represents several limitations to move 'freely' in time and space patients with CCRF experience in their lives. **(3) Invisibility** is a combination of a material and social dimension that describes the objectification of the experience of CCRF in their body in a social context. Objective time is used to indicate when they expect to be worn out. **(4) Regaining one's 'I can'** is a functional dimension that refers to ways of adapting their active time and movement in space to the experience of CCRF, the functional limitations of one's 'I can' and the material and social objectification of their bodies.

Worn out

Participants used different synonyms to describe their feelings of CCRF, including tiredness and exhaustion. The commonly used word 'fatigue' was not always appropriate to describe their feelings of chronic fatigue because this is often confused with the fatigue everyone experiences in their daily life. Daisy compared her feelings of exhaustion with experiences of fatigue after flu she had in her pre-cancer life:

To be honest, that fatigue, I never had it so intense (...) Fatigue, normal is like recovering from the flu like I'm very weak, but this extreme fatigue, I did not know it before. (Daisy, FNK-MBCT, 51–60 year, 2–5 years CCRF)

These sudden moments of 'really extremely exhausted' are not recognized or comparable to the feelings of fatigue that rarely occurred in their pre-cancer life. Most participants did not expect to experience chronic fatigue after treatment. Various combinations of superlative adjectives (e.g. total, extreme, overwhelming, intense, debilitating, or intangible) were frequently used to reinforce the meaning and express the intensity of their feelings.

Participants experienced difficulties to put their experiences with fatigue into words and sometimes used powerful metaphors to indicate the severity of CCRF. Examples of expressions included: 'I am dog-tired', 'I was drowning' or 'I am "totaled"' (i.e. like a car that is totaled).

Several participants expressed their experience of CCRF in terms of what they 'lacked' in their current situation, that is 'energy'. The use of the word 'lack' marked that before cancer, their energy level was in most cases not a problem. George experienced more problems with his energy levels after cancer treatment was finished:

(...)I constantly have the feeling that I have somewhat less energy than an average person of my age. Actually, I always experienced this to some extent and I also noticed this during my student life. And afterwards, after the first years of my disease and finishing chemotherapy etcetera, then you notice you have taken a huge hit. (George, FNK-MBCT, 31–40 year, >5 years CCRF)

However, some participants described this lack of 'positive' feelings of being well-rested, recovered, energetic or fit, even at awakening, other participants had some moments of being more fit during the day or on some days.

In the descriptions of fatigue, a time indication was frequently used to express the chronicity of CCRF. Fatigue was experienced each and every day. Lynn described her complaints prior to the study:

Participant Lynn: "Uuuh extreme fatigue"

Researcher: "Yes... and uh in what way did you mean fatigue?"

Participant Lynn: "Yes when I woke up in the morning I wanted to go to bed again"

Researcher: "Yes, yes..."

Participant Lynn: "And actually the whole day oh how tired I am ohh phew I am tired." (Lynn, FNK-AAF, F, 61–70 year, 2–5 years CCRF)

While fatigue can be constantly present for some, for others it was more unpredictable and unexpected. Christian described how he experienced 'fatigue attacks':

It is possible, I mean in a weekend when you take it easy, you sleep in, I do that on Sundays, then you wake up at 11 a.m. ... and at 1 p.m. you get dressed and at 1 p.m. I totally collapse. (...) Then I really have to, well usually I go on the couch, lay flat for a moment. (...) Yes, then I say: "I just have to lay down for a moment", because the fatigue is so intense at that moment...but I am sometimes asleep for one hour. (Christian, FNK-eMBCT, M, 61–70 year, 2–5 years CCRF)

Several patients reported that the severity of fatigue is a dynamic experience, because it fluctuated within and between days. Most patients indicated that they experienced more intense fatigue at the end of the day. They also mentioned how they could be extra fatigued during the day(s) after activity. Therefore, participants often needed to rest, either after activity or during 'moments of being totally exhausted'. During the day participants could suddenly fall asleep. Sebastian illustrated the time of sleeping is prolonged:

Extremely fatigued, really like: I lie down in bed, then I had the feeling I sink into my bed as if I disappeared in the mattress and then I could sleep, well I was comatose. And then not just for one quarter, hours! (Sebastian, FNK-AAF, M, 61–70 year, 1–2 years CCRF)

The depth of sleep was mentioned: ‘comatose’ in this quote, other participants had similar experiences with a deeper sleep than before cancer. Contrarily, sometimes individuals had problems sleeping at night.

The feeling of CCRF is experienced by participants as being a part of their bodies, for example, ‘fatigue in your bones’ and ‘the energy runs out of my legs’. Some patients compared their fatigue to doing extreme physical activity: ‘climbing the Mount Everest’ or ‘running a marathon’. Different physical sensations were experienced. In several cases, the fatigue was predominantly felt in their limbs, which made their limbs feel ‘heavier and heavier’ and resulted in difficulties standing on their feet, walking or climbing stairs. Because their body changed after cancer and treatment, patients reported that they experienced different symptoms (e.g. stiffness, pain, lymphedema) in their body related to fatigue. Some patients suffered from various chronic comorbidities (Table 1), which impacted their bodily experiences as well.

Although CCRF was their main symptom, patients also suffered from other (cancer-related) problems: sensory, cognitive, emotional, sleep (insomnia or hypersomnia), and physical difficulties. Isabelle illustrated how these different aspects were interrelated with her fatigue:

It is often when I am at a birthday party, where the fatigue and sensory overload are related, and that’s why I get a panic attack because previously I did not have this, so to say. Thus, it is all connected to one another. (Isabelle, REFINE, F, 21–30 year, 1–2 years CCRF)

Patients described several situations in which they are overstimulated: driving a car, multitasking, working, or going out. In this quote, June reported how difficult it is to process the various stimuli at once:

(...) Memory, concentration, I am quickly...out of sorts. I cannot function in groups either. There were way too many, way too many stimuli too. (June, FNK-AAF, F, 61–70 year, 2–5 years CCRF)

This indicates how stimuli could have stronger effects post-cancer limiting their tolerance for processing stimuli. Some participants experienced particularly a lack of mental energy, sometimes combined with physical fatigue. These participants expressed sensations of their fatigue as: ‘in my head’ or ‘absent-minded’. They used metaphors, such as ‘I feel like I am hung-over’ or ‘I feel like I am a heavily drunk driver’. The effect of CCRF on participants’ cognitive functions resulted in different cognitive problems (e.g. concentration, attention, memory, thinking, communication and understanding). Quinty commented:

And that started maybe 5 years ago, I don’t know exactly, but in any case, the consequence of fatigue, I see it as consequences, is also concentration problems. (Quinty, FNK-MBCT, F, 51–60 year, > 5 years CCRF)

Many patients experienced a loss of concentration which hindered their overall functioning, because they cannot be mentally active (e.g. working) anymore. In most respondents, the physical and mental limits of CCRF and cancer invoked various types of emotions and negative thoughts. They felt more vulnerable, worried more and experienced regularly (more) negative emotions (e.g. anger, sadness, depressive feelings, shame, and anxiety) than before cancer and its treatment. Emotions seemed to

come more easily to the surface because most people felt frustrated about their fatigue and limitations in daily life. Some patients reported they did not recognize their fatigued bodies and their selves, which were reinforced by intense emotions, resulting in feelings of alienation. Zoe reported:

I notice that it reinforces when I am tired, so fatigue is a sort of plus factor, which also makes me more depressed or sometimes very emotional all of a sudden. Thus, it all brings things closer to the surface, even more than usual. And then with that somewhat stronger fatigue, you sometimes think: I don't recognize myself. (Zoe, FNK-MBCT, F, 41–50 year, >5 years CCRF)

These feelings of becoming suddenly overwhelmed by intense negative emotions and severe fatigue were not recognized from before cancer and could make them feel like losing (control of) their selves.

Diminishment of one's 'I can'

CCRF confronted patients with several limitations. Before cancer, most patients were physically at 100%, whereas afterward their bodies were different and not completely recovered. Most patients were limited by and more aware of their bodily sensations, emotions, sensory stimuli and cognitions after cancer, losing trust in their bodies. As such, the complexity of CCRF also impaired patients' activities and social life. Several participants described how they were not always able to go out, function in a group or take care of children. Consequently, the suffering from CCRF indirectly affected participants' partners, family, and friends. Brian reported that his partner was just as much impacted by his disabilities as he was:

(...) And for my wife, it is of course also, yes for her, my limitations become her limitations, because walking in the city alone is not the same as walking together (...). (Brian, FNK-eMBCT, M, 61–70 year, 1–2 years CCRF)

The fatigue limits activities. Close others had to take into account the patient's limitations and emotional reactions, and were required to take over certain tasks (e.g. driving a car or care for children), but it was usually impossible to take over all tasks.

Patients' daily schedules were disturbed and complicated because they actually felt they had no time to be fatigued. Because of CCRF, the time in which they were active was shortened, which results in unintended delay, or even the inability to perform everyday activities. For example, patients reported that more time is needed to get out of bed and get dressed. Almost all participants mentioned that they cannot do all of the things they used to do in one day. Rose reported that her daily activities are limited, which means that she is limited in her 'I can':

(...) because I am always tired, and that is really an understatement, I am really every day, at the end of the afternoon nearly exhausted (...), you face it every day. I can no longer do everything in my life that I would like to do (...). (Rose, FNK-eMBCT, F, 41–50 year, 1–2 years CCRF)

Patients experienced daily struggles with their activities, as they had to select one or two activities a day. Physical activity (e.g. doing sports, climbing stairs, lifting things) as well as mental activity (e.g. reading, watching movies) were limited. Patients were unable to move 'freely' in time and space. Patients also expressed motivational

problems, such as difficulties to start or make time for activities or travel. Jasmine reported about her motivational problems to start making dinner:

Picking up the piece where you left off, look. A household does indeed have things of which you say, yes at 5 p.m., I have to eat anyway, I will start making dinner. It is just that things that are common throughout the day, of which you think, oh yes, now I have to do that again. (Jasmine, REFINE, F, 71–80 year, 6–12 months CCRF)

The normal daily tasks were experienced as things that ‘have to be done’ because everything took so much more time and effort, reducing their motivation. Patients tended to avoid or postpone things, or make up excuses in order to not being active throughout the day. They also experienced a diminished or lack of interest in activities. Activities were preferred at, and performed at, a lower intensity. They were unable to reach their pre-cancer working pace or training level.

Not only their present but the perception of their future life has become disrupted as well. Many patients started living day-by-day after cancer. Amy reported:

Yes, it varies, sometimes it goes very well and I have cleaned the windows and sometimes that is just not possible. It just varies a lot. And you just have to accept that it happens and don't worry too much about it (...). (Amy, FNK-eMBCT, F, 51–60 year, 6–12 months)

In this example, acceptance without worrying helped to respond to the daily variations in the experience of CCRF. Other patients became more and more aware of the finite nature of life after cancer and were uncertain about their future. Because of its chronic nature and the impact on their functioning, almost all participants were worried and frequently raised the question: ‘Will the fatigue ever resolve?’

Invisibility

The body of cancer patients could have different persistent changes and/or damages after cancer and its treatment. Patients could focus on their bodies as ‘an alien thing’ because of the changed nature of their bodies or because of the negative attitude of others towards them, both resulting in objectification of their bodies. Some changes were visible on their bodies, such as lymphedema or scars from surgery. Others were invisible, such as the experience of pain or CCRF. This invisibility, the fact that others were unable to see CCRF, led to several problems. The interaction with others was impacted by CCRF. Many patients felt supported by their partner, friends and family, because they took over some activities, helped to protect their limits or just gave them the space they needed for a moment. In these situations, their loved ones recognized and asked about their feelings. On the other hand, some patients took the first step and communicated openly about their invisible fatigue and their possibilities in daily life with their close others, and asked for help if necessary. In these cases, there was a positive interaction between the patient and their loved ones. Other patients chose to contact new people that were unaware of their fatigue to avoid the judgment of others who do know about their medical situation. Other patients described how their family started to make decisions for the patients. However, after cancer treatment was finished, several participants reported a switch in the amount of positive attention they received from other people. While the experience of CCRF is still present, it is invisible to other people. As Britt described how she experienced the invisibility of CCRF as an extra disability:

I'm only 10% of who I was, it's really absurd. And I look like nothing is wrong you know. That is also an extra disability. (Britt, FNK-AAF, F, 51–60 year, 1–2 years CCRF)

Several participants experienced a lack of social recognition because other people formulated the following questions, such as 'Don't you feel bored?', 'When will you be well?' and 'Are you leaving already?' Other people, particularly, children expected them to be fit and active. Some patients understood these reactions and normalized these comments as they understood that healthy people could not recognize their experience of feeling extremely fatigued. Other patients felt ashamed and became more reluctant to show their feelings and talk about their fatigue experience:

Yes and there, finally I come in such a modus that you do not even mention it [CCRF] anymore to other people (...) Yesterday, for example, I played tennis with my girlfriend, and my mother said: "Yes it is about time that you start doing something". I said to my girlfriend: "So yes, instead of that, she could have said: "Ow how good of you that you started again". Yes, that kind of support is very important for me to pick up my life again. (Oliver, REFINE, M, 41–50 year, 2–5 years CCRF)

Patients often did not feel acknowledged in their fatigue experience. Some patients did feel acknowledged by their health professionals, as they explained that their fatigue was caused by cancer and its treatment. Other patients experienced problems, because of the lack of recognition of professionals. Finley reported how the company doctor pushed him to return to work:

When I visited the company doctor: "Why aren't you working?" He said to me: "You look great". "Yes, even when I look so great, I don't feel like that". But try to explain to other people who don't know what cancer and treatment means. Try to explain how you feel. You hit the wall. I went to another company doctor. (Finley, REFINE, M, 41–50 year, 6–12 months CCRF)

The company doctor misinterpreted the situation based on what was expected to be visible on the outside, which does not correspond to how the patient feels. Patients frequently reported similar situations with other people in which they 'hit the wall'.

Besides the impact of social invisibility of CCRF, participants could also themselves focus on their bodies as 'an alien thing' because of their awareness of bodily changes. Patients experienced their bodies as 'ill', 'alien' or 'older' and felt 'betrayed' by their bodies. Logan described how, as a consequence, mind and body grew apart:

Well, this is the body I have to deal with. (...)Body and mind grow apart. The body ages but the mind stays young (...) Thus, body and mind grow apart, which is comparable to what you increasingly see in older people. They think of being 18 or 20 again and want to do things, like when they were 30 and could do anything. But that is not possible anymore. (Logan, REFINE, M, 61–70 year, >5 years CCRF)

Logan reported in the same interview how his body lost the taken-for-granted dimension:

Before [cancer], you weren't concerned about your body. You were your mind, as the motor of activities and you could do everything and your body went along with it. At a certain moment, the body starts saying: 'stop, stop, stop' and it starts slowing down (...). (Logan, REFINE, M, 61–70 year, >5 years CCRF)

This example illustrated how he experienced that his body has become a limiting factor for being and staying active. Their bodies suffered from severe fatigue for a

certain amount of time during the day. In searching for an explanation of their fatigue, patients objectified their body and used objective time to refer to the moment of their fatigue started. Some patients could mention the objective time of 1–2 hours that they were able to be active and concentrated. Most patients also knew almost exactly at what time of the day they would be exhausted.

Regaining one's 'I can'

Patients became aware that: 'this is the body you have to deal with' and realize that 'you have to take into account that you will not reach your former level because your body has changed'. Most patients anticipated on being fatigued. They would reduce the quality (i.e. intensity) and quantity (i.e. the number of) of their activities. Participants used different metaphors to express that they had to manage this complex situation through balancing their energy: 'you have to break daily activities into pieces', 'do not empty the tank at once' or 'make sure that the man with the hammer does not hit you too hard'. The experience of CCRF taught them to protect their limits, listen to their own needs and focus on what they can do. Sometimes they were forced to a timely stop of some of the daily activities that caused fatigue or to ask other people to help them.

Many patients searched for new ways to strengthen and move with their fatigued body, frequently supported by physiotherapists. Daniel commented on the need of physiotherapy:

Eh, now yes, I had of course the physiotherapy for weight training as well. That was important. You need that. Because if you don't have that, you stay weak, like a cracked egg. And it is important that you endure. Of course the physiotherapist advised to go walking, go biking, because that's good for you, because then you get your muscles back. Thus uh, yes the support of the physiotherapist was essential. (Daniel, FNK-AAF, M, 41–50 year, 6–12 months CCRF)

Other participants practiced yoga or balance exercises. Their ways of moving around changed as well, both inside and outside their house. Kyra reported about her difficulties to climb the stairs and vacuuming at home:

Now, I can do the housework again, there have been periods when I was not able to do that, I was also very short of breath from fatigue, well then you should not walk behind a vacuum cleaner, because that doesn't work, and a lot of bending over and bending is not convenient and climbing stairs is still tiring, but nowadays it is possible again, but also in a dosed way, so with breaks. So if I want to vacuum the whole house, I do the attic and then I take a break and then I do two of three rooms on the first floor, break, and that's how I work down stairs. (Kyra, FNK-AAF, F, 51–60 year, 6–12 months CCRF)

Patients adapted their movements to their energy level. For example, biking or walking distance and pace were adapted to their situation, by taking breaks regularly. The public transport was rarely used. Driving a car or motor was not always possible and only possible for short distances, preferably outside the rush hours.

Most patients had to carefully plan and select their activities during the week and weekends because the time they could be active was shortened. Some participants mentioned that they preferred to plan their activities in the morning because during that moment of the day they felt more energetic. Patients reshaped their social life

in response to their fatigue. Samuel described how he planned his social activities for the whole week:

Yes, nowadays, it is mainly scheduling everything. I keep track of my appointments with an agenda, and dinner with friends is all in there. So, yes, I have a schedule for the week, so I know where to go and what to do. Like today, yes, I am free of activities, now you [researcher] are here for one hour, maybe longer. And afterward, I will rest for an hour. (Samuel, REFINE, M, 31–40 year, 2–5 years CCRF)

Most patients adapted their lives to their chronic fatigue experience and found new ways to function in daily life. The support of close others (also see Theme 3) facilitated this adaptation.

Discussion

In this study, we explored the disruption of the lived body, lived time, lived space and lived social relations in patients suffering from CCRF. This chronic fatigue expressed itself in a broad array of experiences in patients who had finished their cancer treatment. We identified four interrelated themes that reinforce each other and illustrate the dynamic process of patients' bodily-felt experience of CCRF, which incorporated Worn out, Diminishment of one's 'I can', Invisibility, and Regaining one's 'I can'. The chronically fatigued body is experienced from two perspectives: as a subject that is feeling and acting and as a material object that is felt and observed. These experiences of subject and object are closely intertwined. That is, patients experience the intense affective sensations of CCRF in close relationship to the functional limitations of one's 'I can', and the consequences of the social invisibility of CCRF. Patients respond to these interrelated affective, functional, material and social dimensions of the CCRF experience by searching for new ways to adapt their lives towards CCRF in the process of regaining one's 'I can'.

Our interview data illustrated how bodily dys-appearance (Leder, 1990), that is, awareness of the body as an object, is present in patients with CCRF. The chronically fatigued body is experienced as an obstacle ('ill', 'alien', 'older') and a limitation by losing its taken for granted position to act 'free' in this world. Patients experience negative and intense bodily sensations, emotions, cognitions, and sensory stimuli that come to the foreground of their awareness and as such 'stand in the way' of their functioning in daily life. These findings of bodily dys-appearance are similar to other qualitative studies on patients' experiences with CCRF and other chronic illnesses (Bootsma et al., 2020; Groven et al., 2013; Zeiler, 2010).

The results showed that patients experience interrelations between the themes, and they report how their experience of CCRF can exacerbate. For example, when extremely fatigued (affective dimension), the body is negatively present in one's awareness (material dimension), limiting one's daily life functioning (functional dimensions). The mutual interaction and reinforcement of these affective, material and functional dimensions of CCRF are in line with embodied affectivity, which means that the body has a central position in how one perceives sensations and emotions, and how one's movement is affected (Fuchs & Koch, 2014).

During the interview study, we observed that participants obviously struggle to put their experience of the invisible problem CCRF into words caused by the various

feelings and potential cognitive problems. These difficulties to tell what they are feeling or explain this to others, could lead to miscommunication and misjudgment of the problem by close others and health professionals (Carel & Kidd, 2014). Leder used the term 'social dys-appearance' when a disruption in communication exists that is affected by 'the objectifying gaze of others' (Leder, 1990). The awareness of the body incorporates an intersubjective mode because self-understanding always involves seeing oneself through the eyes of others (Leder, 1990). The problem of CCRF is invisible to others and not explained by medical professionals. As such, the invisibility and differing expectations about fatigue after cancer can stigmatize and isolate patients.

Previous research on embodied experiences of cancer-related fatigue during and after treatment showed that regaining a sense of control could be an important aspect of boosting one's 'I can' (Bootsma et al., 2020; Wu & McSweeney, 2007). For example, if a patient is better prepared for their chemotherapy and fatigue is recognized, the patient will experience more control, which can reduce the level of uncertainty and improve their wellbeing. In turn, this can facilitate patients in regaining one's 'I can', which is not a disabling dimension, like the other themes, but a productive dimension that entails adaption (Grinfelde, 2018). The re-functioning results in a positive transformation of one's habitual identity that could facilitate new possibilities of perception, action, and self-understanding (Bootsma et al., 2021, 2020). It helps to respond in a healthy way to CCRF.

The experiential changes of space were part of all the dimensions of embodied CCRF. Patients with CCRF experienced affective sensations and objectification of their bodies that influenced their functional limitations to move 'freely'. Because of their loss of mobility, caused by their chronically fatigued bodies and the heightened sense of distance similar to motor disorders (Toombs, 1995), transitions in spatial arrangement (e.g. taking an elevator instead of the stairs), driving a car (instead of using public transport) and walking or biking a short instead of a long-distance) were practiced to regain one's 'I can'.

Previous research showed that how a partner responds to chronic fatigue impacts the fatigue of the patient. For example, when patients and partners worry together about the fatigue and its limitations, patients will experience more fatigue (Müller et al., 2019). Although we did not directly ask patients how fatigue influences their intimate relationships, several patients described how their partner was also affected by CCRF. Partners had to get used to the fact that patients were unable to do everything they used to do and need more time to rest. Open communication and support from partner, friends, and family appeared essential in regaining one's 'I can'.

Biographical, subjective, and objective time were used to refer to lived experience of CCRF. The frequently-made comparisons with pre-cancer fatigue experiences and activity levels are related to the disruption in biographical time (Charmaz, 1983; Corbin, 2003). Due to the affective sensations and functional limitations, patients experienced alienation of their bodies and a loss of their previous selves and expected a future with CCRF. Patients experienced different subjective time patterns that consisted of continuous experience of fatigue (e.g. omnipresent) and non-continuous experience of fatigue (e.g. fluctuations in severity). When patients describe how they perceive the cause of CCRF, objective time was used. Although patients tried to be attentive to objective time when planning activities, they could be overwhelmed by 'fatigue attacks'.

Similar to patients with other chronic diseases, such as diabetes (Morris, 2008), the chronically fatigued body has difficulties to improvise with time or to foresee what is needed. In a healthy situation, objective time is more structured around daily life and its activities (Corbin, 2003), while in the case of CCRF time is structured around moments of feeling less severely fatigued. Because of associated functional limitations, it took patients more time to carry out their daily life activities. The quality (e.g. reduced intensity), as well as, the quantity (e.g. fewer activities) of their activities had changed.

Strengths and limitations of the study

The small sample of 25 participants in total was homogeneous regarding characteristics of severe CCRF, that is, patients suffered from fatigue for at least three months after completion of treatment, and were active in seeking treatment for their fatigue. Nearly half of the sample suffered from severe depressive symptoms, while other severe psychiatric comorbidities were excluded. The experience of CCRF is often accompanied with anxiety and depressive symptoms (Agasi-Idenburg et al., 2017; Schellekens et al., 2020). Because we have investigated a diverse group of patients, we also reported a wide range of experiences and responses to CCRF. The open questions of the interviews started with the cancer experience and focused on experiences with CCRF, but we could not rule out that patients' answers were sometimes diffused with experiences of other comorbid conditions. We expect that the presence of partners during (part of the) interviews has led to more interaction and greater openness about the experiences. We cannot exclude that differences exist between patients with different cancer types and treatments. Another possible limitation is that the interviews were conducted by three different interviewers, but we expect that the influence was minimal because of the careful interpretative and inductive participant-oriented analysis process (Alase, 2017; Smith et al., 2009). We performed member checks with six new participants and they all agreed with the descriptions, which improved the credibility of the data. Although the sample (N=25) was quite large for the idiographic analysis process, the IPA methodology was carefully performed throughout all case-by-case and cross-case stages of analysis (Smith et al., 2009). During the analysis we continuously checked if our interpretations were consistent with the underlying data. The philosophical framework we applied; enabled us to improve and direct the inductive analysis of the findings at a more in-depth level and put it into a broader context of chronically lived experiences.

Clinical implications

The present study provides new clinically important information on how patients experience CCRF. Patients use different words to express their experience with CCRF which could help professionals to better recognize, report and treat patients. These insights could also improve the understanding and communication between patients, close others, and professionals with a focus on softening bodily objectification and supporting them in their functioning.

Health professionals could ask patients questions about their experiences with CCRF to come to a shared decision with the patient on what therapy is most suitable.

Questions could entail: what do you experience (intensity and interrelated symptoms), when do you experience CCRF (time and situation), what do you do about CCRF (when, how much, how and future expectations), how is your social support, how do you deal with CCRF and what is helpful?

Psycho-oncological care is a form of care that is lifeworld-led and focuses on the person as a whole and their significant others, which provides an existential view of well-being rather than focusing on one's illness. This type of care seems a promising way of helping patients handle the complex, dynamic, embodied problems that CCRF poses (Dahlberg et al., 2009; Schuit et al., 2021; Todres et al., 2007). Because patients are easily fatigued after travelling, web-based interventions for CCRF could offer a valuable alternative (Bruggeman-Everts et al., 2017).

Conclusion

This interpretative phenomenological analysis has provided a window into the inter-related affective, functional, material and social dimensions of the embodied experiences of CCRF and sheds light on the everyday world of those who live with it. This study shows that experiencing CCRF is a personal, complex and dynamic process that consists of different interrelated dimensions. This experiential knowledge adds additional embodied dimensions to the multidimensional problem CCRF and broadens the context with bodily, time, spatial and social aspects of how patients experience and communicate about CCRF. This information could help to design studies to measure individual patterns of fatigue to assist therapist to personalize effective treatment in clinical practice. We suggest more qualitative research in addition to quantitative methods is needed on this topic to explore how to best address the personal challenges individual patients with CCRF face daily in their social context.

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Data availability statement

Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data is not available.

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