

**Existential themes in the background of cancer-related
cognitive impairments in breast cancer survivors:
An interpretative phenomenological analysis**

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Abstract

Background: Cancer-related cognitive impairments (CRCI) are an important issue for breast cancer patients during the re-entry phase. This study aims to explore the existential themes that interact with the experience of CRCI in breast cancer survivors at the re-entry phase, to gain a holistic insight into the lived experience of breast cancer survivors.

Methods: Eleven breast cancer patients with CRCI 6-36 months after their last chemo treatment were interviewed. The semi-structured in-depth interviews were analysed using Interpretative Phenomenological Analysis (IPA).

Results: The qualitative analysis identified four themes: *'Awareness of death'*, *'Personal changes'*, *'Schism with others'*, and *'Responsibility'*. A heightened *'Awareness of death'* was evident in all participants at the re-entry phase, which appeared to invoke feelings of fear and gratitude. The experience of *'Personal changes'* seemed to depend on the subjective orientation in illness-trajectory. Heightened emotionality and different view on life were identified as profound changes, the latter leading to a re-evaluation of life. Participants felt a *'Schism with others'* due to a lack of acknowledgement for their CRCI and difficulties to share their new outlook on life with others. Participants differed in their perceived ability to take up *'Responsibility'* to live their lives authentically and in accordance with their new view on life.

Conclusions: These four themes closely aligned with Yalom's four existential concerns: death, meaninglessness, loneliness, and freedom. This research emphasized the importance to acknowledge the existential concerns that are latently present at the re-entry phase and optimize current interventions accordingly.

Keywords: *Breast cancer, Interpretative Phenomenological Analysis (IPA), Cancer-Related Cognitive Impairments (CRCI), Existential themes*

1 INTRODUCTION

Breast cancer is the most common cancer in Belgium, with 10 627 newly diagnosed women in 2017 (Belgian Cancer Registry, 2019). Improved treatment and early detection have led to a reduction in mortality rates and an increase in the number of breast cancer survivors. Currently, the five-year survival rate for Belgian women is 90.9 % (Belgian Cancer Registry, 2019). Nonetheless, breast cancer treatments like chemotherapy can lead to long-lasting physical, psychological, and social side-effects such as infertility, cardiotoxicity, premature menopause, fear of recurrence, sleep disturbances, cognitive problems, fatigue and a higher risk for a major depression (Ewertz & Jensen, 2011). These side-effects can become especially bothersome when patients try to re-assume their previous roles in life. This period is known as the 're-entry phase' of cancer survivorship and refers to the first 12 to 18 months following treatment (Stanton, 2012).

One of the side-effects prominent in the re-entry phase are Cancer-Related Cognitive Impairments (CRCI) (Stanton, 2012). CRCI are recently getting recognized as an important issue for breast cancer survivors (Ahles & Hurria, 2018; Bounous, Rosso, Cipullo, Francesca, & Biglia, 2020; Schmidt et al., 2015) and refers to difficulties in memory, concentration, verbal fluency, executive function (e.g. time-management, decision-making) and slower processing speed. Janelsins, Kesler, Ahles, & Morrow (2014) reported that approximately 75% of cancer patients are affected by cognitive impairments during treatment, and 35% report symptoms post-treatment, with 12-82% of breast cancer survivors demonstrating CRCI.

CRCI negatively affect daily functioning and Quality of Life (QOL) (Janelsins et al., 2014; Schmidt et al., 2015) and self-perceived CRCI are more frequently associated with higher rates of depression, stress, and anxiety than objectively measured CRCI (Yang & Hendrix, 2018). A recent study on the lived experience of CRCI found that CRCI negatively impact survivors' identity, relationships, and the ability to return to a pre-diagnosis sense of well-being (Henderson, Cross, & Baraniak, 2019). However, Henderson et al. (2019) noted inconsistencies regarding the severity of CRCI and their impact on QOL. The researchers suggest these contradictions may either reflect recall issues or can be explained by the fluctuating awareness of the existential threat of the cancer diagnosis. That is, the psychosocial impact is different when CRCI are viewed in isolation or compared to the existential threat of the cancer diagnosis (Henderson et al., 2019). Therefore, to adequately understand the experience of CRCI, a holistic understanding of

the experience of breast cancer is essential, recognizing the existential threat cancer poses and its impact on breast cancer patients lived experience.

The existential impact of breast cancer has recently been highlighted and 'the existential ordeal' has been identified as a core-theme across qualitative studies, present throughout the entire illness-trajectory of cancer (Smit, Coetzee, Roomaney, Bradshaw, & Swartz, 2019). Also, recent reviews have confirmed the potential of existential interventions to improve patient QOL (Bauereiß, Obermaier, Özunal, & Baumeister, 2018; Mozafari, Rahimian Boogar, Talepasand, & Ghahreman Fard, 2018).

There has been a lot of research confirming the negative impact of CRCI on daily functioning and quality of life (Janelsins et al., 2014; Schmidt et al., 2015). Mostly investigating CRCI with breast cancer patients in isolation, despite the well-established existential impact of (breast)cancer (Vehling & Kissane, 2018). However, the link between CRCI and existential concerns has not thoroughly been studied yet. Therefore, this study aims to explore the existential themes that interact with the experience of CRCI in breast cancer survivors at the re-entry phase, to gain a holistic insight into the lived experience of breast cancer survivors.

2 METHODS

Eleven breast cancer patients with CRCI were interviewed during the re-entry phase as part of a larger study on CRCI. These semi-structured in-depth interviews were analysed using Interpretative Phenomenological Analysis (IPA) and Yalom's existential psychotherapy (1980) served as the theoretical framework of the analysis.

2.1 Participants

Participants were recruited through the Ghent University Hospital as part of a larger study on CRCI (Schrauwen et al., 2020). Selection criteria stipulated that participants must be Dutch-speaking women with a stage I-III diagnosis of invasive breast cancer who have been treated with chemotherapy (FEC/Taxotere) within the past 36 months and who have cognitive complaints for more than 6 months after the last chemotherapy cycle. The study obtained full ethical approval from the University of Ghent and the Local Research Ethics Committee of Ghent University Hospital (Ref. B67020108507). No financial compensation was offered for participation in the study.

Interviews with eleven participants form the basis for this IPA-study. Traditionally, IPA-studies have small, fairly homogeneous samples to allow a detailed case-by-base analysis on a selected group for whom the research question is significant (Smith & Osborn, 2008a; Smith, Flowers & Larkin, 2009b). Participants were all white women with children, aged between 31 and 60 with a mean age of 46.8. In our sample, seven of the participants were married and three were in a long-term relationship, one participant was widowed. One participant was retired, the others were employed at the time of the interview. All received radiotherapy after chemotherapy and nine received hormonal treatment at the time of the interview. Time from last chemotherapy treatment to interview ranged from 6 to 36 months. All names in the paper have been changed to safeguard confidentiality.

Participant pseudonyms	Age	Time since chemotherapy	Marital status	Employment status
Ann	32	7 months	Married	Employed
Betty	50	12 months	Married	Employed
Carol	43	12 months	Married	Employed
Denise	54	8 months	Married	Employed
Eve	46	8 months	Living together	Employed
Fay	31	30 months	Living together	Employed
Gemma	51	6.5 months	Widowed	Employed
Holly	60	18 months	Living together	Retired
Irene	41	12 months	Married	Employed
Jane	52	36 months	Married	Employed
Kate	55	12 months	Relationship LTA	Employed

2.2 Data collection

Semi-structured interviews were chosen because it allows the participants to talk about how they experience CRCI and, provide the opportunity for the researcher to further elaborate on topics introduced by the participants. The interviews were conducted by the second author, a skilled qualitative researcher, at the Ghent University Hospital and lasted between 60 and 90 minutes. The interview guide, based on both scientific and grey literature, was used in a non-prescriptive and flexible way. Interviews were audio recorded and transcribed verbatim. For the specific aim of this study, we have re-analysed eleven interviews in order to investigate the existential impact of cognitive impairments.

2.3 Data analysis

The depth and richness of the interviews, together with the experience-focused nature of the research question are highly compatible with an IPA-design (Smith et al., 2009b). The first author collaborated closely with the qualitative researcher, who conducted the interviews, to preserve the contextual embeddedness of data for current analysis.

The interview transcripts were analysed using IPA, following the guidelines described by Smith et al. (2009b). IPA is a qualitative research approach dedicated to understanding how people make sense of major life experiences. It is nested within the phenomenological, hermeneutic

and ideographic tradition: *phenomenological* because it is concerned with the exploration of experiences in their own terms, *hermeneutic* because it is an interpretative endeavour acknowledging that both the interviewee and researcher are in a process of interpretation, and *ideographic* because it is committed to the detailed examination of the particular case (Smith et al., 2009b; Smith, 2011c).

The existential approach has a long history, with a disparity in theories and conceptualisations. In this study, Yalom's '*Existential psychotherapy*' (1980) was chosen as the theoretical framework for the analysis. Firstly, it provides a useful, coherent, research-based, and systematic paradigm to define and examine the existential background of CRCI. And second, it is compatible with the basic tenets of the IPA-approach, as it is oriented within the same philosophical traditions to understand the (existential) meaning of phenomena for a particular individual. Yalom (1980) describes four ultimate concerns that flow from the human being's existence in the world: death, freedom, isolation, and meaninglessness.

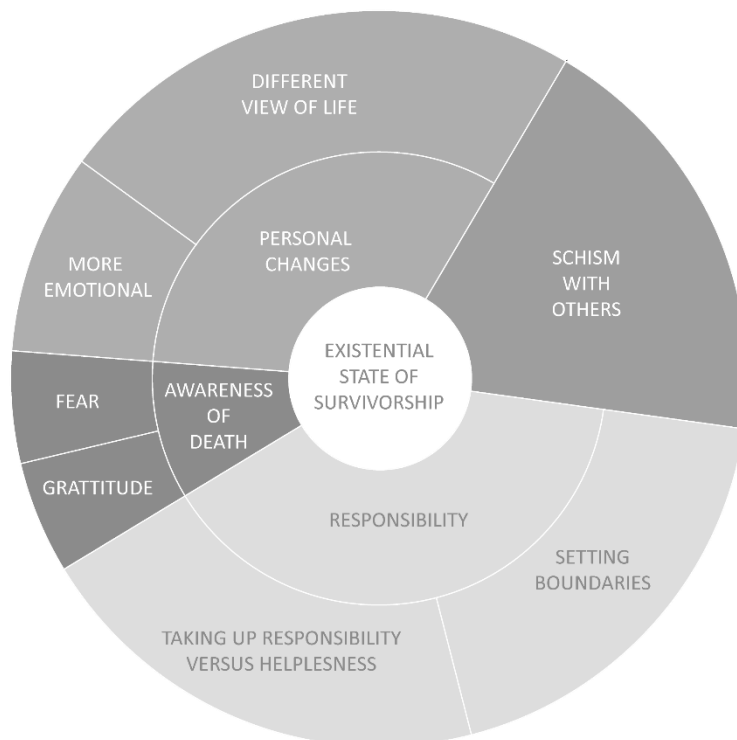
Immersion in transcripts was obtained by repeatedly reading them while making conceptual, descriptive, and linguistic notes. These notes informed the identification of initial emergent themes, which were later thematically clustered into superordinate themes. Once all cases were analysed separately, a cross-case analysis was carried out (Smith & Osborn, 2008a; Smith et al., 2009b). Throughout the analysis, the original interview transcripts were repeatedly revisited to check all interpretations against the participants' original wording, grounding the interpretations and ensuring internal homogeneity and external heterogeneity between themes (Smith et al., 2009b). To assist the analyse and keep an overview of the process NVivo, a qualitative data analysis software, was used (Bazeley & Jackson, 2013). In addition, the researcher kept reflective notes and continuously discussed emotional reactions during the analytic processes with the second author.

3 RESULTS

The interviews provided rich data on CRCI, participants' coping mechanisms, and the broad influence of CRCI and illness on their relationships and lives. However, this paper concentrates on one unprompted superordinate theme '*The existential state of survivorship*'. This term is derived from the book '*Surviving Survival*' and refers to the state of a cancer patient after finishing – hopefully – curative treatment (Little, Jordens, & Sayers, 2001). Concentrating on one superordinate theme enabled a focused analysis and reporting, which is central in the IPA-approach (Smith, 2011c).

'The existential state of survivorship' in our study consists of the following 4 identified themes: '*Awareness of death*', '*Personal changes*', '*Schism with others*', and '*Responsibility*'. The results-section will be structured based on these themes and subthemes.

Figure 1. Schematic representation of '*The existential state of survivorship*'



It should be noted that, although these themes are presented as separate entities, they are interlinked. For example, participants attribute personal changes to their heightened awareness of death.

3.1 Awareness of death

All participants commented on the link between cancer and death. Some only touched upon this topic very sparsely, while other participants talked elaborately about a heightened awareness of death and how this has changed them:

If you get diagnosed with cancer, then you actually get some kind of death sentence. I mean, because for all we know, you can die from cancer. Cancer is still, uhm, in general - I know the medical world has come very far - but cancer is still equated with dying. And for me, uh, yeah it made me live in a different way. (Eve)

In the extract above, Eve explicitly acknowledges the common view on cancer, linking it to death. The sudden awareness of death seems to confront participants with life's finiteness and evokes feelings of vulnerability and uncertainty. The fundamentals on which participants build their lives are put into question, leading to a drastic change in the way some participants lead their life. The extent and nature of these changes are discussed in the theme 'Personal changes'. Even though all participants talked about death, some patients considered this topic a taboo in the re-entry phase:

During chemo, oh, ... yeah at that time it was considered normal that you are afraid of dying. And now people around you expect you to Well, I can still talk to people about that ... But I have the feeling of ... Actually, it comes down to me not wanting to burden them... all the time... with my negative thoughts if I can call it that. It is always there ... [...] Yes, I'm happy, yes, I enjoy living, and gosh I love being with my kids. and ... But sometimes that thought comes up again: It might stop here. And I allow that. (Ann)

Ann stated that it is considered normal to talk about death and fear of death at the time of diagnosis and active treatment. In the re-entry phase, however, it is less accepted to speak about this fear and to 'burden' others with it. She emphasizes that being aware of life's finitude does not prevent her from being happy and enjoying life. This was also expressed by other participants and analysis distinguished two potentially co-existing reactions to heightened awareness of death: fear and gratitude.

Fear Fear of death is experienced as overwhelming and ever-present in the background but nonetheless, participants try to contain it. This fear seems to be more pronounced at times when death is most salient, such as before routine-testing and when experiencing bodily ailments. This is illustrated by the following quote of Irene:

The fear... what if they find something in my blood, that thoughts haunts me (Yes) And that week, for 4-5 days – I do not want to exaggerate but – I do not function well until I have the results. I ask for the results myself and then pfff tumor markers are good and I am reassured (Irene).

Some participants aim to contain this fear by rationalizing: they emphasize the useless and adverse effect of negative thoughts, and focus on the high survival rate of breast cancer. However, rationalizing does not always give the desired reassurance, as fear is irrational. This is showed in the following quote:

I have several colleagues who have had breast cancer, aggressive breast cancer and all of them survived it... But there is always that one person that doesn't make it through... That will probably be me? Negative thoughts... Negative thoughts ... you know that is not good, but... (Holly)

In describing her fear, Holly was aware that these negative thoughts are not helpful, but they are present. The quote suggests that rational thoughts, like the high survival rate amongst breast cancer patients, cannot help her contain this fear. She expects to be the exception who will die from breast cancer.

A second method participants applied to cope with the heightened awareness of life's finitude was to make arrangements in the event of death. This gave participants something tangible to do. Fay, a mother of 2 young children, said that this was her way to anticipate a sudden death:

I have two children, aged five and seven, for both I've made a booklet, in which I regularly write stories or make a drawing [...]. It gives me some sort of peace of mind that I can leave them something in case it does not end well for me... (Fay)

This extract suggests that these preparations can be interpreted as an extension of motherly care from beyond the grave. The certainty that their children will remember them or will be taking care of appropriately seems to reduce the threat of dying.

Gratitude Gratitude was the second reaction of participants on the heightened awareness of death, showing that death salience can also make a positive contribution to life. Key elements of gratitude include being more appreciative about what is present in one's life and the fact that one is still alive. The following extract illustrates this:

I think you realize that you need to be grateful for the blessing of having a family and children. Suddenly you have been confronted with the fact that this is not so... evident. You come to realise: oh, I have a child and it's healthy... We have everything we need and can go on a vacation every year... Because now you come from a situation where last year, we could not travel... And there was no longer a certainty. Will I see my child grow up? I've doubted whether I would see my child grow up... (Carol)

Carol emphasized her gratefulness for what is present in her life. This suggests that awareness of death can act as a driver to enjoy life to the fullest.

3.2 Personal changes

The first part of this section clarifies the extent of perceived changes, the second and third part of this section focusses on the two personal changes that have emerged from the analysis, respectively: (i) *'Being more emotional'* and (ii) *'A different view on life'*. *'Being more emotional'* is situated in the emotional realm, describing the experience of deep, overwhelming emotions that patients can hardly master. *'A different view on life'* is situated in the cognitive realm, describing how patients' outlook on life has changed. It is important to note here, that there is overlap and exchange between the two realms.

Participants' narratives entailed a wide variety of changes caused by their illness. Most participants acknowledged that illness influences them beyond the experienced side-effects

Kate expressed that although there are some personal changes, she does not feel changed at her core, she is still the same person but with a different focus now:

No, I have not become another person. Uhm, I can do things a little more intense than before. I think so. Appreciate life even more ... I can enjoy life more than before. Even though my friends say: 'you really didn't need that because you already did so. But I think it's more conscious ... (Kate)

The difference between participants on the extent of personal changes seemed to be linked to the imagined endpoint and to the stage in the illness-trajectory in which patients perceive themselves. At the onset, patients frequently view the return to 'status quo ante' as the endpoint of their illness-trajectory and all changes are considered temporary. However, after some time, the endurance and/or magnitude of changes start to show, bringing participants to realise that a 'status quo ante' is not always a feasible goal and that some changes may be permanent. In sum, when changes are considered temporary, it is unlikely that a patient will experience them as personal changes with a profound effect on their life. However, if changes are experienced as permanent, they are more likely to be considered to affect the sense of identity:

You no longer think the same about yourself. It is like there is a person before and a person after. And it is not that one is better or worse than the other. But it is no longer the same. (Carol)

In the extract above Carol describes her illness as a rupture, with a clear 'before' and 'after'. It is important to note that she does not prefer one over the other. It implies the importance to distinguish the nature of changes (that is superficial versus personal) from the appreciation of those changes (that is good versus bad). It seems that the appreciation of change depends on the interpretation of the change, and on the point of reference.

3.2.1 Being more emotional

Four participants called themselves more emotional after treatment of cancer compared to before. They noticed a difference in both quality (more intense) and quantity (more frequent) of their emotions. Each participant described similar experiences of suddenly appearing, intense and (almost) overwhelming emotions after listening to music, looking at art or seeing the beauty

of nature, etc., as if daily experiences suddenly touched the patients at their core, generating a range of emotions. The intensity of the emotions seems to dominate the experience:

While I was sick, I had to fight against the sickness so much that I did not cry a lot... And now it feels like all those tears that have been there all these months are coming out... So, all those emotions are coming now. And It can start because of something silly, a beautiful image or a beautiful painting [...] Something that touches me... Not necessarily something negative... But when I start crying, I cannot stop... It is for the rest of the day... (Denise)

The extract of Denise suggests that these deep emotions are almost disproportionately to the 'silly' things that provoked them. Furthermore, the extract underlines that these emotions are not necessarily negative. This is in line with the claim that the appreciation of change, in this case profound emotions, depends on the patient's interpretation. Some participants interpret their heightened emotionality as a mark of progress, a sign that they are now ready to handle these deep emotions. This implies that those participants see these emotions as manageable. However, other patients interpret these heightened emotions as a weakness. For them, these overwhelming emotions are perceived as beyond their control and, therefore, as much more disturbing.

3.2.2 A different view on life

All participants discussed being conscious of a changed view on life. This changed life perspective entailed a new sort of focus that was described as being more conscious of what is present in their lives:

When you are going on a bike ride, for example, you could pass everything before and now you notice things that could be there for years... You look at everything more consciously and with a different stance... Giving attention to... Having a different attention (Jane)

This extract illustrates how participants have a different awareness of their surroundings. Participants still do the same things as before, such as enjoying a drink or a bike-ride, but with an added intensity, a different consciousness, and a more pronounced feeling of fulfilment afterwards. It seems that instead of focusing on what cannot be done, the focus lies on what can still be done and on the happiness coming from these achievements (instead of striving for more or better). Kate explained that this new perspective on life made her life simpler and easier: *'No muss, no fuss'*. Participants stated that it became clearer what is important in life. Our analysis revealed that what is important in life, can be crystallised into two priorities: (i) enjoying life to the fullest and (ii) being present for significant others.

Enjoying life to the fullest This includes the participants' assessment of their appreciation of life as well as their determination to keep enjoying life more:

Oh, I enjoy my life a hundred times more. [...] I mean enjoyment, and that is a nice word for what I am encountering now, enjoyment of of... I try to get everybody on board with that, and I have succeeded with some, and with my husband it works very well, uhm... the quality of your life is much and much better. (Irene)

The extract of Irene visualises the greater joy of living and of transferring this to others. The transference of this outlook on life will be discussed in detail in *'Schism with others'*. It is important to note that the determination to enjoy life to the fullest seems to add to the overall quality of life. Participants seem to be able to achieve a certain level of joy in life more easily than before, realising that they do not need a lot to enjoy life. This can relate to the second priority of *'being present for significant others'* which can also boost joy into life.

Being present for significant others This is the second identified priority in life, reflecting a change in contact with important others. Participants report an experience of a deeper and more valued connection with loved ones: being more responsive to other people's needs, being more compassionate, human-oriented, and able to communicate on a deeper level with loved

Now in the exam period, I took half days off on some days that I knew she had a big exam. Before I wouldn't do that. My work would... and now I say no. I will enjoy taking care of her, taking a pause... [...] I would make sure there was pastry for her, I would bake a pancake and before... No, I would probably not have thought about that. Or maybe I would have thought about it but would not have done it. And now I do... (Carol)

In the extract above, it is not the attention for others that is different than before, but rather the urge to act accordingly. Acting upon this nurturing feeling seems to give this mother a lot of joy.

Two participants highlighted that the re-alignment of priorities led to an explicit re-evaluation of their career. Eve and Carol said that they did not see themselves going back into the rat race and they questioned whether they could do their job as before:

At my job I was a hunter and earning money and doing long hours and going to customers and trying to be the best and win. But now I think I am not going to do that job anymore, I do not want to do that job anymore. Give me a job at the secretary of in administration, customer service, let me take care of costumers and help people but not that... And if I earn a thousand euros less a month so be it. Before I was like a donkey, following the carrot hanging in front of my nose. Working till ten, eleven at night every day... I no longer think it's worth it. (Eve)

Relapse in old habits Although participants considered this new perspective on life as positive, it is not always easy to uphold:

Towards the future, I really want to hold on to that, that more intense experience that I have now. I want to keep doing that. That... Well, I've got this now more than before... And sometimes you do things, and it is like I'm relapsing... I call that relapsing now, when I think to myself: What are you doing now, that does not matter at all... Come on stop it... And then I stop doing that. (Denise)

Remarkably, Denise and Carol both used the phrasing 'to relapse in old habits' to explain their tendency to return to their old ways. Carol even stated that she is disappointed in herself when stepping back into the rat race or setting the bar high for herself. This suggests that while these new priorities are highly valued, they are not easily translated into everyday life and it takes constant effort to live by them.

3.3 Schism with others

All participants conveyed a feeling of distance from others. This was particularly mentioned when participants discussed others' reactions on their cognitive impairments, and on their new view on life.

All but one participant felt that their cognitive impairments were being misunderstood, and participants experienced a lack of acknowledgement by others. This lack of acknowledgement became salient regarding others' expectation of them being completely recovered because they look like their old selves.

I think, for other people, uh, yes, my hair is grown back, and I look good and it's over. You are cured, and that's it. And they understand if you begin to explain it to them, but every time again and it is like... yeah It is unbelievable or hard to explain that I forget- Yeah I tell them 'Yes I forget everything, you have to help me remember in case I forget or tell me.. But you notice that... Well other people don't care about that, and it is not their problem, so I get that, but it is, they don't make that link... And you can't expect them to... (Fay)

Fay's quote illustrates that participants notice implicit expectations of other people to be their 'old self' when active treatment has ended. Failure to re-assume their roles can be interpreted as malicious intent by others, for example participants recalled being told they came across as rude or uninterested when they forgot things which implied that others believed they

When people say: 'Oh that is not serious, I have that too'. Then I get so angry inside because they cannot know what I have been through... You know what I mean. People say: 'Oh no, that is not because of that, I have that too'. They cannot know what I feel. I can't stand that, I don't speak up to them but... Uh actually I can't stand it. (Denise)

These types of phrases are commonly used to reassure people, but they seemed to have the opposite effect, leading to frustration or anger. Betty even acknowledged that she deliberately conceals her cognitive impairments to avoid being hurt by the reactions of others.

The changed perspective on life, received mixed responses from others. Participants talked very fondly about their changed view on life, how they are now living more authentically, and their desire to share these insights with others in the hope to defer this authentic mode of being to other people. Kate described her willingness to share these new insights and the risk to be rejected for it:

Towards other people. I can look at them like why are you making things so hard... Just enjoy getting up and... Yeah, but I have to be a bit careful with my friends because after a while you look like Alice in Wonderland. [...] If I try to sell that to them saying: Come on guys, the shopping, the fuss... just enjoy the simple things like being able to sit and reading the paper. That is like... Although I used to enjoy that stuff too, that is not the point but still... (Kate)

An interesting point Kate makes is how she needs to be careful not coming across as 'Alice in Wonderland', living in a different reality. This suggests that participants want to transmit their new perspective on life towards others, but they are aware it can seem like they have their heads in the clouds. While Kate is still sympathetic towards the problems other people experience, Irene seems to have run out of patience:

How can I explain this, I can't handle people with futilities that come nagging about a dress that wasn't the right colour or something... I have a problem with my best friend, a very good friend of mine, that took excellent care for me for a while but I cannot stand her bullshit, her problems, do you understand what I'm trying to say?
(Irene)

Irene describes having difficulties being empathetic towards the – according to her – first-world problems of other people. This seems to create a schism between her and her best friend, because they lost a way to relate to each other in a meaningful way.

Both the lack of acknowledgement for cognitive complaints and failing to share new life insights confront participants with a feeling of existential loneliness. Despite being surrounded by supportive friends and family, this existential loneliness prevails. The following quote illustrates this, stressing the fact that other people do not understand what the participants had to go through, and that others cannot help or fix things for them:

I can have a whole network of fantastic friends so to speak, which I can call day and night... But the fear and insecurity are strongly connected to loneliness. Alone, Alone, in the end you have to do it alone... Maybe everybody has to do it alone...
(Gemma)

3.4 Responsibility

3.4.1 Taking up responsibility versus helplessness

Participants perceived breast cancer as entering their lives unexpectedly and at the most inconvenient time and mentioned the importance of having a reason or assignable cause for their illness and symptoms. Irene, for instance, said, '*For me, it is very important that everything has an explanation*'. While Holly explicitly wondered why illness had befallen her, because '*she did nothing wrong*'. This reveals the latent belief that illness is something one deserves, that there should be a logical and assignable cause for getting breast cancer. This theme highlights that the explanation participants give to their illness and symptoms can also enable or prevent participants to take up responsibility. Our analysis suggests that when a feeling of helplessness predominates, it prevents participants to take up responsibility. However, when participants

feel they can impact their experience of illness and symptoms, participants can assume ownership.

Helplessness Several participants engaged in a search for the cause of their illness and symptoms, believing that the only meaningful way to relieve the burden of illness, is by interjecting on the identified causes. However, this reasoning becomes problematic when no (modifiable) causes can be found:

No, because you cannot find a solution for it. Uh no, you can't find a solution uhm. Not by thinking, not by doing something because ... It is something that happens in your body over which you have no power. You can't say: I'm going to do exercises. It is not like that; you can't do anything about it uh. It is totally out of your power. And it is that helplessness that is so frustrating. You can't help it. If I had to say: you have to do a lot of exercises, then you will improve and you will wear out, or I don't know, but that is totally not. (Holly)

Holly differentiates her illness from other hardship that she had previously encountered in her life. For her illness, she saw no solutions and felt helpless. This experience of illness as something that befalls her without the possibility of doing anything about it, led to feelings of frustration. Other participants also described feelings of anger, sadness, and fear. Participants felt defeated by the illness and rendered any change to the situation impossible. Ann's narrative centred around this feeling of helplessness: *'It is my body, it is medical, so I have no choice'*. This leaves her in a passive role and at the mercy of this unpredictable illness. When participants experience this helplessness, they are unable to live authentically.

Taking up responsibility. Several participants believe they can impact their experience of illness and symptoms. Subsequently they felt able to play an active role, which allowed them to stay true to themselves during their illness-trajectory. The starting point was the acceptance of their changed reality, enabling them to assume responsibility. However, the process of acceptance was considered a struggle: acceptance did not equal surrender nor make everything suddenly easier. Kate emphasised this: *'I 've accepted that things will be different. Well accepted... Not in the sense of 'I surrender myself and I'm a patient for the rest of my life'. Because that is not who I am'*. Accepting the reality of illness enabled participants to examine instead of fighting the situation and to investigate the different roles they can adopt. This allowed participants to make a more deliberate choice in how to face their situation.

Furthermore, even when reality could not be changed, the way reality was interpreted could influence the experience of illness and symptoms:

Well yes... Somehow... Somehow you probably need to experiment and there must be an external stimulus to get me started. And it is like there is no external stimulus coming... But I cannot give this stimulus to myself... [...] ... Or I do not allow that stimulus, that is a different question... Am I currently not allowing that stimulus? Maybe that's it... (Betty)

While talking, Betty contemplates the different ways she can interpret her situation. On the one hand, she could wait for an external stimulus to help her 'get to action'. On the other hand, she questions whether maybe she is not allowing this stimulus. Depending on her interpretation, there are different roles she can embrace. In the first interpretation, she is passively waiting for something to happen, and there are limited things she can do. In the second interpretation, there is much more ground for her to take an active stance, to gain self-control and be empowered.

However, it is important to also acknowledge there are limits. Accepting a situation and taking up responsibility does not mean participants chose to be in this situation or are taking the blame. It is about doing what is within your limits to make the best out of the situation. While most participants talked about the assumption of responsibility in reference to their illness, some participants applied this insight to other life domains. For example, Eve changed the way she handles relationship problems by questioning her own share in what happens in her life:

I discovered it (her partner is on a dating website) two weeks ago. We talked it out, insofar as that is possible... But it haunts me. Before I would have said: okay, take your bags and leave. But now I'm like: Okay stop, why are you doing that? Why did he do that? Is there a reason? I wouldn't do that before. Eventually I admitted: I am also partially to blame, well to blame in the sense that there must be intimacy in a relationship and that wasn't there anymore. (Eve)

3.4.2 Setting boundaries

In order to lead the life they value, participants described a need to be honest about what they want in life and to set boundaries with others and themselves to live authentically. There seems

to be a delicate balance between focussing on themselves and focussing on others. An imbalance in either way could turn away participants from an authentic way of living.

Setting boundaries with others Setting boundaries with others was seen as crucial to avoid being caught up in problems of others. Several participants portrayed themselves as overly concerned with others before their illness. Denise even believed that she got sick because she allowed too much of others to affect her. Participants highlighted that setting boundaries is not meant to reject others, but rather to protect and be true to oneself. This increased assertiveness required participants to say 'no' to people and societal expectations. Although participants realised why they were setting boundaries with others, feelings of guilt and selfishness made it difficult to uphold these boundaries. Nevertheless, these feelings did not frighten participants, indicating the importance of taking care for oneself and living authentically.

Intuitively, '*setting boundaries with others*' seems to be in contradiction with participants new priority of '*being present for significant others*'. But as one participant explains: one can be there for others on the important matters, but refuse to take the unimportant things to heart:

If it's important, just come to me. But about those silly little problems, um, for example: 'I forgot my USB-drive again and I can't find it'. I'm going to help you search if necessary, eh, but I'm going to take that to heart ... I cannot bear that anymore ... (Kate)

Setting boundaries with oneself Setting boundaries with oneself is needed to avoid negative thoughts, sorrow, and fear to take over. Eve depicted these negative thoughts as a '*train of thought*' that, once set in motion, cannot be controlled. The next extract of Denise shows how simple rumours can result in uncontrollable negative thoughts and even distort experiences:

Yeah, I try, well try, If I feel now, I'm going too far I get myself together. For example: they told me at Eureka, drinking coffee is not good because that is made with tap water and that is actually not healthy because it contains hormones. And at a certain moment I realized that when I drank coffee, I didn't enjoy the taste anymore. Then I thought, you are going too far, that is overdoing it. (Denise)*

**Eureka is the name of the hospital's cancer-rehabilitation program*

Participants emphasized the importance of letting go of worries, as a way of caring for themselves. Different methods to do so were identified:

For example, I could worry about my daughter having that mutation or not. But I don't. I did fear that I would. But to this day I can honestly say that I don't. I hope that science will have progressed enough by then so that those worries will be outdated by then. (Carol)

Carol appears to use logic to counter the worries about her daughter potentially having a gen-mutation. Another way participants tried to prevent worrying was by using mindfulness-inspired techniques such as focusing on the present. When setting boundaries with themselves it seems important that participants experience trust in themselves to hold up these boundaries.

4 DISCUSSION

Recent studies on the experience of breast cancer survivors show the existential domain is omnipresent (Smit et al., 2019) and suggest it may influence the experience of Cancer-Related Cognitive Impairments (CRCI) (Henderson et al., 2019). This study examined the existential themes that underlie the variety of experiences of breast cancer survivors with CRCI during the re-entry phase. Four major existential themes were identified, closely aligning with the four existential concerns described by Yalom (1980).

The first theme '*Awareness of death*' illustrates the heightened awareness of death among all participants, which continues throughout the survival period and triggers feelings of fear and gratitude. This theme correlates with Yalom's description of the existential concern of death that refers to the conflict of humans' inevitable death and the wish to stay alive (Yalom, 1980). Awareness of death is commonly acknowledged at the time of diagnosis and in patients with advanced disease (Smit et al., 2019). However, our results indicate that breast cancer patients with early-stage disease at the re-entry phase still experience a heightened awareness of death, impacting their thoughts and behaviour, and this despite the high survival rates of non-metastatic breast cancer. Our study found that this consciousness of the finiteness of life – although concealed sometimes – can affect participants both negatively and positively. Negatively, when fear restricts breast cancer survivors in living their lives, and positively when it leads to a greater appreciation of life. This is in accordance with Ochoa Arnedo et al. (2019) view that responses of stress and growth in cancer both stem from the threat to one's physical or psychological integrity. During recent years, the study of the co-existence of post-traumatic stress and posttraumatic growth became a dynamic research area in itself, that is getting more recognized. However, much remains unclear on this topic due to some contradictory outcomes (Ochoa Arnedo et al., 2019)

The second theme '*Personal changes*' describes how patients give meaning to profound changes in personality and perspective on life. In line with previous research on CRCI (Henderson et al., 2019), changes appear to be considered minor and superficial if participants believed that a return to status quo ante (i.e. before illness) is possible. However, when this return to quo ante was questioned or deemed impossible, because of the extent of the (physical and/or psychological) changes or the sustainability of these changes, participants were more likely to regard these as personal changes.

The construction of a new perspective on life focusing more on enjoying life and being present for others, was defined by our sample as a personal change. Most participants linked this shift in life perspective to their awareness of finitude. It aligns with Heidegger's description that awareness of personal death can bolster a shift from a 'forgetfulness of being' to a 'state of mindfulness of being' (Heidegger, in Yalom, 1980). And is consistent with the literature on breast cancer as a biographical disruption (Bury, in Smit et al., 2019) or a boundary situation (Jaspers, in Yalom, 1980) which describes illness as an event that may stimulate an authentic life.

This new perspective on life coincides with previous research describing positive self-growth amongst breast-cancer patients (Parikh et al., 2015; Smit et al., 2019). Furthermore, Lui and colleagues identified 'personal strength' and 'relating to others' as two domains in which growth quickly develops (Lui et al., 2013).

For two participants this new life-perspective prompted a re-evaluation of their careers, leading them to conclude they did not want to return to their previous jobs. This aligns with a recent literature review describing a reduced work engagement and ability to work among breast cancer survivors. The researchers suggested further that a re-evaluation of priorities could drastically affect the meaning of work (Sun, Shigaki, & Armer, 2016).

The pursuit of an authentic and personally meaningful life confronts breast cancer patients with a plethora of possibilities to constitute their lives, and subsequently reveals that there is no external meaning present. Therefore, the core of the theme '*Personal changes*' corresponds with the existential concern of meaninglessness described by Yalom (1980). Participants seemed to have an urge to give meaning to illness and its effects, while at the same moment being confronted with existential meaninglessness. The confrontation with meaninglessness may be most salient at the re-entry phase when struggles to resume previous roles in private and work life lead to a re-evaluation of those roles' meaning.

The third theme '*Schism with others*' captures how the experience of illness and CRCI can confront patients with existential loneliness. Participants portray others as a source of support, but nevertheless there remains an unbridgeable gap because of two reasons. First, other people do not know what breast cancer survivors have been going through. Participants in our study felt a lack of acknowledgement for their experience from others. Especially well-intended phrases like '*Don't worry about that*' or '*Oh but I've got that too*' appeared to hinder any further conversation because patients felt their right to speak about their CRCI was revoked by these statements, and because patients felt they cannot respond without coming across as overly defensive. Henderson et al. (2019) also found a lack of medical acknowledgement for

CRCI, which was not present in our study. A possible explanation is that being asked to participate in a large study focussing on CRCI signified a form of medical acknowledgement for our participants. Second, even the most supportive person cannot alleviate participants' burden of cancer. These experiences can be linked to the ultimate concern of isolation (Yalom, 1980).

Social support is very important, as it is linked with well-being (Fong, Scarapicchia, McDonough, Wrosch, & Sabiston, 2016). Fong et al. (2016) found that female breast cancer survivors at the re-entry phase report low-to-moderate levels of satisfaction with the quality of their social support system which may reflect this unbridgeable gap. Fortunately, low social support has previously been identified as an important and modifiable predictor of distress in breast cancer survivors (Brandão, Schulz, & Matos, 2016; Syrowatka et al., 2017).

The fourth theme '*Responsibility*' emphasizes the varying degrees of ownership participants experience when facing their illness. Although some participants expressed being overwhelmed by the illness and by the loss of control, most participants tried to take an active role against illness, its side-effects, and life. They did so by, firstly, accepting the reality of their situation, and secondly, focusing on what is still within their control. To gain control and live authentically, participants felt the need to set boundaries for themselves and others. Several participants emphasized that, even though they could not control what happens in their lives, they could control how they perceive it. This theme echoes the existential concern of freedom, the individual is responsible for his or her own world, life design, choices, and actions (Yalom, 1980). Our findings are consistent with recent studies that found a link between subjective appraisal of illness and the coping strategies patients employed (Badana et al., 2019; Hamama-Raz, Pat-Horenczyk, Roziner, Perry, & Stemmer, 2019).

Our analysis showed that the four identified themes were interlinked. We found a heightened '*Awareness of death*' that confronted participants with a potential ultimate loss of self. Moreover, the enduring CRCI confronted participants with a loss of ability that undermined a sense of self, which is also found by Henderson et al. (2019). This loss of identity appeared to urge participants to let go of their previous self and accompanied view of life, and create and find new meanings, which is reflected in the theme '*Personal changes*'. However, participants experienced a '*Schism with others*' as both CRCI and their changed self, especially their new life-perspective, were misunderstood by others. This experienced schism confronted them with feelings of existential loneliness. The way participants searched to create meaning to build a sense of identity and coherent view of life is reflected in the theme '*Responsibility*' together with

the need to set boundaries in order to guard this new found life perspective and sense of self. While the theme focusses on the assumption of responsibility in order to live authentically, the researchers noticed a parallel with how participants coped with CRCI. That is: participants that actively coped with their CRCI seemed more able to assume responsibility to live life authentically and vice versa, while other participants expressed helplessness in coping with CRCI and in other life domains.

Our findings support Stanton's (2012) observation that the re-entry phase creates particular challenges. The focus in the re-entry phase is returning to one's life as before and resuming social roles. Our findings suggest that this return is not always feasible or even desired, and leads to confrontations with societal expectations. Participants seem to feel that even though they are concerned about death, they ought not to talk about these concerns at this phase. Doubts about the ability to pick up their former roles while having CRCI are present, but most participants are creative in finding ways to overcome practical difficulties. Nevertheless, apart from the practical difficulties, some participants realise they do not want to resume previous roles because they have experienced a shift in meaning. When the environment does not understand this, participants can experience existential loneliness.

4.1 4.1 Strengths and limitations

This qualitative study entailed a comprehensive examination to uncover the existential themes present in the experience of breast cancer patients with CRCI. However, it also has its limitations. First, inherent to the chosen IPA-design, this study has a small sample to enable the in-depth - analysis IPA requires. This means that empirical generalisability of the findings cannot be assumed, however, that was never the intention of this study. (Smith & Osborn, 2008a). Second, this is a secondary analysis of previously collected qualitative data. The principal researcher, together with the original interviewer, returned to the data to address a new research question. This could have influenced the results because participants' interviews were conducted to initially answer another research question. This matter was reflected upon, but due to the broad and flexible interviews and, thus, the richness of the data, a secondary analysis was deemed favourable. Contextual embeddedness was ensured by close collaboration with the original interviewer. Third, our study examined the connection between CRCI and existential dimensions using Yalom's existential psychotherapy as a theoretical framework. The benefit of using this theoretical framework is twofold. First, it provides a coherent, theoretical, and empirical-based structure to define the existential approach that can form a base to integrate the plethora of

constructs and different operationalisations currently present in the existential research field (Vehling & Kissane, 2018). Second, it provides a solid foundation to understand current interventions and develop future interventions to promote positive outcomes for breast cancer survivors. However, while our data support this existential framework, it is a paradigm to structure and understand the illness-experience of breast cancer survivors among other paradigms.

4.2 4.2 Future clinical and research directions

These conclusions lead us to encourage future research by giving the following recommendations. First, our research emphasizes that CRCI is not experienced in isolation but is intertwined with four existential themes that are present during the re-entry phase. However, more research is needed with early-stage cancer patients at the re-entry phase. Our sample consisted of breast cancer patients who had enduring CRCI after chemotherapy, and it is possible that these lasting cognitive complaints, together with the experience of chemotherapy enhanced the existential impact and personal changes found in this study. Future research can investigate if the existential impact is also present with breast cancer patients at a curative stage that only needed limited treatment and did not experience lasting cancer-related impairments such as CRCI.

Second, our study found a heightened awareness of death during the re-entry phase. While qualitative research has highlighted the presence of fear of death in cancer survivors, quantitative research on death anxiety is lacking, partly because of the absence of a valid measure of death anxiety in cancer survivors treated with curative intent (Sharpe, Curran, Butow, & Thewes, 2018). Therefore, more research is needed to understand what death anxiety means for patients treated with curative intent, and in patients at the re-entry phase of the illness-trajectory.

Third, existential interventions that proved to be beneficial have been predominantly studied in advanced cancer patients (Bauerei et al., 2018). Our findings suggest that these interventions could also have their merit for early-stage cancer survivors in the re-entry phase. Especially since the re-entry phase can signify a transition phase in which it becomes clear if one can hold on to their basic beliefs or needs to create new vital meanings. Our findings on personal changes support Ochoa Arnedo's suggestion that after primary cancer treatment, meaning-making therapies are more relevant, as patients begin to accommodate their experience and become more open to consider vital changes (Ochoa Arnedo et al., 2019).

Fourth, existential loneliness was identified as an existential theme in our analysis. More qualitative research is needed to continue exploring the concept of existential loneliness in the field of oncology. Also, interventions that target social support should be wary of the presence of feelings of existential loneliness. Even though existential loneliness cannot be eliminated, it can be shared in a way that compensates for the pain of isolation (Yalom, 1980) and therefore it does not preclude support interventions. Especially peer support can be valuable to share feelings of loneliness. Skirrbekk and colleagues (2018) found that peer supporters (i.e. other cancer patients) are perceived as a valuable source of support, since they could understand patients in ways that neither friends, family, nor healthcare providers were able to. Informing friends and family about the effects of breast cancer (such as CRCI) will increase knowledge about the illness and in turn, increase acknowledgement towards patients and strengthen feelings of connectedness.

Finally, this analysis showed that the assumption of responsibility enables participants to live authentically. Interventions that focused on this assumption by targeting personal strengths, mean-making, and self-regulation abilities, have shown to enhance well-being in breast cancer patients (Casellas-Grau, Font, & Vives, 2013; Pat-Horenczyk et al., 2015). Therefore, we find it necessary that future psychological care programs for breast cancer patients disentangle and target adequate responsibility assumption.

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