

DEVELOPING EMOTION-FOCUSED THERAPY FOR FEAR OF CANCER
RECURRENCE IN SURVIVORS OF CANCER

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Dedication and acknowledgements

I dedicate this thesis to all the patients – children and adults – I have had the privilege of working with at the *Portuguese Institute of Oncology of Porto (IPO-Porto)* over the years. Assisting each of you through one of your hardest life challenges has profoundly shaped who I am today, both personally and professionally.

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Abstract

The present work endeavors to expand the understanding and application of Emotion-Focused Therapy (EFT) within the context of the cancer population, focusing specifically on the issue of Fear of Cancer Recurrence (FCR), a common difficulty for cancer survivors. Comprising three distinct studies, this research sought to establish EFT as an effective alternative for assisting individuals with cancer managing their dysfunctional FCR.

Study 1 consisted of a qualitative meta-analysis, synthesizing qualitative descriptions of FCR, and corroborated the widespread presence and importance of the FCR experience for cancer survivors. This thorough examination yielded a comprehensive understanding of FCR, highlighting its multidimensional nature, which encompasses emotional, mental, physical, and behavioral facets. FCR was found to be a diverse, complex, and challenging experience, observed along a continuum from adaptive to maladaptive responses. Some participants described FCR in terms suggestive of trauma and employed vivid metaphors reflecting conflict and vulnerability.

Study 2 involved an exploratory EFT intervention for FCR carried out in a hospital setting with 17 participants. In this study, significant differences were found between pre- and post-intervention and useful aspects of the therapeutic process were identified by the participants, underscoring EFT's potential as a valuable alternative to conventional psychological interventions for mitigating dysfunctional FCR.

Study 3 delved deeper into the EFT process for FCR by employing task analytic methods to scrutinize a case study from Study 2. This analysis elucidated the possible underlying structure of EFT intervention tailored to address FCR, i.e., an EFT model for FCR, highlighting both the aspects common to other EFT interventions and some specific aspects of EFT for FCR.

Key findings from this thesis corroborate the viability of EFT as a treatment modality for dysfunctional FCR, due to its effective conceptualization of FCR within the EFT framework. The humanistic, experiential, and existential elements of EFT are particularly suited for assisting people dealing with FCR. This research highlights two pivotal clinical areas often overlooked in existing psychotherapeutic interventions for FCR: the importance of addressing traumatic experiences, whether cancer-related or not, for this client population; and the need to explore existential core pain aspects, such as death, loneliness, and the search for meaning, when helping clients coping with their dysfunctional FCR. Additionally, this thesis suggests that maladaptive grieving processes related to cancer experiences may contribute to dysfunctional FCR.

By combining qualitative insights, exploratory outcome data, and the development of a specific therapeutic model, these distinctive contributions bridged theoretical insights and practical applications to the fields of psycho-oncology and psychotherapy, holding value for researchers, clinicians, and practitioners. Further research is required to further validate and develop these findings.

Key-words: fear of cancer recurrence, emotion-focused therapy, trauma, existential, grief

Resumo

O presente trabalho procura expandir a compreensão e a aplicação da Terapia Focada nas Emoções (TFE) ao contexto da população oncológica, focando especificamente a questão do Medo de Recidiva do Cancro (MRC), uma dificuldade comum nos sobreviventes de cancro. Composta por três estudos distintos, esta investigação procurou estabelecer a TFE como uma alternativa eficaz para ajudar os indivíduos com cancro a lidar com o seu MRC disfuncional.

O Estudo 1 consistiu numa meta-análise qualitativa, que sintetizou descrições qualitativas do MRC, e corroborou a presença generalizada e a importância da experiência de MRC para os sobreviventes de cancro. Este exame minucioso permitiu uma compreensão abrangente do MRC, realçando a sua natureza multidimensional, que engloba facetas emocionais, mentais, físicas e comportamentais. Verificou-se que o MRC é uma experiência diversificada, complexa e exigente, observada ao longo de um continuum entre respostas adaptativas e desadaptativas. Alguns participantes descreveram o MRC em termos sugestivos de trauma e utilizaram metáforas vívidas que reflectem conflito e vulnerabilidade.

O Estudo 2 envolveu uma intervenção exploratória de TFE para o MRC, realizada num contexto hospitalar com 17 participantes. Neste estudo, foram encontradas diferenças significativas entre o pré e o pós-intervenção e os participantes identificaram aspectos úteis do processo terapêutico, sublinhando o potencial da TFE como uma alternativa valiosa às intervenções psicológicas convencionais para mitigar o MRC disfuncional.

O Estudo 3 aprofundou o processo de TFE para o MRC, recorrendo a métodos de análise de tarefas para analisar um estudo de caso retirado do Estudo 2. Esta análise

elucidou a possível estrutura subjacente à intervenção da TFE adaptada para lidar com o MRC, i.e., um modelo de TFE para o MRC, destacando tanto os aspectos comuns a outras intervenções de TFE como alguns aspectos específicos da TFE para o MRC.

Os principais resultados desta tese corroboram a viabilidade da TFE como uma modalidade de tratamento para o MRC disfuncional, devido à sua conceptualização eficaz do MRC no âmbito da TFE. Os elementos humanistas, experienciais e existenciais da TFE são particularmente adequados para ajudar as pessoas que lidam com o MRC. Esta investigação destaca duas áreas clínicas fundamentais, muitas vezes negligenciadas nas intervenções psicoterapêuticas existentes para o MRC: a importância de abordar experiências traumáticas, relacionadas ou não com o cancro, nesta população de clientes; e a necessidade de explorar aspectos existenciais da dor central, como a morte, a solidão e a procura de sentido, ao ajudar os clientes a lidar com o seu MRC disfuncional. Além disso, esta tese sugere que os processos de luto desadaptativos relacionados com as experiências de cancro podem contribuir para o MRC disfuncional.

Ao combinar percepções qualitativas, dados de resultados exploratórios e o desenvolvimento de um modelo terapêutico específico, estes contributos distintos estabeleceram uma ponte entre os conhecimentos teóricos e as aplicações práticas nos domínios da psico-oncologia e da psicoterapia, sendo de grande valor para investigadores, clínicos e profissionais. É necessária mais investigação para validar e desenvolver estes resultados.

Palavras-chave: medo de recidiva do cancro, terapia focada nas emoções, trauma, existencial, luto

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Chapter 1

Introduction

The central problem in psychotherapy is the nature of anxiety.

Rollo May (*in* The Meaning of Anxiety, 1977)

1.1. A scientist-practitioner journey: The story of this thesis

When I started the Ph.D. program in 2015, I had already dedicated a decade to my work at cancer hospital. Throughout those years, I consistently maintained periods of training and supervision alongside my daily practice. In the initial years, my focus lay primarily in the domain of Psycho-Oncology, which gradually transitioned into a deep engagement with Psychotherapy, specifically Emotion-Focused Therapy (EFT). I identified myself as a scientist-practitioner, embodying the role of a psychologist who employs and integrates scientific psychological knowledge into their practice. This integration often involved reflection on my clinical practice through supervision and ongoing professional and personal development (Blair, 2010). However, the heavy caseload at the hospital, characterized by diverse and highly demanding situations, disrupted the balance between my clinical practice and my commitment to research and scientific inquiry (Blair, 2010). This discrepancy compelled me to seek a more profound understanding of my practice within a scientific framework and to better acknowledge and reflect upon my own acquired experience.

The University of Maia's Ph.D. program, rooted in the scientist-practitioner model, offered a perfect alignment with my needs. It respected my practitioner expertise while simultaneously enriching and expanding my scientific proficiency in clinical theory and research methodologies, as well as their practical application. I consider myself

fortunate to have had the guidance of dedicated teachers and the camaraderie of supportive colleagues, some of whom have become genuine friends, throughout this demanding yet rewarding journey.

The duration of this path, spanning about 9 years, mirrors the challenges I encountered along the way. The initial two years of the Ph.D. program were characterized by enthusiasm and easiness, during which I transformed some of my implicit knowledge into explicit understanding, thanks to the guidance of my teachers. I highlight two of the works I developed in that period, particularly stimulating for reflecting on my hospital practice and for providing a basis for my Ph.D. studies: a) “Discourses about the hospital psychologist: reflections on the Critical Discourse Analysis” (for Professor Sofia Neves; original title in Portuguese) and b) “The centrality of the therapeutic relationship in psychotherapy with cancer patients – an argument for humanistic-experiential approaches in Psycho-Oncology” (for Professor Carla Cunha; original title in Portuguese).

Subsequent years proved more arduous as I navigated my Ph.D. studies amid the demands of a bustling clinical hospital practice, confronting the very difficulties that prompted my decision to pursue this PhD. In the latter stages of my studies, I experienced burnout, culminating in my departure from the oncological hospital where I had dedicated nearly 18 years of service – the place where this research work was cultivated. Completing this thesis has become both the realization of many of my clinical and research insights and a means of concluding a significant and transformative chapter in my professional journey.

1.2. Statement and definition of the research topic

Worldwide, the number of individuals surviving a cancer diagnosis is increasing (<https://canceratlas.cancer.org/the-burden/cancer-survivorship/>), mostly due to treatment advances and early detection of the disease (Hawkes, 2019; Miller et al., 2022). However, whether someone has successfully overcome cancer after treatment, or continues to deal with a chronic condition, there persists a multifaceted array of challenges across various dimensions of a person's life: physical, psychological, social, and spiritual (Fobair, 2007). The most identified concerns by cancer survivors are anxiety, stress, or worry about cancer returning, living with uncertainty, fatigue/tiredness, long-term treatment effects, financial concerns, and sleep disturbance; additional particular concerns relate to specific diagnosis (e.g., gastrointestinal problems in gastrointestinal cancer) (Chua et al., 2021; Link et al., 2022; Ness et al., 2013).

Among the myriad concerns faced by cancer patients and survivors, the Fear of Cancer Recurrence (FCR) emerges as a prevalent and pressing issue. FCR is defined as “fear, worry, or concern relating to the possibility that cancer will come back or progress” (Lebel et al., 2016, p. 3266). A meta-analysis by Simard et al. (2013) reveals that 73% of patients experience FCR, with approximately half enduring it at a moderate to high intensity, and a minority (7%) facing it as an intensely distressing experience (Simard et al., 2013). In its more dysfunctional manifestation, FCR can wield a profoundly negative impact on emotional well-being, daily functioning, and the ability to envision one's future (Mutsaers et al., 2016, 2020).

Recognizing the critical importance of this theme for individuals dealing with cancer, research, and knowledge about FCR have burgeoned in recent decades. This evolution has ranged from establishing a consensual definition (Lebel et al., 2016) to developing theoretical perspectives (e.g., Fardell et al., 2016; Lee-Jones et al., 1997),

devising assessment tools (Thewes et al., 2012), and proposing a range of psychological interventions (e.g., for a systematic review and meta-analysis, Tauber et al., 2019). Predominantly, the cognitive-behavioral paradigm has been employed for these interventions, both in traditional and contemporary iterations, whereas humanistic-experiential psychotherapies have remained relatively underexplored and under-investigated in this context.

Emotion-Focused Therapy stands as a well-established intervention for addressing various psychological difficulties, such as depression, anxiety, and trauma (Elliott, 2013; Greenberg & Watson, 2006; Paivio & Pascual-Leone, 2010; Timulak & McElvaney, 2015). Substantial portions of patients who currently have cancer or who have survived cancer struggle with one or more of these psychological challenges (Tsai et al., 2020; Yi & Syrjala, 2017). Building on previous promising results from our exploration of EFT's applicability to the cancer population (Elliott et al., 2014), and equipped with training in EFT, my colleagues and I suggested that this approach could serve as a valuable framework for comprehending and addressing this specific cancer-related experience.

To this end, we initiated an exploration into the hypothesis that EFT could emerge as an apt and effective intervention for individuals navigating the complexities of cancer survivorship while struggling with dysfunctional FCR. Given the relative dearth of research on this approach within the cancer context, we initiated our investigation from a phenomenological standpoint, beginning with a qualitative meta-analysis and subsequently conducting two studies directly relevant to EFT's applicability to this specific cancer-related issue. Using diverse data types, including both qualitative and quantitative information, and blending outcome and process investigation, within the context of a clinical framework, we facilitated a comprehensive exploration of the FCR phenomenon. This approach aimed to serve both theoretical and practical needs,

embodying the essence of the scientist-practitioner model, where research informs practice and vice versa.

1.3. Introducing the Ph.D. studies

The three studies presented in this thesis evolved sequentially, each designed to address distinct yet complementary research questions:

- 1) What is FCR for people experiencing it?
- 2) Can EFT serve as an effective treatment for people experiencing FCR?
- 3) What does EFT for FCR look like?

The first study was intended to respond to the first research question and is presented in Chapter 3 through the article: “Fear of cancer recurrence: A qualitative systematic review and meta-synthesis of patients’ experiences” (Almeida et al., 2019). Honoring the phenomenological roots of the humanistic-experiential therapies (Cain et al., 2016), we sought to understand what it meant for individuals to experience and manage FCR, by conducting qualitative meta-analysis, incorporating data from qualitative studies as well as from mixed-methods research. These qualitative data promised to offer a richer understanding of the quality and texture of people’s experience (Willig, 2008) as well as to consolidate the scattered qualitative information existing throughout the literature. Similar to traditional meta-analysis conducted for quantitative studies, qualitative meta-synthesis offers a broader interpretation of qualitative data derived from selected studies, remaining true to the interpretation of each individual study (Barroso et al., 2003).

The second study of this thesis was “Emotion-Focused Therapy for Fear of Cancer Recurrence: A Hospital-Based Exploratory Outcome Study” (presented in Chapter 4; Almeida et al., 2022). This study was grounded in an exploratory study initiated in 2013, aimed at understanding how EFT could be effectively employed to address cancer-related

issues (Elliott et al., 2014). The original study encompassed 29 patients with diverse cancer diagnosis and associated psychological difficulties, and its initial analysis yielded promising results. The study presented here involved a subset of 17 patients from that larger study who identified FCR as a significant concern warranting psychotherapeutic intervention. The primary objective of this study was twofold: firstly, to assess the effectiveness of EFT as a treatment modality for individuals struggling with FCR, and secondly, to identify the specific EFT therapeutic aspects that clients found most beneficial. To achieve these goals, we employed a mixed methods research approach, including both quantitative and qualitative data.

It is important to acknowledge the inherent limitations of a naturalistic study, in contrast to a randomized controlled trial (RCT). However, such naturalistic investigations can provide valuable insights into the potential relevance of further exploring the application of EFT in the context of this specific and pressing issue within the realm of cancer care.

From the 17 patients with significant FCR treated with EFT (Study 2), two good-outcome cases have been closely analyzed by our research team and presented elsewhere: (fictitious names) *Louise* (Almeida et al., 2016) and *Tom* (Almeida et al., 2019).

The third study “Developing an EFT Model for Fear of Cancer Recurrence: A Case-level Task Analysis” (Almeida et al., 2023), presented in Chapter 5, evolved from the Study 2, and was intended to answer the research question, “What are the main components of EFT for FCR?”. In order to pursue this goal, an adaptation of the task analysis methodology (Greenberg, 2007) was done, using the single-case study *Louise*. This allowed us to build a rational-empirical model of EFT-FCR, which constitutes the first phase of a task analysis, the discovery-phase (Greenberg, 2007).

These three studies provide a picture of EFT as a viable alternative for helping cancer survivors dealing with dysfunctional FCR.

Chapter 2

Literature review

2.1. The experience of cancer

In ancient times, cancer was synonymous with inexorable suffering and death. Significant advancements in treatment and cure in the last century, particularly in the developed world, have been transforming the expectations and experiences of those affected by cancer, which are now more varied and even include more positive aspects. Cancer no longer universally equates to death or intense suffering; nevertheless, although there are some contradictory meanings and resignification in current social representations of cancer, there is still a core connection to death and pain (Higuita-Gutiérrez et al., 2023; Pocinho et al., 2021; Robb et al., 2014).

Cancer is the disease people most fear (Vrinten et al., 2014; Watson et al., 2023), with the very word “cancer” still tending to be avoided and dreaded. In the general population, cancer is perceived as a cruel, unpredictable, and indestructible enemy, evoking fears of being close to it, of not having resources to keep it away, of the implications of the diagnosis and of dying of cancer (Vrinten et al., 2017); in cancer patients, fears of death, dependence, disfigurement, disruption, and disability are equally common (Lesko, 1998).

A cancer diagnosis is generally an unexpected and undesirable event, disrupting or permanently altering a person’s life projects and goals, as well as impacting all their life dimensions – physical, emotional, mental, social, spiritual. As Eric Cassell eloquently stated: “Suffering is experienced by persons, not merely by bodies” (Cassell, 1982). As such, throughout the cancer trajectory, individuals often have to face high emotional demands, including dealing with so-called “negative” emotions like anger, fear, and

sadness, as well as the need for effective emotion regulation (Conley et al., 2016). Moreover, they must engage in a coping process, i.e., “constantly changing cognitive and behavioral efforts to manage external and/or internal demands that are appraised as taxing or exceeding the resources of a person” (Lazarus & Folkman, 1984, p. 141).

In the field of Psycho-Oncology, the concept of *distress* has been used to encompass a spectrum of possible responses to the cancer experience, from what may be considered normal and adaptive to dysfunctional and maladaptive. The *National Comprehensive Cancer Network* (NCCN) defines *distress* as:

a multifactorial unpleasant experience of a psychological (i.e., cognitive, behavioral, emotional), social, spiritual, and/or physical nature that may interfere with one’s ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis (Riba et al., 2021, p. DIS-1).

In recent decades, significant distress has been estimated to affect about 30%-50% of patients with cancer (Carlson et al., 2019; Derogatis et al., 1983; Mehnert et al., 2018; Mitchell et al., 2011; Zabora et al., 2001). The most identified psychiatric diagnoses include adjustment disorders, anxiety disorders, mood disorders, sleep disorders, sexual dysfunctions and delirium (Anuk et al., 2019; Venkataramu et al., 2022)

The application of a Post-Traumatic Stress Disorder (PTSD) diagnosis to cancer-related adjustment difficulties remains controversial. This is primarily because cancer is typically a complex, multifaceted situation, involving a succession of multiple and ongoing stressors, rather than a single, discrete event that poses an immediate threat (Cordova et al., 2017). Furthermore, there tends to be a much higher incidence of PTSD-

like symptoms (ranging from 20% to 80%) than cases that meet the full DSM PTSD diagnostic criteria (ranging from 3%-4% to 35%) (www.cancer.gov).

From an individual perspective, the cancer path is highly unique, presenting specific challenges that depends on various factors, including aspects related to the disease (e.g., location, stage, symptoms, and prognosis; types of treatment and their impact); to intra- and interpersonal aspects (e.g., life stage; prior life events, including previous experiences with cancer; spiritual/religious beliefs; coping ability; perceived social support); and to societal aspects (e.g., misinformation related to popular beliefs; involvement on the disease process and with medical team) (Holland & Goen-Piels, 2003). Some aspects have been identified as constituting risk factors for poorer adaptation, such as having a history of psychiatric disorder or substance use disorder, history of trauma/abuse, severe comorbid illnesses, social problems (e.g., family conflicts, social isolation, discrimination, financial problems), younger age, having young/dependent children, spiritual/religious concerns, and uncontrolled symptoms (Riba et al., 2021).

It is also possible to identify periods of increased vulnerability for cancer patients, associated to different phases of the cancer journey: finding and investigating suspicious symptoms; learning the diagnosis; advanced cancer diagnosis; waiting for the beginning of treatments; changes in treatment plan; the end of active treatments; medical follow-up and surveillance; relapse or disease progression; transition to survivorship; transition for palliative treatments and to end-of-life care (Riba et al., 2021).

For the purpose of this thesis, our focus will be primarily on the survivorship phase, keeping in mind that survivors have also traversed some of the preceding phases, with their specific challenges.

2.1.1. Cancer survivorship

The field of Psycho-Oncology evolved alongside the changing landscape of cancer survivorship, increasingly addressing the needs of a growing population of patients who had successfully completed treatment (Holland, 1992). The period of *survivorship* was consequently recognized as a distinct and challenging phase requiring specific attention and psychosocial intervention.

However, various perspectives and definitions exist regarding the concepts of *survivor* and *survivorship*. The *National Cancer Institute* (NCI) defines a *survivor* as “one who remains alive and continues to function during and after overcoming a serious hardship or life-threatening disease” and links *survivorship* to “the health and well-being of a person with cancer from the time of diagnosis until the end of life” (NCI, n.d.). In contrast, European definitions often regard survivorship as beginning at the conclusion of primary cancer treatments (Feuerstein, 2007).

Interestingly, one of the early reflections on cancer survivorship, offered by Fitzhugh Mullan, who referred to himself as “a physician with cancer”, introduced the notion of three distinct *seasons of survival*. These include the *acute phase*, extending from diagnosis to the completion of initial treatments; the *extended phase*, from that point onward, primarily characterized by watchful waiting and the medical surveillance; and the *permanent survival*, which represents the extended period of disease-free survival with a reduced probability of reoccurrence (Mullan, 1985). This model incorporates both NCI and European definitions and illustrates survivorship as a dynamic process, commencing from diagnosis, which presents varying challenges for patients and is closely related to each individual’s unique journey.

At first glance, the survivorship period might seem to be a phase predominantly characterized by positive experiences. These may include physical recovery, feelings of

relief and happiness for having overcome a life-threatening disease, and the possibility to return to familiar routines and functional activities. However, overlapping these positive and restorative experiences, often lie other debilitating and challenging experiences, which can help explain why the term “survivor” is not universally embraced by patients themselves (Berry et al., 2019).

Among the most prominent and frequently identified concerns during this phase are fear of cancer recurrence (FCR), fatigue, living with uncertainty, managing stress, and sleep disturbance (Ness, 2013). Notably, FCR stands out as the most cited and studied concern among cancer survivors, consistently ranking within the top five of their concerns (e.g., Chua et al., 2021; Simard et al., 2013). Given that FCR is the central topic of this thesis, it will be further explored in the next section.

2.1.1.1. Fear of cancer recurrence: the Damocles’ syndrome

FCR has been metaphorically associated to the parable of Dionysius, tyrant of Syracuse (c. 432 – 367 BC), and Damocles, one of his flatterer courtiers, to whom the king proposed to temporarily change places to show him his lived experience. Initially delighted with the richness of the experience, Damocles soon realized his king had always a sword hanging above his head. That made him repudiate his original view of the king’s situation, feeling it was not possible to find happiness in the presence of such an ever-present terror (Cicero, 1886). This anecdote, which named the “syndrome of Damocles”, first applied to childhood cancer survivors (Koocher & O’Malley, 1981), is paralleled to the complex survivorship experience, with the sword representing the possibility of cancer recurring and ultimately death.

Considered a natural and common experience attached to the experience of having had a cancer (Herschbach & Dinkel, 2014), FCR is an almost universal experience for

cancer survivors. In terms of scientific literature, interest in the theme of FCR has increased exponentially since its earlier descriptions in the decade of 1980's (Northouse, 1981), linked to the recognition, in the same period, of the survivorship phase as a distinct one in the cancer journey needing specific investigation (Holland & Rowland, 1989). By the time we began this work in 2015, FCR had already become a major focus of the psycho-oncology literature, with several systematic reviews and meta-analyses on FCR published in the decade of 2010's. Notable among these were some comprehensive reviews, which addressed FCR prevalence, assessment, determinants, consequences and interventions (Cancer Australia, 2013; Simard et al., 2013). Other reviews homed in on specific aspects, such as self-reported measures of FCR (Thewes et al., 2012), FCR among long-term survivors (Koch et al., 2013), FCR psychological treatments (Chen et al., 2018; Tauber et al., 2019) and more recently even on the economic burden of FCR in the healthcare system (Williams et al., 2021). Qualitative studies were also found, although not systematized (e.g., Arnold, 1999; Berman, 2013; Cesario et al., 2010; Raymer, 1993).

According to Simard's meta-analysis, 73% of survivors experience some degree of FCR, 49% in moderate to high levels and 7% high levels of FCR (Simard et al., 2013). Younger age, female gender, lower educational status, lower income, and greater symptom burden have been associated with heightened FCR levels, as well as to higher levels of distress, depression and anxiety (Cancer Australia, 2013).

FCR is frequently identified as the foremost concern and unmet need for survivors of cancer, even years after post-diagnosis (Simard et al., 2013). It might be present in any period of the cancer path and persist over time; and the period around the diagnosis might turn out to be the hardest time for experiencing FCR (Savard & Ivers, 2013). However, the awareness of the real possibility of cancer reoccurrence is not necessarily a

problematic or dysfunctional experience, so that FCR can be seen as ranging on a continuum from adaptive to maladaptive (Lebel et al., 2016). Both positive and negative behavior change can be triggered by FCR, including reassurance-seeking behaviors and the use of complementary alternative medicines (CAM) (Cancer Australia, 2013; Simard et al., 2013). Having some level of FCR can be helpful for the adoption of healthy behaviors (e.g., regular check-ups, healthy diet, using sunscreen, maintaining adherence to medical treatments) and avoiding unhealthy ones (e.g., tobacco use) (Cancer Australia, 2013). In its dysfunctional presentation, FCR can be very debilitating, exerting a negative impact on patient's quality of life, emotional well-being, and functional capacity (Cancer Australia, 2013; Simard et al., 2013).

A consensus definition of FCR was reached in 2016, defining it as “fear, worry or concern relating to the possibility that cancer will come back or progress” (Lebel, 2016, p. 3266). Research has since aimed to better distinguish clinical from non-clinical FCR. A qualitative study by Mutsaers et al in 2016, identified 10 features distinguishing clinical FCR, including death-related thoughts, daily recurrent thoughts that are difficult to control and impairment in functioning (Mutsaers et al., 2016). A later Delphi study with 65 experts in FCR found four key features essential for clinical FCR, such as high levels of preoccupation and worry, their persistence and hypervigilance to bodily symptoms (Mutsaers et al., 2020).

There are also debates on whether to designate clinical FCR as a formal diagnosis, with 84% of the FCR experts consulted in the above cited Delphi study finding it would be helpful to diagnose it (Mutsaers et al., 2020).

Furthermore, there are other constructs close or related to FCR; these are frequently used interchangeably but are not necessarily the same. They include worry, health anxiety/illness anxiety disorder (APA, 2013), uncertainty in illness, or fear of

progression (FoP) (Coutts-Bain et al., 2022; Maheu et al., 2021). Some characteristics are common to FCR, Health Anxiety, Worry, and Uncertainty such as the presence of triggers, both internal (e.g., somatic/physical symptoms) and external (e.g., medical exams and media) (Maheu et al., 2021). In addition, FCR and FoP were found to be highly correlated (Coutts-Bain et al., 2022). However, FCR seems to present unique features such as specific concern about cancer coming back or progressing, cancer-related worry, decisional regrets related to treatments, hypervigilant coping or difficulty in making plans for the future (Maheu et al., 2021). For example, in Illness Anxiety Disorder, the person presents a preoccupation with having or acquiring a serious illness, high levels of anxiety related to health issues and excessive health-related behaviors, without somatic symptoms (APA, 2013), whereas in FCR survivors show a sense of loss of security in their own bodies (Maheu et al., 2021), probably related to their past experience of actual cancer. Also, despite some common predictors of FCR and FoP (e.g., meta-cognitions or the perceived risk of recurrence), the tendency for body checking and reassurance seeking were found to be exclusively associated to FCR and not to FoP (Coutts-Bain et al., 2022).

There has also been research examining the relationship between FCR and anxiety disorders. Dinkel et al (2014) explored the comorbidity between clinical FoP (which for these authors, have been considered equal to FCR) and anxiety disorders, and found that only a small proportion of patients (6,7%) showed high FoP comorbid to an anxiety disorder (Dinkel et al., 2014). In another study, FCR intrusive thoughts were found to be significantly associated with general anxiety disorder (GAD) symptoms and it was possible to find similarities between GAD worries and FCR, as well as resemblance to obsessions more characteristic of obsessional compulsive disorder (OCD) when FCR severity increased (Simard et al., 2010).

There is strong evidence linking FCR to distress, depression, and anxiety (Simard et al, 2013). Moreover, FCR has been associated with post-traumatic stress disorder (PTSD) symptoms, particularly avoidance and intrusion (Black & White, 2005; Simard et al., 2013). It is noteworthy that these intrusions often revolve around future-oriented fears about one's health (Kangas et al., 2002).

Regarding the theoretical formulations of FCR, these have been mainly cognitive-behavioral therapy (CBT), starting from the first proposal of Lee-Jones et al (1997). Lee-Jones et al's (1997) formulation was based in the traditional cognitive-behavioral theory, identifying internal and external cues as *antecedents*; fear of recurrence in its cognitive and emotional aspects; and behavioral responses and psychological effects as *consequents* (Lee-Jones et al., 1997). Later, a contemporary cognitive-behavioral theoretical approach for FCR was presented by Fardell et al (2016), who proposed a cognitive processing approach to FCR, integrating the Common Sense Model (CSM), the Self-Regulatory Executive Function (S-REF) and the Relational Frame Theory (RFT) (Fardell et al., 2016). In a study of 2019, the original model of Lee-Jones (1997) was empirically tested and refined (Maheu et al., 2019).

Most of the interventions developed for FCR are in line with these theoretical proposals, within the cognitive-behavioral paradigm. Tauber et al (2019) meta-analyzed 25 FCR psychological interventions, from which 19 used a cognitive-behavioral therapy framework (10 a traditional framework, 9 contemporary CBTs) and only 6 other theoretical-practical frameworks (which could not be grouped due to their diversity and included psychodynamic therapy and supportive therapy) (Tauber et al., 2019).

A systematic review of CBT interventions for FCR in breast cancer survivors found that in most of the RCTs CBT interventions were effective, with face-to-face

interventions with a duration of at least one month being more effective than brief online or telephone interventions (Park & Lim, 2022).

Given the variability in the severity of FCR among individuals, a stepped model for managing FCR has been proposed. This model allows for tailored interventions based on the person's needs, providing a cost-effective approach that reserves high-intensity treatments, with highly specialized professionals, for those with severe FCR (Pradhan et al., 2021).

As shown in this section, FCR has been broadly investigated in the last decades, although the examination of theoretical and intervention aspects is still ongoing. Considering our proposal for exploring EFT for helping patients dealing with dysfunctional FCR, in the next section we will address how humanistic therapies (including EFT) have been used in the cancer population, paving the way for the possibility of using it for FCR.

2.2. Humanistic-Experiential Psychotherapies in cancer

Humanistic, also referred to as humanistic-experiential or only experiential psychotherapies (HEP), include different therapy models sharing common assumptions, values and a unified theory of human function and dysfunction (Cain, 2001). Fundamental to these therapies is the view of the person as a holistic unit, naturally inclined towards self-fulfillment and growth, exercising freedom and responsibility in their choices and the establishment of a deep, empathic therapeutic relationship to facilitate the process of change (Cain et al., 2016).

Traditionally, HEP included person-centered psychotherapy, gestalt therapy, and existential approaches, later incorporating other modalities, such as focusing-oriented therapy and emotion-focused therapy (Greenberg et al., 2013). In the field of Psycho-

Oncology, where cognitive-behavioral approaches prevail (Hulbert-Williams et al., 2018), a growing body of research attests to the effectiveness of HEPs in medical conditions, including cancer (Elliott et al., 2004, 2013, 2021).

In the more recent and updated review on the effectiveness of HEPs, Elliott et al. (2021) analyzed 57 studies involving people coping with chronic medical conditions, with nearly half being patients with cancer in both early and late stages. The meta-analysis suggests that mainstream HEP (i.e., person-centered, EFT and supportive-expressive group therapy) are efficacious treatments for medical populations, including cancer patients.

Most of the studies described are group interventions, one of the most popular being the Supportive-Expressive Group Therapy (SEGT), originally developed by Spiegel, Bloom & Yalom for women with metastatic breast cancer (Spiegel et al., 1981). This model was developed from Yalom's existential psychotherapy and what he defined as the "givens of the existence": death, isolation, meaninglessness, and responsibility (Yalom, 1981). The main goals of SEGT are helping participants deal with existential concerns, promote emotional expression and enhance social support (Classen & Spiegel, 2011). This intervention has evolved to be used and tested also with non-metastatic or early-stage cancer patients (e.g., Ho et al., 2016).

Meaning-centered group psychotherapy (MCGT), another popular group intervention with an existential orientation, based on Viktor Frankl's concepts of meaning and in Yalom's work, uses didactics and experiential exercises for help patients diminishing despair related to the end-of-life and to search for, connect with and create meaning in their lives (Breitbart & Applebaum, 2011). This group intervention, consisting of 8 sessions, have demonstrated efficacy in randomized controlled trials (Breitbart et al., 2010, 2015). The adapted individual version, with 7 sessions, had also showed significant

treatment effects (small to medium in magnitude) in quality of life, sense of meaning, spiritual well-being, anxiety, and desire for hastened death (Breitbart et al., 2018).

Motivational interviewing, another humanistic-rooted therapy, has also been proposed as a psychotherapeutic tool for helping patients with cancer change unhealthy habits and behaviors (Burkhalter, 2011), and in a meta-analysis it has shown solid evidence for changing lifestyle behaviors and responding to the psychosocial needs of cancer patients and survivors (Spencer & Wheeler, 2016).

Although not clearly defined theoretically, Dignity Therapy, which was developed by Harvey Chochinov and his team for cancer patients near the end of life (Chochinov et al., 2005; Chochinov & McKeen, 2011), might also fit into a humanistic framework, although not explicitly stated by the authors. Dignity can be seen as a universally human right, which relates to personal values, freedom, responsibility, participation and recognition of capabilities (Clancy et al., 2021; Li et al., 2023). In a medical setting, it may also implicate the way health-care providers treat a patient, involving a positive attitude, active listening, empathy, compassion as well the respect and appreciation of the patient as a whole person (Chochinov & McKeen, 2011). A recent systematic review and meta-analysis has shown that dignity therapy is significantly effective in terms of dignity and anxiety outcomes (Lee & Jeong, 2023).

In addition to the mentioned models, we recognize that the overarching term “supportive psychotherapy” in cancer care (Watson & Kissane, 2011) encompasses fundamental elements extensively cultivated in humanistic therapies, such as empathy. However, it does not qualify as a distinct humanistic psychotherapy, for not presenting itself as a precisely defined psychological treatment model. Instead, it seems to underscore the major significance of therapeutic relationship aspects within any psychotherapy approach for cancer patients.

Finally, regarding individual EFT, the therapy on which this thesis is based on and to which the next section is dedicated, there is a scarcity of studies using it with a cancer population. Connolly (2016) treated 6 women with breast cancer presenting Comorbid Anxiety and Depression (CAD) with an EFT intervention and found a significant pre-post in mean scores (Connolly, 2016). Also, Elliott et al (2014) presented promising results of an EFT intervention in an exploratory study with a group of patients with different cancer diagnosis showing diverse cancer-related distress (Elliott et al., 2014). Besides these studies, we are only aware of a randomized controlled trial using a couples version of an EFT intervention, which showed a significant improvement in marital functioning and patients' experience of caregiver empathic care (McLean et al., 2013).

2.2.1. Emotion-focused therapy for Fear of Cancer Recurrence

In the realm of Humanistic-experiential psychotherapies (HEP), Emotion-focused therapy (EFT), as previously mentioned, closely aligns with the foundational values and perspectives on human nature and psychological processes shared by this therapeutic family (Cain et al., 2016). Distinguishing itself as a neo-humanistic therapy, EFT reinterprets key elements of traditional humanistic psychology through the integration of contemporary theories on emotion, attachment, and dialectical constructivism (Elliott, Watson, et al., 2004). Its uniqueness relies on prioritizing work on emotions and a distinctive combination of relationship and task principles (Elliott, Watson, et al., 2004; Elliott & Greenberg, 2015).

In EFT, emotions are viewed as essentially adaptive, containing fundamental information for guiding people's needs and actions; however, they can become problematic due to past traumatic experiences and the way people relate to them, often by ignoring or dismissing them (Elliott et al., 2004). The differentiation between primary

and secondary emotions, and adaptive and maladaptive emotions, guides the work of the EFT therapist. Primary emotions are directly related to the experience and hold adaptive information, while secondary emotions must be addressed to access the primary ones; maladaptive emotions, linked to past experiences that do no longer adequately fit present situations, need to be accessed and transformed to conduce to adaptive emotions (Greenberg & Pascual-Leone, 2006).

Client's emotional difficulties are seen as linked to a core painful and maladaptive emotion (the *core pain*), and the therapeutic process involves an emotional deepening process, in which the therapist assists clients in transitioning from a more undifferentiated distress to the primary adaptive emotions (Elliott & Greenberg, 2015). The processes of emotion awareness, expression, regulation, reflection, and transformation help people make sense of their emotions, enabling change (Greenberg, 2011). Specific therapeutic tasks are offered to clients to address particular difficulties, presented on sessions (e.g., a two-chair work for self-criticism).

As a transdiagnostic therapy (Timulak et al., 2020), EFT has demonstrated efficacy across various psychological difficulties, including depression (e.g., Goldman et al., 2006; Greenberg & Watson, 1998), interpersonal issues, trauma, and abuse (e.g., Greenberg et al., 2008; Paivio & Nieuwenhuis, 2001) and anxiety (Elliott, 2013; Shahar et al., 2017; Timulak & McElvaney, 2015). The hypothesis that EFT could be a useful intervention for FCR, a cancer-related issue, stems from previous research on EFT, particularly its application in anxiety, since FCR can be seen as an anxiety-related issue.

In anxiety disorders, such as general anxiety or social anxiety, emotional avoidance and difficulties in differentiating and staying with painful emotions are common, which constitute processes secondary to more core maladaptive emotions, such as loneliness, shame or terror/fear (Elliott, 2013; Elliott & Shahar, 2017; Timulak &

McElvaney, 2015). Developing and maintaining a secure therapeutic relationship, crucial to any EFT process, is particularly important for anxious clients. For instance, a socially anxious person, who tends to feel judged by others, can benefit from a non-judgmental and deeply empathic therapeutic experience, providing a corrective emotional experience and improving emotion regulation (Elliott & Shahar, 2017). Clients with general anxiety difficulties also identify the soothing and validating relationship with the therapist as helpful aspects of therapy (Timulak et al., 2017).

While the same elements of EFT are used for different disorders, researchers have developed adapted models to treat anxiety difficulties. Elliott and Shahar (2017) proposed a five-phase model for Social Anxiety, including making contact and beginning to explore social anxiety, initial work with presenting secondary anxiety processes, deepening work with primary shame processes, emotional change by working with and repairing the sources of social anxiety, and consolidation and ending. Similarly, Timulak and McElvaney (2015) proposed an EFT treatment for GAD, involving building a safe therapeutic relationship, using a shared case formulation, working with secondary processes such as emotional avoidance, accessing and differentiating core pain, articulating unmet needs, and transforming the core pain.

The accumulated knowledge on both FCR and EFT allowed our research team to explore the use of EFT for helping people deal with dysfunctional FCR. The next three chapters present each article that composes this Ph.D. thesis, aiming to respond to our research questions.

Chapter 3

Fear of cancer recurrence: A qualitative systematic review and meta-synthesis of patients' experiences (Study 1)

Abstract¹

Fear of cancer recurrence (FCR) is a significant issue for most cancer survivors, with nearly half of cancer survivors reporting it at moderate to high levels of intensity. We aimed to further explore the experience of having FCR from the point of view of patients by systematically reviewing qualitative studies. Following PRISMA guidelines, 87 qualitative studies were selected. All participants' quotes about FRC were extracted, then analyzed using a conceptual framework based on the emotion-focused therapy theory of emotion schemes, which consist of experienced/implicit emotions, along with perceptual-situational, bodily-expressive, symbolic-conceptual and motivational-behavioral elements. According to participant descriptions, FCR was found to be an intense, difficult, multi-dimensional experience. Considering the diversity of experiences identified, it is useful to look at FCR as an emotional experience that extends along a continuum of adaptive and maladaptive responses. For some participants, FCR was described in trauma-like terms, including forms of re-experiencing, avoidance, negative thoughts and feelings, and arousal or reactivity related to cancer-related triggers or memories. Vivid metaphors expressing vulnerability and conflict also reflect the strong impact of FCR in patients' lives and can help therapists empathize with their clients.

¹This study has been published in 2019 in the journal “Clinical Psychology Review”, with the doi number 10.1016/j.cpr.2018.12.001 and the following authors: Susana N. Almeida, Robert Elliott, Eunice R. Silva and Célia M. D. Sales.

Introduction

Metaphorically identified as the Sword of Damocles, fear of cancer recurrence (FCR) is defined as the “fear, worry, or concern relating to the possibility that cancer will come back or progress” (Lebel et al., 2016, p.3266). To a certain extent, this fear is an expected response to the real threat of cancer and cancer treatments (Herschbach & Dinkel, 2014). However, FCR has been identified by cancer survivors as one of their major problems (Simard et al., 2013). It is estimated that 73% of cancer survivors experience FCR, half (49%) with moderate to high intensity, and 7% with high intensity (Simard et al., 2013). FCR as a problem appears not to be related to a specific type of cancer (Krok-Schoen, Naughton, Bernardo, Young, & Paskett, 2018; van de Wal, van de Poll-Franse, Prins, & Gielissen, 2016). However, it has been associated to some sociodemographic characteristics: women, younger and less educated cancer survivors report higher FCR (Koch, Jansen, Brenner, & Arndt, 2013; Crist & Grunfeld, 2013; Simard et al., 2013; van de Wal et al., 2016); being Hispanic or Caucasian, not having a partner, having at least one child or being socially isolated have also been associated with higher FCR (Koch et al., 2013; Koch-Gallenkamp et al., 2016); as well as having more (and more severe) physical symptoms and less emotional well-being (Koch et al., 2013; Simard et al., 2013; van de Wal et al., 2016). Longitudinal studies suggest that FCR persists time (Crist & Grunfeld, 2013; Koch et al., 2013; Simard et al., 2013). Moreover, a cross-sectional study with a large sample of survivors (Van de Wal, 2016) found a significant association between time since diagnosis and FCR, with survivors <5 years since diagnosis experiencing higher FCR than those with >5 years. Patients with higher levels of FCR can be affected in their well-being, quality of life, and emotional and social functioning (Cancer Australia, 2011; Herschbach & Dinkel, 2014). Some defining

features of clinical FCR have been suggested, such as high levels of preoccupation, worry, rumination, or intrusive thoughts; maladaptive coping; functional impairments; excessive distress; and difficulties making plans for the future (Lebel et al., 2016). Having recurrent and long-lasting images or thoughts about cancer or death, and believing cancer will return, were some other aspects found to distinguish clinical from non-clinical FCR (Mutsaers et al., 2016). Methods for assessing and screening significant levels of FCR have been also developed (e.g. FCRI-SF; Simard & Savard, 2009). Due to its relevance for the quality of life and clinical implications for cancer patients, there is a growing body of research on FCR, predominantly quantitative. Previous systematic reviews have organized the existing knowledge regarding the prevalence, course over time, determinants, and consequences of FCR (Crist & Grunfeld, 2013; Simard et al., 2013). In addition, there have been reviews of theory (Fardell et al., 2016; Simonelli, Siegel, & Duffy, 2016), assessment (Thewes et al., 2012), and intervention (Sharpe, Thewes, & Butow, 2017), mainly using the cognitive-behavioral paradigm as the theoretical framework for understanding and developing interventions to help people dealing with FCR (Fardell et al., 2016). Qualitative research about FCR has also been conducted, aiming to explore people's experiences of the possibility of recurrence, including the specific contents of their worst fears, their coping strategies for dealing with FCR, or what might distinguish higher from lower levels of FCR (e.g., Mutsaers et al., 2016; Thewes, Lebel, Seguin Leclair, & Butow, 2016; Vickberg, 2001). Seeking to understand how people see important experiences (Taylor, Bogdan, & DeVault, 2016) qualitative research is an interpretive, naturalistic approach to peoples' worlds (Denzin & Lincoln, 2017) giving voice to their own perceptions. Recognized as essential for assessing and improving the quality of health care services (NICE, 2012b), research on patients' views supports the patient-centered model of care (Mead & Bower, 2000), where the patient is

an active and autonomous agent who participates in decision-making processes about their illness and its management (Kaba & Sooriakumaran, 2007; Longtin et al., 2010). Patients' expressed feelings, concerns, and experiences during an illness also facilitate a deep understanding of how it affects the person as a whole human being (physical, emotional, social, spiritual) (Hall, Kunz, Davis, Dawson, & Powers, 2015). Despite its importance, results of qualitative research are scattered throughout the literature. In this paper we present the first systematic review of this difficult human experience (Finlayson & Dixon, 2008), guided by the main research question, "What are people's experiences of fear of cancer recurrence?" We conducted a qualitative meta-analysis that interprets and synthesizes the existing qualitative data about FCR experience, with the aim of creating a more integrated view of the richness and diversity of patients' accounts.

Methods

The researchers

Our research team was composed of four clinical psychologists, all with masters or doctoral degrees, two of whom have worked in a cancer hospital for about 14 years (SNA and ERS) and two university professors, experienced clinical practitioners, researchers and teachers (RE and CS). Three of the researchers are Emotion-Focused Therapy (EFT) therapists (including one of the developers of EFT) and one (CS) is a family therapist.

Search strategy

A systematic search was first conducted in April 2016 using the electronic databases PsycInfo, PubMed and CINAHL in order to find qualitative research on FCR; an updated search was done in June 2018.

The search key-terms were “fear/anxiety/worry” combined with “recur*/relapse/coming back/progress*” and “cancer/neoplasm”. Additional searches were done through grey literature, “snowballing”, journal hand-searches, review-level material (NICE, 2012a) and “berrypicking” strategies (Bates, 1989), in order to find additional relevant studies. We did not limit our search temporally and maintained a Google Scholar search alert until end September 2016 (in the first phase of search).

Selection strategy

The selection of studies was guided by the following inclusion criteria: (a) qualitative and mixed method studies about FCR or about wider topics containing this particular issue (such as “survivors' experience”); (b) concerning adult cancer patients; (c) presented in scientific articles or dissertations; and (d) written in English, French, Portuguese or Spanish. We used a broad definition of cancer survivor, referring to the person from time of diagnosis until end of life (NCI, n.d.), so we did not distinguish between “survivor” and “patient” and will use both interchangeably throughout. Our option followed Mullan's “seasons of survival” idea (Mullan, 1985) and is in consonance with the contemporary definition of the National Coalition for Cancer Survivorship (www.canceradvocacy.org). At the same time we were conscious of the discussion surrounding different definitions of survivor and survivorship (Feuerstein, 2007; Surbone, Annunziata, Santoro, Tirelli, & Tralongo, 2013). Figure 1 presents the PRISMA diagram showing the steps followed from the initial identification of the studies to the 87 final studies. Each step was

completed by two of the researchers (SA and ES); the other members of the team participated in the decisions related to the final phases of eligibility and inclusion. Covidence, a Cochrane software tool for systematic reviews (www.covidence.org) was used to assist the review steps from the importation of citations after the databases searches to the selection of the studies to be included in the final analysis. This review was registered at PROSPERO International prospective register of systematic reviews in April 2016 (PROSPERO 2016: CRD42016036688, available at http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42016036688)

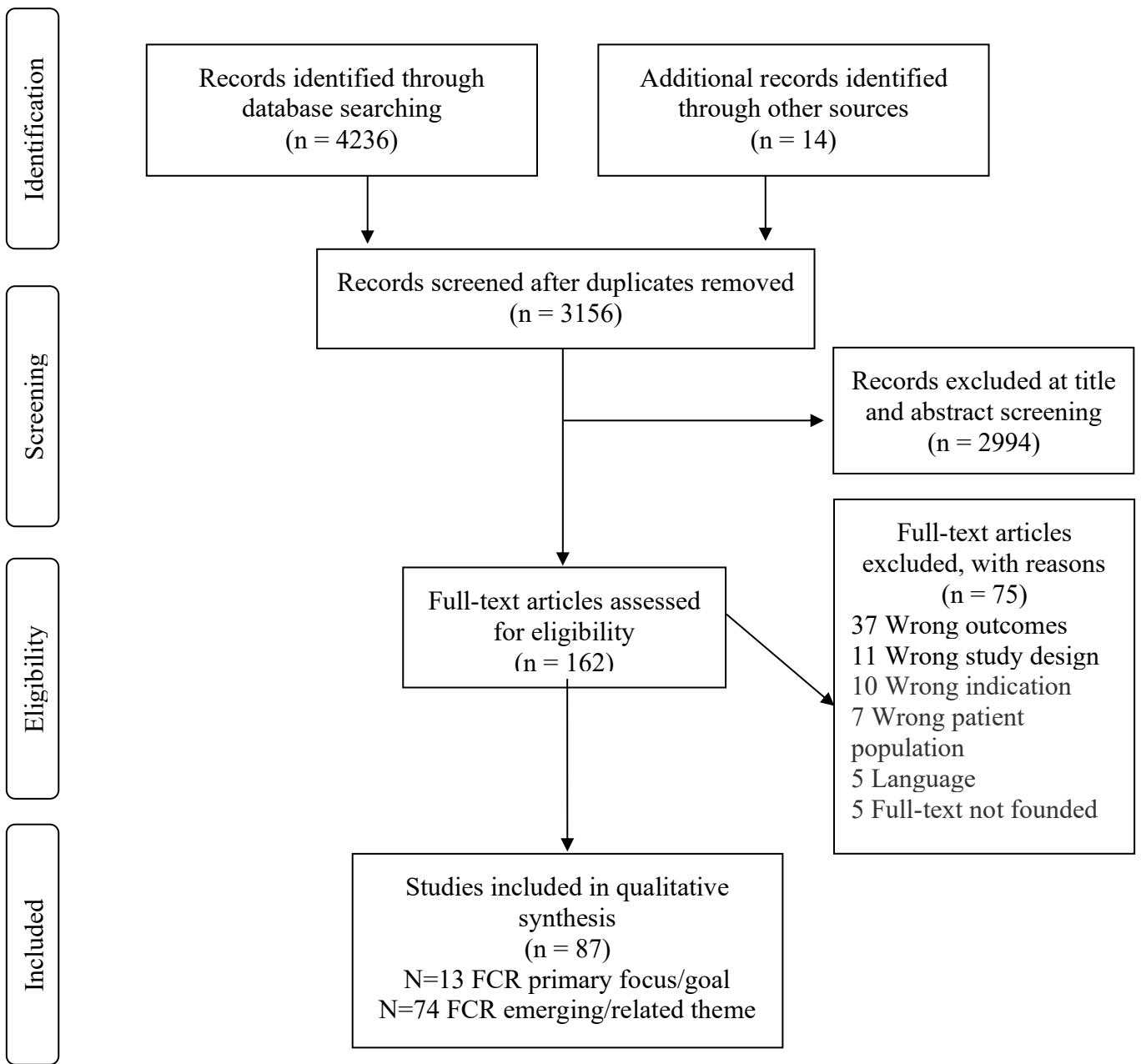


Figure 1. PRISMA flow diagram of the study review.

Quality appraisal

When developing a qualitative meta-analysis, the quality appraisal of the studies informs the choice of the studies for the meta-synthesis, helping to make inferences, analyze and take conclusions from the data retrieved (Timulak, 2009). In the present review, the quality appraisal of the studies was done using a Quality Appraisal Form, adapted from the publishability guidelines for qualitative research developed by Elliott, Fischer, and Rennie (1999). By the time we updated our search, APA had already published the “Journal Article Reporting Standards for Qualitative Primary, Qualitative Meta-Analytic, and Mixed Methods Research in Psychology” (Levitt et al., 2018). Accordingly, we have done a mapping exercise between Elliott et al. (1999) and APA's guidelines, in order to guarantee the adequacy of our assessment's measure in the present study. We verified a substantial overlapping between both guidelines (estimated at about 80%), with Elliott et al.'s presenting three additional aspects not covered by APA's. The main difference found was the degree of specificity, with the APA guidelines more extensive and detailed, while both seem to cover the same general topics. Taking into account our purpose and needs, we consider the guidelines used sufficiently accurate and to correspond closely to the newer guidelines. Fourteen criteria were included (and can be consulted in Appendix A), from which seven are considered pertinent to both qualitative and quantitative approaches and the other seven especially pertinent to qualitative research (Elliott et al., 1999). Every criterion was assessed as “appropriate”, “inappropriate/insufficient” or “not reported”. Each study was classified as having “high quality” (+ +), when all or most criteria were rated as appropriate, or where even if insufficient the conclusions were very unlikely to change; as “moderate/sufficient quality” (+) when some of criteria were rated as appropriate, or where insufficient or not reported the conclusions were very unlikely to change; or as “low/insufficient quality”

(-) when few or no criteria were fulfilled or the conclusions were likely or very likely to change due to the criterion not being met (NICE, 2012a). Only the studies rated as “high” or “moderate/sufficient” quality were included in the analysis. The studies' evaluation was done by one judge who rated all of the studies (SNA); a second judge provided a reliability check by rating half of the studies randomly (ERS). The interrater reliability for the quality judgements was of Cohen's $\kappa=0.855$, which is considered strong agreement (McHugh, 2012). None of the 87 studies selected were rated as “low/insufficient quality”; thus all were included in next phases. Concerning the quality of the studies, the majority (about 83%) were considered as having “high quality”. The criteria “owning one's perspective” (criterion 8), “providing credibility checks” (criterion 11) and “accomplishing general versus specific research tasks” (criterion 13) were the most critical aspects contributing for the lower assessments. Because our focus was on capturing patients' experiences on FCR, we had decided to focus only on direct quotes from participants; thus, every selected study met the criterion “grounding in examples” of the Quality Appraisal Form (criterion 10).

The selected studies

Eighty-seven (87) studies were included, mostly exclusively qualitative studies (90%; the other 10% were mixed qualitative-quantitative studies), the great majority published in articles (87%). The main methods used for data collection were individual interviews (73%), frequently semi-structured and in-depth, and focus group interviews (15%). Together, the studies included a total of 2122 participants, with a range between 1 author reflecting upon his personal experience (Horlick-Jones, 2011), and 360 cancer patients who answered an on-line open question about their worries (Cesario, Nelson, Broxson, & Cesario, 2010). The majority of participants were women (86%), half of

which with breast cancer (50.5%); another 22% of the studies included mixed cancer diagnosis. Although different continents – Europe, North and South America, Asia, and Australia – and different countries were represented, about 39% of the studies were conducted in the United States of America. In terms of language, all but four studies were written in English. Years of publication ranged from 1992 to 2018, with more than half of the studies published between 2010 and (June) 2018. Ninety-three percent of the studies were identified directly from the main database search (for a detailed characterization see Table 1).

Table 1. Characteristics of the selected studies.

Articles	76 (87%)
Dissertations	11 (13%)
Studies exclusively qualitative	78 (90%)
Mixed qualitative/quantitative studies	9 (10%)
Data Collection method	Number of studies (%)
Individual interviews	63 (72%)
Focus group interviews	13 (15%)
Mixed qualitative methods	5 (6%)
Other methods	6 (7%)
Total participants (k=86 studies)	2122 (range 1–360)
Mean (median) per study	26 (17)
Women	1825 (86%)
Age – Mean (range) (k=58)	53 (18–89)
Race/ethnicity (k=49)	European origin 1089 (51.3%) Asian 240 (11.3%) African American 105 (5%) Latina/Hispanic 91 (4.3%) Others/not specified 86 (4.1%)
Off-treatment ^a	1190 (56%)

Diagnosis	Number of studies (%)
Breast	44 (50.5%)
Mixed diagnosis	19 (22%)
Gynecological	11 (13%)
Blood cancers (leukemia, lymphoma, myeloma)	4 (4.5%)
Others (e.g. thyroid; colorectal; melanoma)	9 (10%)
Countries	Number of studies (%)
USA	34 (39%)
UK	15 (17%)
Canada	9 (10.3%)
Australia	6 (7%)
Scandinavia (Denmark, Norway, Sweden)	6 (7%)
Brazil	3 (3.4%)
Others	14 (16.3%)
Language	
English	83 (95.4%)
(Brazilian) Portuguese	3 (3.5%)
Bilingual (French-English Canadian)	1 (1.1%)
Year of publication	
1992–1999	7 (8%)
2000–2009	23 (26%)
2010–2018	57 (66%)

Databases	
Main (PsycInfo, PubMed and CINAHL)	81 (93%)
Additional searches	6 (7%)
Quality appraisal	
High quality	72 (83%)
Sufficient/moderate quality	15 (17%)

^aNot all studies were clear about participants being off/on treatment; some studies only referred being after a particular treatment (mostly surgery); participants under hormone therapy were frequently considered as “off-treatment”.

Data analysis

Considering the diversity of the selected studies, initially the research team roughly divided two sets of studies: (a) studies in which FCR was a primary focus or one major result and was extensively discussed (n=13), and (b) studies in which FCR was one of the topics or emerging themes, but not a main or exclusive issue of the study (n=74). The analysis began with the first set of studies, from which the first themes were derived. Secondly, the information of the second group of studies was fit in the categories already defined, which were checked and adjusted whenever necessary. We used a version of grounded theory analysis (GTA; Strauss & Corbin, 2008) because it is a well-established, widely used, and highly systematic approach to qualitative data analysis. In addition, it allows the use of a general conceptual framework to guide data analysis (sometimes referred to as “axial coding”). Thus, after an initial examination of the data, we adopted the Emotion Scheme framework (ES; Greenberg, Rice, & Elliott, 1993) to organize the data, considering its apparent suitability and in consonance with the research team's assumption that FCR is centrally an emotional experience (Almeida, Silva, Sales, & Elliott, 2016). According to Emotion-Focused Therapy (EFT) theory, an Emotion Scheme is a complex self-organizing process that involves different domains of experience – perceptual-situational, bodily-expressive, symbolic-conceptual, motivational-behavioural – organized around a particular experienced or implicit emotion (Elliott, Watson, Goldman, & Greenberg, 2004). Emotion schemes are seen as the primary implicit source of experience, producing automatically felt experiences and action tendencies (Greenberg & Watson, 2006). The elements of an ES discriminate complementary and interconnected information about a particular emotional experience, in this case FCR. We found this framework to be a useful yet not overly constraining structure to organize our GTA (Strauss & Corbin, 2008). In addition to being a specific

theoretical feature of EFT theory, the ES framework comprises common aspects from most psychological theories (e.g., CBT, psychodynamic, humanistic-experiential), such as cognitive, emotional, bodily, narrative and behavioural aspects of human experience; thus it proved helpful not only to deepen understanding of FCR experience but also to inform psychotherapeutic practice. Different therapeutic approaches may thus read and use this information according to their assumptions and intervention models. After repeatedly reading the data, the extracted material was analyzed “line-by-line” (Strauss & Corbin, 2008), and meaning units were identified, ranging from single words to complete sentences or paragraphs; these could be attributed to a specific ES domain (experienced/implicit emotion; perceptual-situational, bodily-expressive, symbolic-conceptual and motivational-behavioral; dataset available at Almeida, Elliott, Silva, & Sales, 2018). Then, within each ES domain, the quotes of the participants were progressively grouped according to same or similar meaning, creating different categories and later higher and lower-order categories. This process was done by the first author and then carefully audited, discussed, and revised step by step with one of the other researchers (RE), a specialist in both EFT theory and GTA. At the end of the categorization process, we were left with some infrequent or unique meaning units that couldn't be grouped with any others, which we will incorporate in our presentation when relevant.

Results

In relation to our research question, “What are people's experiences of fear of cancer recurrence?” we found ten higher-order categories within the broad structure of the five ES domains:

1. ES experienced/implicit emotion: Emotions associated with the experience of fearing cancer recurrence;
2. ES perceptual-situational domain:
 - 2.1. Trigger–situations that elicited FCR;
 - 2.2. Objects of fear;
 - 2.3. When, how long and how FCR emerged;
 - 2.4. Episodic memories related to FCR.
3. ES symbolic-conceptual domain:
 - 3.1. Metaphors for FCR;
 - 3.2. Distinct dimensions of mental activities;
 - 3.3. Internal process and meta-cognitions about FCR.
4. ES motivational-behavioural domain: Action tendencies related to FCR.
5. ES bodily-expressive domain: Bodily expressions of the different emotions.

Table 2 shows the number of studies representing each of the categories and sub-categories. We next present our main findings for each of these, using some illustrative quotes from participants.

Table 2. Number of studies reporting each of the categories and sub-categories.

Category	Number (%) of studies
1. Emotions associated to the experience of FCR	82 (94%)
• Fear	74 (85%)
• Depression	17 (20%)
• Undifferentiated distress	34 (39%)
• Positive emotions	29 (33%)
• Others (e.g., anger; shame; surprise; disappointment)	13 (15%)
2.1. Trigger–situations that elicit FCR	61 (70%)
• Noticing something in the body	37 (43%)
• Waiting for a medical exam or appointment	31 (36%)
• Encountering reminders	20 (23%)
• Others (e.g., being on/off treatment; being under stress)	16 (18%)
2.2. Objects of fear	56 (64%)
• Cancer recurrence/spreading/other cancers	49 (56%)
• Death	14 (16%)
• Doing new treatments/physical limitations or suffering/dependency	10 (11%)
• Fear of future/uncertainty/waiting periods	7 (8%)
• Others (e.g. of suicide; of having stress; of enjoying life)	15 (17%)
2.3. When, how long and how FCR emerged	54 (62%)
• Always there or constant/every day	40 (46%)
• Occasionally or trigger-related/intermittent	25 (29%)
• At night/when waking up	13 (15%)

• Since diagnosis/after treatment/5-year mark	18 (21%)
• Suddenly or out of the blue	7 (8%)
• Different durations	7 (8%)
• Others (e.g., be in silence; before cancer)	6 (7%)
2.4. Episodic memories related to FCR experience	49 (56%)
• Before cancer	7 (8%)
• Around cancer diagnosis	16 (18%)
• Around cancer treatment	14 (16%)
• After cancer/check-ups	25 (29%)
• Conversations with doctors/nurses	15 (17%)
• Others with cancer	8 (9%)
• Other situations (e.g., at work; with neighbors; previous depressions)	5 (6%)
3.1 FCR metaphors	33 (38%)
• Conflict	28 (32%)
• Vulnerability	32 (37%)
3.2. Mental activities	83 (95%)
• Thinking	61 (70%)
• Degrees of certainty	62 (71%)
• Change process	10 (11%)
• Sensorial pathways	20 (23%)
3.3. Internal process and meta-cognitions about FCR	13 (15%)
• FCR internal process	9 (10%)
• Meta-cognitions about FCR	6 (7%)

4. Action tendencies related to FCR	65 (75%)
• Avoiding FCR	43 (49%)
• Approaching FCR	54 (62%)
5. Bodily expressions of FCR experience	27 (31%)
• Fear (e.g., “I was in a sweat”)	8 (9%)
• Depression (e.g., crying; “my heart sinks”)	10 (11%)
• General body expressions (e.g., “it's in my body”; “it's in my bones”)	10 (11%)
• Mind (e.g., “I usually feel it my brain”)	7 (8%)
• Disgust (e.g., “it gives me a sick feeling”)	4 (5%)
• Others (e.g., anger; laughter)	7 (8%)

1. Emotions associated to the experience of fearing cancer recurrence

The dominant emotion of the experience of FCR was, as expected, fear. Participants described fear using several different terms, including the word “fear” itself (or “being afraid”) and its synonyms such as “anxiety”, “worry”, “scared”, or “dread”. In reading the excerpts, we noticed that the fear was mostly characterized by expressions of great intensity: “pretty strong” or “horrible” fear, “real frightened”, “big dread”, “scared the hell out of me”, “terrified”, “panic”, which were much more common than “apprehensive” or simply “nervous”. We also included in the emotion of fear the feelings of insecurity, uncontrollability and uncertainty reported by some participants: “had no sense of security” (Fang & Lee, 2016); “I feel very exposed” (Brooks, Poudrier, & Thomas, 2014); “I don't have control over it”, “always walking with uncertainty” (Berman, 2013). Blended fearful states were also detected, particularly fear and surprise, as expressed by “fright”, and fear and disgust, as expressed by “horror”. Another set of accompanying emotions was labelled as depression, in which we included feelings of “sadness”, “loss”, “grief”, “alone” and feeling “set apart” or “abandoned” but also descriptions of feeling “more vulnerable”, “weaker” as well as being “helpless” and with “no hope” or having “no power about it”. Intense levels of undifferentiated distress were also found, probably connecting either to fear, sadness or more confusing or unclear states: “extremely stressful”, “distressing”, “painful”, “hard”, “very difficult”, “dramatic”, “devastating”, “so many feelings”, “freaked out”, “messed up”.

Positive or pleasant emotions appeared as well in participants' reports about FCR, namely when talking about getting out a fearful state. Participants described being “relieved”, getting “more confidence”, feeling “reassured”, comforted or even “elated” after good news: “Well, the test showed nothing. There was nothing there, which was very comforting...” (Berman, 2013). Feelings of gratitude were also described when

referring to past or present cancer experiences: “I was lucky this time” (Vickberg, 2001); “I am thankful that I have a next day” (Cesario et al., 2010). Acceptance was another emotional state referred as opposed to fear: “I’ve gotten some peace of mind, too, from the acceptance. I don’t have the same level of anxiety” (Berman, 2013). The emotions of anger, shame/guilt/regret and surprise were much less referred by participants: “I am just angry at my body, it let me down.” (De Vries, Den Oudsten, Jacobs, & Roukema, 2014); “I am working way too much and what if I had a recurrence? I should be spending this weekend with [my children]. And then that just kind of unfolds because you feel guilty and you start thinking about death.” (Berman, 2013); “It preoccupies me a lot and that surprises me.” (Mikkelsen, Søndergaard, Jensen, & Olesen, 2008).

2.1. Trigger–situations that elicit fear of cancer recurrence

Noticing something in the body was one of the most referred-to triggers for FCR, whether it was a pain or other physical symptom: “Every little pain or lump on your body” (Jones, 2012) or a difference in the body related to cancer experience: “your breasts just don’t feel the same because the way they construct it with the muscle or insert, you can feel all that. They just don’t feel like natural breasts. It’s just another trigger” (Berman, 2013). Waiting for a medical exam or appointment (even in the waiting room), particularly to receive the results of medical tests, was another common identified situation: “But when I really start to think about it is when I have to do scans” (Jones, 2012). Encountering reminders such as hearing, talking or reading about cancer (in TV/newspaper/magazine or by other people), just thinking about it or remembering the experience of having had cancer or treatment were also identified triggers of FCR: “when I see people in my village dying because of these diseases even years after treatment” (Saraf, Singh, & Khurana, 2013). Other situations people described as activating FCR

were both being in some kind of treatment (such as daily hormone therapy or taking pills for pain) and being off treatment (“not having that ‘safety net’ of treatment”, Arnold, 1999). Being under stress or engaging in risky behaviours was also a trigger for some: “They say that stress is a trigger for getting cancer. So, it's like every stress has extra stress with it” (Berman, 2013). As unique or infrequent triggers we highlight: dreaming, thinking about the future, starting a new project or relationship, dealing with a family problem or just looking at one's child.

2.2. Objects of fear

It was possible to identify different objects of fear, when people referred to FCR. The reoccurrence of the same cancer or of a different one (and even of a different serious illness), the spreading of cancer and the fear of the cancer “still being there” were directly expressed by participants, as well as fear of cancer itself. The possibility of not being able to identify a new/recurrent cancer worried one of the participants too. Death as a main concern was identified, frequently associated with not wanting to leave family, especially children: “I don't survive it and die, and then my kids are left without a mother” (Siegel, Gorey, & Gluhoski, 1997). Other fears related to doing treatments again, feeling weak, suffering or having a diminished quality of life, including being dependent and having physical limitations: “It worries me that if comes back, it's going to be stronger” (Berman, 2013). Fear of the future, of planning ahead or “of enjoying life”, and more generally fear of uncertainty, were described as well. Some patients referred likewise to worry about the worry itself: “Sometimes I worry that the worry is going to grow” (Berman, 2013). One participant described her fear of the genetic mutation she had, which could lead to the reappearance of cancer.

2.3. When, how long and how FCR emerges

Narrative elements were often observed in participants' discourse, although this information was quite heterogeneous across studies and participants. The presence of FCR ranged from “always present”, “every day”, “constant” to “occasionally” or “intermittent”. For some patients, it was only present on specific occasions (as reported above in Trigger–situations), or at specific moments of the day, frequently at night, especially during quiet times, while trying to relax or sleep, and in the morning, when waking up. Others described it as appearing “suddenly” or “out of the blue”: “Sometimes I'll think more about that, but sometimes it's just ‘that’” (Berman, 2013). Regarding its duration, FCR appeared to be episodic, and could be present “for 10 seconds there” (Berman, 2013) to “a good part of the day (...) six hours maybe” (Mutsaers et al., 2016). We can also locate the emergence of FCR along a chronological line, in relation to the cancer diagnosis event. Although for some people this fear has been presented “since ever”, even before diagnosis, for most, FCR emerged at the point of the cancer discovery, after the treatment ended, or around 5-year mark: “From the moment I was told I had cancer in my body” (Crouch & McKenzie, 2000). For some others it was associated to a certain event, as someone's death from cancer.

2.4. Episodic memories related to FCR

Specific vivid episodic memories were evoked when people talked about FCR (whether asked directly or not), especially related to the different stages of the illness trajectory: around cancer diagnosis, situations during the period of treatment, check-ups situations, and episodes after the cancer experience. As a participant recalled: “They say you never forget the day you find your lump and it is true. It was last year...and it was Mother's Day (...) I said I bet it is malignant.” (Raymer, 1993).

Remembrances of past situations previous to cancer diagnosis were also reported, including childhood memories such as the first recognition of mortality: “I remember the first time I thought ‘someday I am going to die’ and it scared me and I sat up in bed and I remember just yelling for my mom” (Sadler-Gerhardt, 2007). Other remembered situations concerned or included others, such as conversations with doctors/ nurses, others' reactions to his/her illness or relatives/friends/others having and/or dying with cancer. Less frequently described were memories related to decision-taking and particular situations with others, namely at work.

3.1. Fear of cancer recurrence metaphors

We were particularly struck by people's use of vivid conceptual metaphors to describe their FCR. These were diverse but we grouped them as much as possible under similar ideas or meanings and included different sub-themes that we present and provide examples.

3.1.1. FCR is conflict

We found a root metaphor (Elliott, 2006; Lakoff & Johnson, 1999) about FCR that we called FCR Is Conflict. For some patients, feeling FCR is like being in a war: “I feel under attack again” (Horlick-Jones, 2011); “like a sword hanging over my head” (McLoone et al., 2012); other patients find themselves in face of adversarial situations: “It is like the bad guy and the good guy. I would say, yeah you are out there, but let's you know... let's have a fencing match, you know, let's get out the duelling pistols... so I would be willing to put up a battle...” (Raymer, 1993); FCR is also described as Guarding Against Attack: “I feel like if I am caught off guard it will sneak round the edges ... I'm always waiting for it to come back” (Balmer, Griffiths, & Dunn, 2015); “Now I feel like

the rest of my life is spent fighting and looking over my shoulder” (Miller, 2015); or being Attacked by Monsters: “It basically means just a deep-seated kind of boogie monster that could resurface again”; “like a little ghost that hunts you” (Berman, 2013).

3.1.2. FCR is vulnerability

Another set of metaphors revealed complementary qualities of the experience of FCR, as being under the power of an external negative force. We called this second set of metaphors FCR Is Vulnerability. FCR is described as being subject to a controlling entity: “it (FCR) absolutely controlled my life. Totally. Totally overshadowed it and totally controlled my life” (Scott, 2014); something that remains under the surface: “it's like an undercurrent in your life” (McLoone et al., 2012); which makes people feel vulnerability/insecurity: “Until something's happened, we all operate under this false sense of security. But once something has happened, like this, it's kind of like, the bubble's been burst. We realize that something could happen, because it has” (Cohen & Ley, 2000); and that causes injury/illness: “It can become almost crippling if you let it”; “The worry undermines that things will always work out” (Berman, 2013).

3.2. Dimensions of mental activities: degrees of certainty, verbal tenses and sensorial pathways

The most common and general mental activity identified was thinking, either presented as an active reflective process: “When I think of recurrence, I really think of dying” [emphasis added] (Berman, 2013); or as a passive process, indicated by sentences as “the first thing that comes to my mind is cancer” or “because it brings the fear running in my head” [emphasis added] (Berman, 2013). Exploring the other mental activities described by participants, we could identify different layers or axes that can be related to

each other, which we named as: degree of certainty vs uncertainty; verbal tenses/timeline; and sensorial pathways. The first of these dimensions, knowing and not knowing, seemed particularly relevant in participants' discourses, revealing the poles of the continuum degrees of certainty vs uncertainty, which included other mental activities such as supposing, wondering or believing: “You don't know if you're gonna live through it or not” (Mutsaers et al., 2016); “Now I guess I know it's something that can betray you without you even knowing what's going on” (Thomas- Maclean, 2001). We also identified mental activities reflecting change processes derived from FCR, such as realizing, making sense, understanding, being aware or acknowledging: “This made me realize that I will die—not maybe—but I will die!” (Berman, 2013). Crossing this axis was a second dimension, the verbal tense/time line: We found that different mental activities connected with past (remembering), present (noticing) or future (expecting). We also noticed a preponderance of subjunctive grammatical modes and interrogative forms, probably reflecting the uncertainty and doubts evoked by the FCR, but interestingly for some participants the cancer recurrence was assumed as inevitable and, in these cases, present and future tenses were used: “My question is not if it's coming back...It's when” (Allen, Savadatti, & Levy, 2009).

A third dimension, sensorial pathway, also intersected the other two axes: Verbal and auditory sensory channels seemed to relate to “if” statements and questioning, as well as with conditional grammatical mood. Somatic (as in feeling) usually reflected present statements, while the visual-perceptual channel, depicted in verbs as imagining, noticing or remembering, traversed the whole time line: “I almost feel as if it's inevitable” (Mutsaers et al., 2016); “I imagine... that maybe it [recurrence]... it may be the end... may be the end and... that this would take you” (Raymer, 1993).

3.3. Internal process and meta-cognitions about FCR

When sharing FCR experiences, patients also include reflections about the internal, psychological process of fearing and meta-cognitions about FCR. For example, one patient explained her internal process as follows: “[There were] two halves... on the one side of the balance there was the fear of enjoying life because of the other side of the balance which was the possibility of recurrence... This is like a step along the way: that I might be able to actively enjoy life on that side of the balance. On the other side of the balance is the fear of recurrence, and after that — death.” (Raymer, 1993); another patient reflects: “I call it fear because it was paralyzing. There was something that was paralyzing to me, and I can only think of it as fear because it was this. And I don't know what I was afraid of. Was I afraid of being sick again? I don't know what I was afraid of...maybe it wasn't fear of recurrence. Maybe I was confident that the cancer would come back, but not being at peace with it? Or not being accepting of it?” (Berman, 2013). Some meta-cognitions about FCR revealed opposite ideas about FCR. For instance, some patients say it is “not an irrational fear”, while others present it as “totally irrational” (Berman, 2013); or “it is just a fleeting thought” (Shachar Siman-Tov, 2008) versus “I was obsessed with recurrence” (Scott, 2014).

4. Action tendencies related to FCR

Two chief and opposing action tendencies were identified concerning FCR: avoiding and approaching, and within each, we could find aspects related to illness/treatment/death, to self-experience, and to others.

4.1. Avoiding FCR

Experiential avoidance was common and involved pushing or moving oneself away from experiences involving illness/treatment/ death. For example, participants referred not wanting to do treatments, not to live with cancer again, or not wanting to die with cancer: “This is not how I want to die” (Berman, 2013). Avoiding medical examinations, disregarding bodily changes, believing doctors can prevent a recurrence or simply hoping cancer is not coming back were some other desires, wishes, intentions and action tendencies identified: “I hope that my cancer doesn't come back so I can retire and so my wife and I can travel and see the world” (Jones, 2012). Avoidant self-related action tendencies included mainly trying not to think, or talk, or hear about FCR, putting it aside or out, forget it, distract from, wishing “it's over” or get beyond cancer; wanting to keep normalcy but also not wanting to make long-term plans: “I wish that I just broke a bone and it's reset and I'm all healed now and I can close the door, like desperately I want to close the door, but I feel like I can't because it is not over” (Berman, 2013). Keeping FCR to oneself or isolating oneself, not wanting people to feel sorry for them and the need to be independent and to not be a burden to the family were other-related avoidant behaviours or motivations: “I have never said that to anybody” (Sadler-Gerhardt, 2007); “I didn't tell them [family] anything about the cancer probability because I didn't want them to be worried” (Mehrabi, Hajian, Simbar, Hoshyari, & Zayeri, 2016).

4.2. Approaching FCR

Some cancer survivors also experienced FCR as a factor impelling them to do something, for example to take some control over a possible recurrence, particularly self-care through changing food habits and exercise, monitoring and paying attention to body signs, or preparing somehow for a recurrence: “So, I started on this watching what I eat.

Not necessarily a diet, just eating correctly what I'm supposed to eat, my vegetables, my fruit ...” (Kvale, Meneses, Demark-Wahnefried, Bakitas, & Ritchie, 2015). A related action tendency in face of FCR was fighting or planning to fight against a future cancer recurrence: “I sure as hell would give it [recurrence] a fight, ha ha. I would fight, you know... I would not accept death you know... I wouldn't just lay back and say all right, you know, I am going to die.” (Raymer, 1993). Facing FCR, patients also experience the need to accept, deal or recognize their mortality and ultimately prepare for their own death: “Then you have to learn to... I guess deal with the question... How can I put it? Of then really learning to accept the fact that, you know, to accept death” (Raymer, 1993). Regarding self-experiences, we recognized self-talking, mainly self-coaching and self-assurance: “I can kind of, you know, calm myself down, this kind of thing.” (Cohen & Ley, 2000), the need to deal or live with FCR, but also the wanting to live and appreciate life better. We also included in this sub-theme spirituality, expressed by having faith and praying. Sharing their experiences with others, talking about FCR and receiving comfort and help from others (including in therapy) were other helpful approaching strategies people described when dealing with FCR: “Another cancer survivor telling me ‘it's okay, don't worry’, would be such a great comfort and I wouldn't feel scared anymore” (Wang et al., 2016). Finally, FCR was described by a small number of people as paralysing or blocking any action tendency: “I was just so paralyzed by fear” (Berman, 2013); “it's just almost crippling” (Mutsaers et al., 2016).

5. Bodily expressions of fear of cancer recurrence experience

In this subdomain, represented by the smallest number of meaning units and studies, we identified primarily expressions of fear and expressions of depression. Examples of bodily expressions of fear are “shiver” (Raymer, 1993), “shaking” (Berman,

2013), “get tense” (Saraf et al., 2013) and “um frio na barriga” (literally, “a chill in the belly”; Salci & Marcon, 2010). People also described FCR as “nerve-racking” (Thompson et al., 2010), “ficava igual uma corda de violão, bem esticada” (It was like a guitar string, stretched tight; Salci & Marcon, 2010), “I am just a bunch of nerves (...). And I get pains in other places in my body” (Raymer, 1993). “Crying” was the most presented physical expression of sadness; other examples of depression and sadness are “my hearts sinks” (Saraf et al., 2013) and “aquele aperto no coração” (tightness in the heart; Salci & Marcon, 2010). We also identified general body expressions as “it's in my bones”; “That feels to me like hurt. That feels to me like pain”; (Berman, 2013). Specific expressions related to head/mind were recognized as well: “você fica com a cabeça ‘perturbadinha’” (disturbed head; Salci & Marcon, 2010); “I usually feel it in my brain” (Berman, 2013). Physically-expressed laughter was found in different interviews, and we considered it as probably expressing different underlying feelings: sometimes it was expressed when people were talking about worry, seeming to be a nervous laughter; other times it looked more related to underlying anger (as when someone described feeling annoyed for having been, as one participant said, “false-advertised” in relation to the end of treatment).

Discussion

For most patients, surviving cancer means living with FCR (Simard et al., 2013). The purpose of this qualitative meta-synthesis was to bring together what is known about this experience, using direct words from cancer survivors. Our results showed FCR is a complex, intense and difficult human experience. It appears to be not a unique/simple fear, but rather a set of different fears for different people, or even for the same person at

different times. Fears of death, dependence, disfigurement, disruption and disability have previously been identified as common in cancer patients (e.g. Lesko, 1998). Also Raymer (1993) and Vickberg (2001) found that while talking about FCR cancer patients present different specific fear objects and not always or uniquely of death. Some fears are about something known, such as going through certain treatments again, while others are about the unknown, such as the uncertainty of the disease course or death itself. This supports the distinction made between fear and anxiety (Elliott, 2013; Steimer, 2002), the former relating to a present or specific danger, the latter to a future or undefined danger. The intense FCR emotional experience might also connect to feelings of sadness, as expressed by this participant in Berman's study (2013): "The sadness of thinking that I might not be there is horrifying; it really is". Considered as adaptive emotions, fear relates to a situation of danger, sadness to a lived loss or psychological injury and anger to a situation of violation or attack on self (Greenberg & Paivio, 1997). All these situations can be easily met in the cancer trajectory, given the life-threatening nature of cancer, the various losses that the disease often carries and the sense of violation of physical and psychological integrity eventually brought by the disease itself or by its treatments. Those feelings can however be maladaptive, and if not adequately managed and regulated, can compromise successful adjustment to cancer experience (Conley, Bishop, & Andersen, 2016).

Participants tended to describe FCR as always present, or in the back of the mind, and existing since having had the cancer diagnosis. Daily recurrent thoughts and duration of 30 min or more have been identified as possible features of clinical FCR (Mutsaers et al., 2016). Although in our sample of studies it was not possible to distinguish different levels of FCR, it is very likely that our review includes the experiences of dysfunctional levels of FCR. Our findings suggest that FCR is a concern with major impact on people's lives that runs along a continuum ranging from normal/adaptive worry to a maladaptive

clinical distress and dysfunction. The magnitude of FCR experiences were also shown by the strong metaphors people used to symbolize it. Metaphors structure what people think and understand, as well as their actions (Lakoff & Johnson, 2003), therefore helping cancer survivors to grasp indescribable aspects of this extremely difficult experience (Berman, 2013). Our categorization of the metaphors resembles some of the conceptual metaphors for fear described by Kövecses (1990): FEAR IS AN OPPONENT IN A STRUGGLE, parallels our categories “adversarial situations” and “being in a war”; FEAR IS A HIDDEN ENEMY fits our “under the surface”; FEAR IS AN ILLNESS goes with “injury/illness”; FEAR IS A SUPERNATURAL BEING fits “being attacked by monsters”. We have noticed as well that descriptions or metaphors about FCR were inseparable from patients' views/metaphors about cancer itself: the above conceptual metaphors for fear might actually overlap with cancer metaphors – cancer as an opponent in a struggle; cancer as a hidden enemy; cancer as an illness; cancer as a supernatural being. Metaphors for FCR thus vividly portray an unavoidable and unequal struggle between the person and the cancer, leaving the person feeling vulnerable or weak. A recent meta-synthesis about cancer fears in the general population also found a core view of cancer as a vicious, unpredictable and indestructible enemy (Vrinten et al., 2017).

Activators of the FCR experience were most commonly noticing something in one's own body, waiting for medical exams and results, encountering reminders such as talking or hearing about cancer, or simply thinking or remembering about cancer experience or its potential recurrence. External and internal triggers have been included in most theoretical approaches already developed for understanding FCR phenomenon (Fardell et al., 2016), although their frequency does not necessarily distinguish clinical from non-clinical FCR (Mutsaers et al., 2016). Physical symptoms and hearing about someone else's cancer were previously found to be common triggers for FCR (Gil et al.,

2004). Moreover, certain episodic memories recalled by participants might act as internal triggers for FCR, possibly stemming from traumatic experiences during the illness trajectory. We could find some the DSM-V criteria for PTSD in patient discourses in our review, in line with previous findings (Black & White, 2005; Simard et al., 2013). These included re-experiencing of aspects of traumatic cancer-related events, in the form of flashbacks, emotional distress or physical reactivity after exposure to trauma reminders; avoidance of trauma-related stimuli; negative thoughts or feelings after the trauma; and trauma-related arousal and reactivity, including hypervigilance, heightened startle reaction or difficulty sleeping (APA, 2013). Although FCR is not always linked to traumatic cancer-related event(s) it nevertheless appears critical that therapists be able to recognize and treat traumatic responses, especially when treating clinical FCR.

Certain verbs and verb tenses revealed different mental activities related to FCR. The common subjunctive grammatical mode can easily recall the uncertainty experienced by cancer survivors (e.g. Elmir, Jackson, Beale, & Schmied, 2010; Scott, 2014) and the role of tolerance of uncertainty (for a review of the concept, see Hillen, Gutheil, Strout, Smets, & Han, 2017) as related to FCR (Fardell et al., 2016). However, the above-mentioned cognitive activities also reflected the embodied mind (Lakoff & Johnson, 1999) and its sensory activities, such as when participants used visual or somatic terms (as seeing or feeling). Some bodily-expressive elements can be seen simultaneously as direct and metaphorical expressions, as when people referred to shivering or being paralyzed by fear, whilst others were direct bodily expressions, as when people cried during the interviews when expressing sadness. Body-oriented therapeutic strategies, as focusing or clearing a space, have been used with cancer patients (Katonah & Flaxman, 1991; Klagsbrun, Lennox, & Summers, 2010) and could be explored for helping people dealing with FCR.

Responding to FCR appeared to be a challenging task, and people either showed efforts to face the possibility of recurrence and their fear itself or else avoided the experience of FCR or its activators; this resembles the engagement versus disengagement coping strategies found in other studies (e.g. Conley et al., 2016) but also the biological responses of fight or flight before a dangerous situation. Each of these action tendencies can be either adaptive (assist with successful coping) or maladaptive (be applied rigidly so as to interfere with successful coping). It was also possible to find conflict or ambivalence between these two opposing action tendencies, making it difficult to assess the adaptive value of each of these responses, and pointing to an internal motivational conflict over learned maladaptive responses to possible traumatic aspects of the cancer experience. It's interesting to note that in the general population, greater familiarity with cancer has been shown to increase fear, while a greater distance diminished it and brought a sense of safety to people (Vrinten et al., 2017). Although the experts in the field of FCR have suggested maladaptive coping (often exemplified by avoidance, reassurance seeking and body checking) as a possible characteristic of clinical FCR (Lebel et al., 2016), Mutsaers et al. (2016) failed to find a difference in coping strategies between clinical and non-clinical FCR (Mutsaers et al., 2016). As considered generally for the anxiety problems, possibly the main issue is how much distress the avoidance process brings the person and how much it disturbs his/her life functioning or goals, since the avoidance can affect not only the feared situations/triggers but also may involve avoiding the internal painful emotional experiences as well (Behar, DiMarco, Hekler, Mohlman, & Staples, 2009; Elliott, 2013). The fear of emotional pain and its avoidance are recognized by different therapeutic approaches as hampering the processing of difficult experiences (Timulak & Pascual-Leone, 2014) in psychotherapy.

Accounts of each of the dimensions of human experience: emotional, perceptual, cognitive, bodily and behavioral firmed the multi-dimensionality of FCR recognized from the earliest theoretical formulations (Fardell et al., 2016; Lee-Jones, Humphris, Dixon, & Hatcher, 1997). Common aspects of the diverse explanatory theories of FCR actually include triggers, appraisal processes and the role of cognitions and beliefs, as well as behavioral/coping responses (Fardell et al., 2016; Simonelli et al., 2016). Apparently, emotional, metaphorical and bodily aspects have not been much explored yet. All these aspects make FCR a complex human experience.

Practice implications

Our exploration of the range of different expressions and meanings of FCR for cancer patients adds insights for and can inform more effective communication between health care professionals and patients in oncology clinical practice in general. It points to a wider perspective on the human experience of FCR, reinforcing the importance of humanizing health care by considering the person as a whole and simultaneously attending to the different dimensions of his/her experience. This seems to be relevant regardless of whether FCR is in the clinical range or not. It is known however that higher levels of FCR are frequently under-recognized by health professionals with insufficient referrals of these patients to psychosocial or psychotherapeutic interventions (Thewes et al., 2014). With regard to psychotherapeutic practice, the wide range of experiences mapped here points to the need for a broad approach, including but quite possibly extending beyond the cognitive-behavioral paradigm that has so far been the main framework for approaching FCR (Fardell et al., 2016). Other approaches that can provide additional lenses of understanding and treating FCR, include supportive (Simonelli et al., 2016), supportive-experiential therapies (Herschbach et al., 2010), both of which have

been supported by research evidence. Going further afield, FCR can be seen as a problematic experience that needs to be assimilated (Stiles et al., 1990) through an emotional deepening process (Pascual-Leone & Greenberg, 2007; Timulak & Pascual-Leone, 2014). This can be done first through the differentiation of negative emotional states from global to specific, followed by exploration of secondary or defensive reactions (e.g., fear of fear) to find the underlying primary emotions, some of which are maladaptive (e.g., trauma-based fear or shame) and need to be transformed into adaptive emotions with corresponding adaptive actions. From this point of view, non-clinical FCR is likely to an adaptive emotional response, related to the real threat of a recurrence, leading to adaptive needs and actions of protection and surveillance. On the other hand, a dysfunctional FCR might be initially experienced as an undifferentiated fear-based emotion or a secondary fear of fear or an avoidant emotional numbing. These might be related to past traumatic events that cause high distress when they break through. The Cancer Australia review on FCR found, on one hand, a relationship between FCR and increased screening, prevention behaviors and increased contact with the health system and, on the other hand, an association between FCR and previous anxiety or PTSD (Cancer Australia, 2011). The main point that we making, however, is that FCR is highly diverse, requiring that psychotherapy proceed from the exploration of specific meanings of FCR for each patient. In helping clients address their FCR therapists need also to work holistically and comprehensively with the range of aspects of each unique person. In addition, difficulties of emotion regulation can impact negatively on psychological and physical well-being (Brandão, 2017; Giese-Davis, Conrad, Nouriani, & Spiegel, 2008). Psychotherapy can allow the exploration and differentiation of the different emotion states, especially the more undifferentiated ones, thus facilitating successful emotional processing (Pascual-Leone & Greenberg, 2007). The dimensions examined in this review

point to the need for research on a range of available therapeutic approaches, including cognitive-behavioral, in order to develop and evaluate multidimensional treatments of clinical FCR, as more light has been brought to aspects less explored so far in the literature on FCR, including emotional or bodily features. Based on available evidence (Elliott, 2013), it appears that humanistic-experiential psychotherapies such as person-centered and emotion-focused therapies have potential as treatments for people coping with chronic medical conditions, including FCR (e.g., Herschbach et al., 2010; Manne et al., 2007; Spiegel et al., 1999). Our review, however, does not speak to this issue but instead primarily helps to map out the experiential territory of FCR, which we hope will sensitize therapists of various approaches to key aspects and variations of their clients' experiences of FCR.

Methodological issues

Our team's choice of using only participants' direct quotations was congruent with our main goal of trying to understand people's experiences of FCR using their own voices and also with striving to respect the qualitative nature of the studies analyzed. Nevertheless, being a secondary analysis, the data of our review was a potentially biased collection of published excerpts selected by the original authors. Overcoming this limitation would require access to and reanalysis of the primary data of a sample of the studies reviewed here.

Our selection of studies embraced a wide scope of studies with very different objectives and a heterogeneous amount of information, especially due to the inclusion of broad qualitative studies of the experience of cancer not specifically focused on FCR. Although this option can be questioned, it did make it possible to examine the presence of FCR in a variety of samples and types of studies, finding similar aspects of this

experience independent of the goals of the studies. Another limitation is the impossibility of distinguishing non-clinical from clinical FCR in the selected studies, which could be quite important for psychotherapeutic purposes. Systematic evaluation of the difference in intensity of FCR experience awaits further systematic research.

Our sample of studies was quite heterogeneous, in terms of number of participants and their characteristics, and data collection methods. Although nearly half of the studies included other cancer diagnoses, breast cancer was the most represented diagnosis and regarding the totality of studies, participants were mostly women. Our findings are thus more applicable to women, although it proved impossible to distinguish quotations based on gender, because this information was often missing. Comparing the quotations of breast cancer patients with those with other kinds of cancer, we found the same categories in both of them; this is consistent with studies that failed to find significant differences in the experience of FCR based on type of diagnosis (Krok-Schoen et al., 2018; van de Wal et al., 2016). Despite the specificities of each study, in all the studies participants considered FCR to be an important concern. Interestingly, FCR was strongly represented in studies that were not directly studying it: even if not asked about, cancer patients spontaneously referred its presence, importance and impact. This idea is highlighted by previous reviews of FCR as a universal experience among cancer patients even if to varying degrees (Simard & Savard, 2009).

Organizing our data around the emotion scheme structure can as well be questioned as arbitrary; however, it did allow us to explore FCR as an emotional experience, reflecting simultaneously our theoretical assumptions from a constructivist-interpretivist stance (Ponterotto, 2005) and our specific allegiance to Emotion-Focused Therapy. Considering the therapeutic utility of this review, we note that the emotion scheme elements are nevertheless recognizable as core aspects of the human experience,

and therefore potentially useful within any psychotherapeutic approach. Considering the qualitative nature of this systematic review, we carried out and audited our analysis carefully, including following clear criteria for the studies to be included in the analysis. We also incorporated recent recommendations for qualitative research (Levitt et al., 2018; Levitt, Motulsky, Wertz, Morrow, & Ponterotto, 2017). Even taking into account the goals of reviewing and synthesizing, we were particularly concerned about the lack of context for data analyzed (referred to as “situatedness” in Levitt et al., 2018). Therefore, the general results we presented might not fit exactly specific samples or participants with different ages, different cancer diagnoses, cultural backgrounds, or nationalities; instead, we have tentatively approached possible common or main features consistent across different samples and are recommending further research to examine these potentially important differences.

Conclusion

Cancer survivors describe FCR as a complex lived experience that affects their perceptions, emotions, body, cognitions and behavior/ motivation. These components are part of an overwhelming emotional experience that can be strikingly different for different people. This review can help health professionals and therapists attune to the varied impacts of fear of cancer progress or return, a sensitivity that is essential to effective patient-centered care.

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Chapter 4

Emotion-Focused Therapy for Fear of Cancer Recurrence: A Hospital-Based Exploratory Outcome Study (Study 2)

Abstract²

Fear of cancer recurrence (FCR) is a main concern for most cancer survivors and can bring significant distress impacting well-being and quality of life. Although other psychological approaches have been developed for dysfunctional FCR, based on previous research, Emotion-focused therapy (EFT) might also be a relevant intervention for treating this concern. Seventeen adults with a cancer diagnosis and presenting FCR among other cancer-related concerns were offered EFT, delivered in a regular practice in a cancer hospital (mean number of sessions: 13, range 4 – 25). Outcome and process instruments were used to assess general psychological distress, client-generated outcome items and helpful and hindering aspects of therapy. Significant pre-post outcome differences were found, both for client-generated ($d= 1.53$) and standard ($d= .88$) measures, with no cases of reliable deterioration, although most patients did not show clinically significant change by the end of therapy. The most frequent helpful in-session processes were client verbal expression of experience and work on parts of self; the most common immediate session impacts were positive feelings and self-realizations. EFT may be a useful alternative treatment for FCR.

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Introduction

Fear of cancer recurrence (FCR), the “fear, worry, or concern relating to the possibility that cancer will come back or progress” (Lebel et al., 2016, p.3266), is a major concern for over 70% of cancer patients and is frequently cited by survivors as their most important concern (Simard et al., 2013). FCR has been described by survivors of cancer as a complex, intense and difficult experience, affecting multiple dimensions of their lives (perceptions, emotions, body, cognitions and behavior) (Almeida et al., 2019) and taking the form of existential distress (Vehling & Kissane, 2018). Also, there is strong evidence that higher FCR is associated with poorer quality of life and higher psychological distress, anxiety, depression and avoidance/intrusion (Sarkar et al., 2014; Simard et al., 2013). Patients experiencing clinical FCR have high levels of preoccupation or worry, recurrent and long-lasting thoughts or images related to cancer or death, which increase over time, are difficult to control, cause excessive distress and impact their daily lives, making it difficult to plan for the future (Lebel et al., 2016; Mutsaers et al., 2016). Psychological interventions for helping people dealing with FCR have been developed mainly in the last decade and a recent systematic review concluded that there is a small but robust effect on decreasing FCR (Tauber et al., 2019). Most of these interventions rely on cognitive-behavioral approaches, either traditional or contemporary. For example, a randomized controlled trial using a blended (face-to-face plus online) cognitive-behavioral intervention with a sample of people with different cancer diagnoses, showed significant clinical improvements with a moderate-to-large effect size (Van De Wal, Thewes, Gielissen, Speckens, & Prins, 2017). Another intervention for FCR combining meta-cognitive and acceptance/commitment elements was also successfully tested in a randomized controlled trial, with significant results not only by the end of therapy but

also after 3 and 6 months later (Butow et al., 2017). Although less frequently, other therapeutic approaches have been used successfully, such as supportive-experiential group therapy (Herschbach et al., 2010) or a gratitude intervention, which showed a significant decrease on death-related fear of recurrence (Otto, Szczesny, Soriano, Laurenceau, & Siegel, 2016). In addition, a psychoeducational booklet plus 3 individual telephone-based psychodynamic sessions have also proved to be effective in reducing FCR in a sample of melanoma patients at high risk for developing another melanoma (Dieng et al., 2016). In any event, considering the importance of combined or tailored interventions (Leichsenring et al., 2018) as well as the need for taking into account client preferences (Swift, Callahan, Cooper, & Parkin, 2018) it is important to further explore different therapeutic options. Emotion-Focused Therapy, an individual humanistic-experiential psychotherapy stemming from Person-centered, Gestalt and Existential traditions (Elliott & Greenberg, 2007), is an evidence based approach shown to be efficacious for several psychological problems, including depression, interpersonal problems, anxiety and trauma (Elliott et al., 2004; Elliott et al., 2013; Elliott, 2013). As an individual therapy, EFT combines contemporary emotion theory (Goldman & Greenberg, 2015) with active therapeutic tasks such as two chair work and empty chair work for helping clients deepen and transform stuck or reactive emotions into adaptive (useful) emotions (Elliott et al., 2004). In cancer populations, Connolly (2016) reported significant pre-post results in six women with cancer and comorbid anxiety and depression involved in individual EFT therapy. A randomized controlled trial using an EFT couple intervention with patients facing advanced cancer and their caregivers also proved to be effective (McLean, Walton, Rodin, Esplen, & Jones, 2013). Other studies with cancer population have successfully used particular emotional deepening or regulating interventions commonly employed in EFT, such as focusing or clearing a space

(Katonah & Flaxman, 1991; Klagsbrun, Lennox, & Summers, 2010). At this point, however, it is not clear from these studies what elements of EFT are likely to contribute to client change. The present study was carried out mainly to explore the effectiveness of EFT for helping people dealing with FCR, but also to identify the specific aspects of therapy that clients find helpful.

Method

Clients

Sample selection. Participants for this study were selected from a wider sample of patients (N=29) who agreed to participate in an exploratory study on the applicability of EFT to people with cancer (Elliott, Silva, & Almeida, 2014). These were adults (≥ 18 years old) with a cancer diagnosis treated in a Portuguese cancer hospital and referred to the Psychology consultation of a psycho-oncology service; exclusion criteria were having a limiting physical condition for psychotherapy or major cognitive deficits. All participants were of Portuguese nationality, European origin/white and spoke Portuguese. Because it was the most common presenting problem, a sub-sample of 17 patients who presented with FCR was selected for the current study. The selection process of participants was done by the first and third authors (SNA and ERS; they were also the therapists of these patients), by analyzing each participant's Personal Questionnaire (PQ) items for the presence of FCR (see measures section for more on the PQ): each PQ was classified as Main FCR, when FCR was explicitly referred to (i.e. "fear that the disease comes back") and a main identified concern for the patient (among their 3 most highly ranked PQ items) or as Minor FCR, when there was no FCR either in the first three items of the PQ or FCR was implied but not referred to explicitly (e.g. "uncertainty about the future"). Each rater independently categorized each participant into one of three subgroups (Main FCR,

Minor FCR, not FCR); disagreements or doubts were later discussed by the two raters until consensus was reached. Before discussion of ratings and reaching consensus, the initial interrater reliability between the two raters on the inclusion and assessment of participants was good (Cohen's $k=0.74$; McHugh, 2012). Nine people were included in the subgroup Main FCR; eight people were in the Minor FCR group (53% vs 47% of the sample). The two raters also extracted from the PQ all the items they considered related to FCR (PQ-FCR; item examples: Fear of the disease coming back; Fear of not having cure, of suffering, of the worsening of the disease), for later analysis (all the participants included had at least one of these items). From the 22 participants who presented FCR, five were excluded: three dropped out of therapy (two patients had 3 and 4 sessions respectively, not attending the following one; the other had 11 sessions and stopped attending due to deterioration of her medical condition, which eventually led to her death); one had no assessment measures (although the therapist confirmed the patient had FCR as a main issue) and another was still in treatment when the data began to be analyzed. The demographic and clinical characteristics of the final sample for the present study are presented in Table 3. The research was approved by the Hospital Ethics Committee and participants gave their informed consent for participation in the study and research purposes.

Table 3. Demographic and clinical characteristics of the sample.

Participants	N=17
Female	14 (82%)
Mean age at study entry (range)	45 (range: 24-69)
Married/Civil partnership	11 (65%)
Single	4 (23%)
Divorced	2 (12%)
With children	13 (76%)
Level of education	
0-4 years	2 (12%)
4-9 years	4 (24%)
9-12 years	6 (35%)
12+ years	5 (29%)
Cancer site	
Hematological	6 (35%)
Colorectal	5 (29%)
Gynecological	3 (18%)
Urologic	2 (12%)
Breast	1 (6%)
Stage of disease	
0/I	5 (29%)
II	8 (47%)
III/IV	4 (24%)
Medical treatment status	
Off-treatment	13 (76%)

On treatment	4 (24%)
Psychiatric medication	
Yes	6 (35%)

Therapists

The two therapists of the study (SNA and ERS) were clinical psychologists who had been working in the cancer hospital site of the research for more than 10 years at the time the study began. In the previous years each had formal training in EFT, following the standards for accreditation of EFT therapists set by the International Society for Emotion Focused Therapy (ISEFT). Their main supervisor was the second author (RE), one of the developers of EFT, who assessed treatment integrity. These three authors were engaged in a wider project of exploring the applicability of EFT to people with cancer. In the present study, one of the therapists delivered therapy to 10 patients, the other to 7 patients.

Measures

The *Personal Questionnaire* (PQ; Elliott, Mack, & Shapiro, 1999; Portuguese version: Sales et al., 2007) is an individualized client-generated outcome measure designed to measure changes in psychological difficulties during therapy. It consists of a list of problems identified by the client, described in their own words and which they want to work on in therapy; each item is rated by the client according to how much it had bothered them in the past week (for procedure manual and blank forms see Elliott et al. 1999). The PQ has been shown to be a robust measure with good psychometric properties as well as clinical utility, with an established cut-off of 3.25 (on 1 to 7 scale) and a reliable change index value of ≥ 1.5 points for pre-post reliable change (Elliott et al., 2015). In this

study, a PQ was created for each client during their first session and was subsequently filled out at the beginning of each session, constituting a session-by-session outcome measure (although only the scores from first and last sessions were used for analysis). As no specific measure of FCR was available in Portuguese, we retrieved from each participants' PQ all the items related to FCR, which we called PQ-FCR.

The *Clinical Outcome in Routine Evaluation – Outcome Measure* (CORE-OM; Evans et al., 2002; Portuguese version: Sales et al., 2012) is a measure of general psychological distress. It includes 34 items on four different dimensions: subjective well-being, problems/symptoms, life functioning and risk (to self and to others) and each item is rated in a five-point scale ranging from 'not at all' to 'most or all the time'. CORE-OM is a well established measure with extensive data supporting its psychometric properties as well as clinical utility with patients presenting with a broad range of psychological problems (Evans et al., 2002). The recommended cut-off is 10 (Connell et al., 2007), with a reliable change index value of 5 points (Barkham, Mellor-Clark, Connell, & Cahill, 2006). In this study, the CORE-OM was administered at the first session and completed every 5 sessions (although only the scores from first and last sessions were used for analysis).

The *Helpful Aspects of the Therapy Form* (HAT; Llewelyn, 1988; Portuguese version: Sales et al., 2007) is a post-session questionnaire in which the client describes in their own words the most helpful and hindering event in the session and rates its helpfulness on a 5-point scale, from 1 to 5, corresponding to the degree of the positive or negative impact of the event. The HAT Form helps clients reflect on their therapy sessions and describe significant events (Stone & Elliott, 2011). In this study, the HAT form was to be given at every session; generally, clients took it home between sessions bringing it the next session or in some cases sending it by e-mail to the therapist.

Psychological treatment

The treatment was the version of EFT developed by Greenberg, Rice and Elliott (1993), which uses a range of different kinds of emotion work (“tasks”) as appropriate. Patients were offered individual EFT, presented to them as “EFT for people with cancer” (EFT-Ca) and adapted for common characteristics of this population, such as having a potentially life-threatening illness, frequently difficult and prolonged treatments, and various cancer-related sequelae. Existential issues are particularly relevant, including cancer as a “boundary” situation, touching people’s ultimate concerns: death, freedom, isolation and meaninglessness (Yalom, 1981). Considering all the possible losses that the cancer experience may involve (e.g., infertility due to cancer treatments; loss of an organ or limb; changes or impairments in communication and feeding), grieving processes are other typical aspects therapists must work with. Also, it is common for patients to present strong self-interruption processes, such as holding back awareness or expression of their difficult emotions in order to “be strong”, to not interfere with their treatment, or to avoid burdening their loved ones. Nevertheless, sessions were generally carried out in a manner typical for EFT, valuing emotion as a main source of meaning, direction, and growth (Elliott & Greenberg, 2007) and working through the relational and task principles described by the developers of the approach (e.g. Greenberg, Rice, & Elliott, 1993). The distinctive feature of this form of EFT is its combination of a deep empathic work with specific experiential tasks, which provide different ways to help clients deepen and transform their emotions (Elliott et al, 2004). The therapists therefore identified markers for working with particular therapeutic issues (e.g., self-criticism) and offered to engage with the client in a particular emotion process to work towards resolution (e.g., therapist proposes two chair work between the critic and the criticized aspects of the self). To work specifically on the FCR issue, the therapists most frequently used two chair work for

anxiety splits (in which the person makes self anxious; Elliott, 2013), trauma retelling as well as meaning creation (Clarke, 1989). Vulnerability markers were also frequently present in these patients, either related to deep existential suffering and/or cancer-related traumatic experiences. Some of these cancer-related traumatic experiences were linked to other previous traumatic experiences. Sessions generally lasted 50-60 minutes. The scheduling of the sessions was adjusted to patients' ability to attend, including distance from the hospital, financial situation, and physical status, with the result sessions were not always weekly (ranging from 1 to 4 per month). The general conditions for the treatment of these patients reflected what was available in the regular clinical practice of psychology in the hospital, considering that there were not any extra resources for the research. Although we expected highly variability of the number of sessions (based on our hospital experience), we were aware that 16-20 sessions were common in previous studies (e.g. Elliott, 2013; Timulak et al, 2018). Data for this study was collected between 2013 and 2017.

Data analysis

Statistical analyses for quantitative data were performed using SPSS. Paired samples t-tests were conducted in order to compare scores before and after therapy on both PQ and CORE-OM; this was also explored for PQ-FCR items. Additional exploratory analyses were done to test whether the sub-samples Main FCR and Minor FCR were significantly different from each other regarding the pre-post scores of the outcome measures, through independent samples t-tests and covariance analysis. Effect sizes for pre-post therapy differences were determined using Cohen's d. Rates of clinical improvement and deterioration (Jacobson & Truax, 1991) were determined according with the established criteria for each measure (Elliott et al., 2015; Barkham, Mellor-clark,

Connell, & Cahill, 2006). For analysing qualitative data from HAT, we used descriptive-interpretive qualitative analysis (R. Elliott & Timulak, 2005, 2021). As the HAT Form generally provides information on within-session processes (things client or therapist did in sessions) and client reactions to these processes (Elliott, Slatick, & Urman, 2001), the first and second authors (SNA and RE) first divided the HAT content in meaning units, then allocated them to either process or effects domains and then clustered them into categories and sub-categories within each of these domains based on similarity of meaning units. The first author identified a set of categories, which the second author audited and revised and sent back to the first author and so on until consensus was arrived at. The representativeness of each category/subcategory was determined by recording the number of participants referring to it. The categories/subcategories were classified as “general” when occurring in at least a 75% of the sample; “typical” when present for at least half of the sample; “variant” when reported for at least two participants (but less than 50%) and “unique” when only one participant indicated it (Elliott & Timulak, 2021). All but one meaning unit referred to helpful aspects of therapy sessions. A case study retrieved from the sample was briefly analyzed to help illustrate EFT for FCR, including elements of EFT case formulation (Elliott, 2015; Goldman & Greenberg, 2015).

Results

Outcome data for EFT for Fear of Cancer Recurrence

On average, therapy lasted 13 sessions (SD 6.26; range 4-25). In the beginning of the therapy, all patients presented clinical levels of psychological distress on the PQ (M=5.78; SD = 0.52) and all-but-one on the CORE-OM (M=18.38; SD 5.15). Twenty-six percent of the PQ items (40/154) were considered to be related to FCR, with a mean

of 2 of these items per person (SD 1.46; range 1-7). All PQ-FCR items were also in the clinical range (> 3.25) at the beginning of therapy ($M=6.15$; $SD 0.95$). By the end of therapy, PQ and CORE-OM scores were significantly lower than at pre-therapy (PQ: $t_{17}=5.67$, $p < .001$; CORE-OM: $t_{16}=5.96$, $p < .001$); the same was true for PQ-FCR post-therapy scores ($t_{17}= 4.28$, $p= .001$) (see Table 2). Eleven patients (65% of the sample) showed reliable change in PQ by the end of therapy and 4 patients (24%) moved from the clinical to the non-clinical range; 4 patients (24%) achieved clinically significant change. For PQ-FCR items, 7 patients (41%) showed reliable change, although only 2 patients (12%) moved to a non-clinical score; 2 patients (12%) achieved clinically significant change. On the CORE-OM, 7 patients (41%) presented reliable change after therapy and 4 (24%) moved from a clinical to a non-clinical range; only 1 patient (6%) achieved clinically significant change. There were no cases of reliable deterioration, based both on PQ (including PQ-FCR items) and CORE-OM measures. Pre-post effect sizes for PQ ($d= 1.53$), PQ-FCR ($d=.98$) and CORE-OM ($d= .88$) exceeded Cohen's (1988) convention for a large effect ($d = .80$). No significant differences were found between therapists. Dividing the total sample in the two sub-samples Main FCR and Minor FCR we also found pre-post significant differences in all measures for both sub-samples (see Table 4), but no significant difference between subsamples, using both independent samples t-tests and one-way ANCOVA.

Complementing the outcome data, and providing a kind of credibility check, there are some spontaneous reports from participants on HAT forms in which specific improvements relating FCR were declared: “I was able to overcome the fears I had and live naturally.” (*Sophie*, 30 years-old); “I felt the fear of recurrence was more controlled” (*Isabel*, 56 years-old); “I realize that I was able to enter the [oncology] hospital without fear and without fear of having a serious disease (*Tom*, 26 years-old).

Table 4. PQ and CORE-OM Pre-post scores.

<i>Measure</i>	<i>Cut- off</i>	N	Mean (SD) <i>Pre-therapy</i>	Mean (SD) <i>Post-therapy</i>	<i>t</i>	<i>p</i>	<i>Cohen's d</i>
<i>Total sample</i>							
PQ	3.25	17	5.78 (0.52)	4.22 (1.34)	5.67	<.001	1.53
PQ-FCR	3.25	17	6.15 (0.95)	4.89 (1.56)	4.28	.001	0.98
CORE-OM	10	16	18.38 (5.15)	13.56 (5.76)	5.96	<.001	0.88
<i>Main FCR subsample</i>							
PQ	3.25	9	5.68 (0.31)	4.10 (1.17)	4.89	.001	1.85
PQ-FCR	3.25	9	5.92 (0.94)	4.61 (1.52)	2.76	.024	1.04
CORE-OM	10	9	18.11 (4.31)	13.89 (4.81)	3.52	.008	0.92
<i>Minor FCR subsample</i>							
PQ	3.25	8	5.89 (0.70)	4.36 (1.58)	3.18	.016	1.25
PQ-FCR	3.25	8	6.42 (0.96)	5.21 (1.64)	3.32	.013	0.90
CORE-OM	10	7	18.71 (6.42)	13.14 (7.20)	5.34	.002	0.82

PQ=Personal Questionnaire; PQ-FCR=Fear of Cancer Recurrence items of PQ; CORE-OM: Clinical Outcome in Routine Evaluation – Outcome Measure; Main/Minor FCR: subsamples of patients in which FCR was a main/minor concern.

Helpful Aspects of EFT for Fear of Cancer Recurrence

Thirteen patients (76% of the sample) fulfilled at least one HAT Form during the psychotherapy process (Mean=4, range 1-13), in total providing 55 completed forms. Quotes from participants exemplifying each category and sub-categories, as well as the proportion of participants presenting them are presented in Table 5.

Within the helpful process domain, we were able to identify therapist and client helpful processes. While therapist helpful processes were quite variable (variant themes present for at least 2 participants and less than 50% of participants), patients most commonly referred to the importance of therapist expert interventions (e.g., differentiating fears), therapist encouragement of awareness and exploration, and therapist empathy. The helpful client processes most frequently referred included verbal expression of experiences, found to be typical themes, such as disclosing particular experiences, discussing difficult or important topics and unburdening, venting or catharting. Aspects related to chair work during sessions, a typical category, were inferred when clients referred to the importance of separating out different parts of self, facing/talking with/from fear/worry/negative parts and finding new or different parts of self. Reflecting on, analyzing, interpreting, and clarifying experiences were also valued by patients, although all were variant categories. Other in-session helpful processes included research procedures (e.g., “the questionnaire”); asking for help from therapist, and general unspecified aspects of sessions. Within the effects domain we found four categories: positive feelings/states, self-realizations, emerging action tendencies, and relational impact. Regarding their representativeness, positive feelings/states and self-realizations were found to be general categories; emerging action tendencies a typical category, and relational impact a variant one. Most frequent were patient descriptions of positive feelings/states resulting from therapy sessions, from general positive feelings to

feeling more relieved, calmer/more relaxed/less anxious, secure/safer; some patients expressed feeling empowered/legitimated, more capable/self-confident, and hopeful. Others reported personal improvements or progress. Feeling better by putting things into perspective, such as relativizing/distancing/organizing, was also appreciated. In the self-realizations sub-category, we identified general realizations about self, awareness (realizing something specific about self, i.e., getting more in touch with it without connecting it to something else) and insight (new realization of some kind of connection involving self, including parallels, causes, sources). The emerging action tendencies category involved subcategories for self-coercion/coaching orientations, action determination, internal suggestions/possibilities, and desiring/idealizing. A much smaller but relevant set of comments were related to relational impact, reflecting the importance of shifts in the therapeutic relationship.

Only one meaning unit involved a hindering process, dysregulated distress (“I start to cry when I want to talk about the theme”) leading to self-interruption (“I start trying to ‘swallow’ the crying”). Based in these qualitative data and the near-absence of reports of hindering aspects, we can conclude this therapeutic approach (and its central therapeutic tasks) was acceptable and valuable for this sample of patients.

Table 5. Examples of participants' quotes regarding helpful and hindering aspects of therapy.

1. Helpful Processes:
<p>1.1. Therapist Processes (5/13; 38%*)</p> <p>1.1.1. Therapist expert interventions (4/13; 31%)</p> <ul style="list-style-type: none"> • therapist tried to separate my fears in order to be easier to solve the various situations <p>1.1.2. Therapist encouragement of awareness/exploration (2/13; 15%)</p> <ul style="list-style-type: none"> • The therapist encouraged the awareness of the 'problem' <p>1.1.3. Therapist empathy (2/13; 15%)</p> <ul style="list-style-type: none"> • After that it was the psychologist understanding me
<p>1.2. Client processes (12/13; 92%)</p> <p>1.2.1. Verbal expression of experience (7/13; 54%)</p> <p>1.2.1.1. Disclosing particular experiences (4/13; 31%)</p> <ul style="list-style-type: none"> • In this session it was important to talk about the time of the diagnostic. The moment I knew I was at a risk of life. The way it affected me, and stills affects emotionally. <p>1.2.1.2. Discussing difficult or important topics (2/13; 15%)</p> <ul style="list-style-type: none"> • Talk about my short-term plans, how to take better care of myself and practice more physical activity to lose weight, continue with dietary education. <p>1.2.1.3. Unburdening, venting or catharting (4/13; 31%)</p> <ul style="list-style-type: none"> • Doing a catharsis of the events that bring me anguish. <p>1.2.2. Reflecting on/stepping back from experiences (3/13; 23%)</p> <p>1.2.2.1 Reflecting on/thinking aloud (2/13; 15%)</p> <ul style="list-style-type: none"> • It helped me to reflect in a more organized way about my conjuncture. <p>1.2.2.2 Analyzing/interpreting/clarifying (3/13; 23%)</p> <ul style="list-style-type: none"> • We analyzed the situations during the session.

1.2.3. Parts of Self-work [client view of chair work] (7/13; 54%)

1.2.3.1. Separating out different parts of self (3/13; 23%)

- To represent, by separating, two of the “entities” that I’m composed of.

1.2.3.2 Facing/Talking with/from my fear/worry/negative parts (3/13; 23%)

- During this session it helped me a lot being face to face with my fear, confront him and find solutions and positivism in what I fear.

1.2.3.3 Finding new/different parts of me (1/13; 8%)

- It was important to find a possible way out, first imagining how it could be and secondly finding a solution to another I could find some way out for me.

2.0. Helpful Effects:

2.1. Self-realizations (10/13; 77%)

2.1.1. General realizations about self (2/13; 15%)

- I’m getting to know myself again.
- Seeing these things, I feel I understand myself better.

2.1.2. Awareness (8/13; 62%)

- I was able to understand the origin of the problems and in that sense, I think it can help solving them
- It helped me to realize that the fear isn’t my enemy at all. I can live with him as he is part of me and he will be for all my life.

2.1.3. Insight (6/13; 46%)

- In this session I was able to identify the fear as the great booster of the majority of the problems.
- Although still not very clear, it’s recognizable a link between the difficulty of facing the “inevitability of death” and the situations of panic (...)

2.2. Emerging action tendencies (7/13; 54%)

2.2.1. Self-coercion/coaching orientations (4/13; 31%)

- I also realized that I must be less demanding of myself, act with less pressure.
- It made me understand that I have to open more to the people who love me.

2.2.2. Action determination (5/13; 38%)

- Set priorities. Minimize my pain by avoiding blaming myself. See the world as it is, accept the facts, the reality.

2.2.3. Internal suggestions/ possibilities (4/13; 31%)

- however, may be to alert me to start acting instead of always postponing what I should do to improve self-esteem.

2.2.4. Desiring/idealizing (1/13; 8%)

- I managed to idealize what I want to solve in relation to myself

2.3. Positive feelings/state (11/13; 85%)

2.3.1. General positive feeling (3/13; 23%)

- and the less positive thoughts weren't so present.

2.3.2. Relieved; calmer/more relaxed/less anxious; secure/safer (8/13; 62%)

- It was useful mainly for calming me down

2.3.3. Empowered/legitimated; more capable/self-confident; hopeful (7/13; 54%)

- I felt human and that my opinion counts.
- I stay with more hope about my problem being totally solved.

2.3.4. Realize/identify own improvements/progress (7/13; 54%)

- I noticed that from the previous session to this I wasn't thinking so frequently about my disease.

2.3.5. Putting things into perspective (2/13; 15%)

• It was important as it helps me to position myself in a more distance and to reflect in a more objective way.

2.4. Relational impact (2/13; 15%)

• I feel confidence in the psychologist and with the patience with which she listens to me.

3.0. Hindering Process (1/13; 8%)

• I start to cry when I want to talk about the theme. And I start trying to “swallow” the crying.

* Proportion of clients and corresponding sample percentage for each domain and category/subcategory.

Illustrative case study

Having presented the results from the outcome and qualitative data, we now present a case study that illustrates how EFT might look in a person with a clinical presentation of FCR. The patient has been de-identified by changing his name and age; no further personal information was used. Tom was a 26-year-old man in medical follow-up since he was 18, after having a surgery for a colorectal cancer, found to be related to a genetic condition that strongly increases the likelihood of getting cancer at a young age. He had no further treatments for his cancer besides this surgery and he had been free from the disease since then. He was referred to therapy for high levels of anxiety related to the possibility of cancer recurrence, as well as for severe depressive symptoms, including despondency, lack of motivation, hopelessness, isolation, and suicidal thoughts. Emotional regulation was also troubled, with Tom presenting frequent panic attacks, which led to several emergency room visits. Coming to the hospital for follow-up was another very difficult situation for him. He also presented sleep difficulties, headaches, abdominal pain, and body tension; he generally interpreted his somatic symptoms as a cancer recurrence and was constantly monitoring his body for signs of possible cancer. These difficulties had started about 6 months before psychological treatment and were interfering with his life goals and ability to work.

Tom's EFT process lasted 17 sessions and included a range of different kinds of emotion work (cf. Elliott et al, 2014). Developing a solid therapeutic alliance was challenging due to Tom's hospital avoidance and general helplessness, leading him to frequently postpone therapy sessions. Experiencing tasks, such as allowing and expressing emotions and experiential focusing, helped the patient to progressively access, express and symbolize his avoided difficult emotions. It was also necessary to help Tom reprocess specific traumatic cancer experiences and memories, namely the terror of dying

he experienced while he was waiting for his surgery (trauma-related fear). Recovering and reconnecting aspects of his memories helped Tom making new meaning associations. Trauma retelling work was intertwined with the meaning creation work, with identification and re-examination of violated cherished beliefs – such as “I’m too young for having cancer”. Two-chair work was proposed for working with anxiety, self-criticism, and self-interruption splits, as well as with compassionate self-soothing. An example of a chair-work for an anxiety split is illustrated by this excerpt at the 6th session:

Client (speaking as the Experiencer): Don’t bug me anymore, I can’t stand hearing you anymore.

Therapist: Right...don’t bug me anymore...right, mm-hm. Can you move over here? (Client changes chairs). What does this side- What does he say to this, “Don’t bug me,” always pessimistic, always saying, “I’ll never make it, I’ll never make it, I’m fed up of this”?

C (as critic): But I’m warning you of worse things. (T: Mm-hm) I’m making you alert

T: Right, what I want to do...

C: ...Is to prevent you from suffering.

T: It’s as if somehow what this side wants is ...

C: Deep inside me I want to

T: Tell him (gesturing to the other chair)

C: Deep inside I want you to be alert, active, to avoid greater suffering.

T: Right, as if in some way, I want to protect you.

C: I want you to always be alert, thinking about it so that the symptoms you have don’t evolve. (T: Mm-hm) or get worse.

T: Right, I want you to be always alert. What is it like when you see him like this, because deep inside he is suffering with this, he is suffering from being always reminded, this whole burden, so ... is this what this side wants, to bring this suffering to him? Do you want him to suffer?

C: No...

T: No, no, ok, so it's not exactly ... I don't want you to suffer,

C: What I don't want is for you get into something worse.

T: Mm-hm... I don't want you to suffer more.

C: That you don't stay alert and then the consequences become more serious.

As this segment illustrates, we often found that FCR was a secondary process (e.g., fear of feelings in general) and resulted in further secondary processes such as depression/hopelessness, all stemming from primary maladaptive trauma-related fear, often left over from cancer- or treatment-related medical trauma. Working through Tom's emotional difficulties allowed him to touch and connect his deep vulnerabilities and core pain, unfolding existential anguish, a sense of "loss of meaning and of dignity" and the sadness of being lonely in the face of death and of losing self and others. It allowed Tom to activate primary adaptive emotions, such as protective anger, along with connecting sadness and finally self-compassion. He was also able to reconnect to previously unmet needs for hope, as well as meaning, connection, security, and grieving ("And I feel that I can slowly accept things as they really are in a more natural way", HAT form, 10th session). Tom's perceived changes were likewise expressed in the different assessment measures, with a clinically significant change on the PQ (pre score=5.4; post score=3.2; Elliott et al, 2015 ≥ 1.5 pre-post points) and a reliable change on the CORE-OM (pre score=21; post score=13; Barkham, Mellor-Clark, Connell, & Cahill, 2006, +5 points below).

Discussion

To our knowledge, this is the first study examining the applicability of EFT to FCR in Portuguese people dealing with cancer. EFT was found to be an effective intervention for helping this sample of people dealing with their cancer-related distress including FCR, which was a main concern for more than half of the larger sample. According to our PQ data, participants in this study presented significantly higher pre-therapy distress than broader clinical samples (Elliott et al., 2015) ($M=5.78$ vs $M=5.04$; $t = 3.26$; $p < .01$; $d = .81$). On the CORE-OM, we found similar values to other clinical populations ($M=18.4$ SD = 5.15 vs $M=18.3$ SD = 7.1; Connell et al, 2007). In previous research clinical distress has been estimated in 30 to 50% of cancer patients (Mehnert et al., 2018; Mitchell et al., 2011), reflecting cancer experience as a highly demanding situation. Considering that the patients in this study had been referred to a mental health service within a cancer hospital, they might represent an exceptionally distressed subpopulation, which however seems better captured by an idiographic measure (PQ) than by a nomothetic one (CORE-OM). These high initial scores in our sample might help explain the significant pre-post effects. We also note that most of the participants were women with children, which has been found to be associated with higher FCR (Mehnert, Berg, Henrich, & Herschbach, 2009; Simard et al., 2013; van de Wal, van de Poll-Franse, Prins, & Gielissen, 2016). Having a very heterogeneous sample namely regarding level of education and diagnosis it was not possible to determine whether these variables had also influenced the results. Dinkel et al (2012) found level of education was the only predictor of a long-term reliable change in a group psychotherapy for dysfunctional Fear of Progression, with patients with an educational level above elementary school more likely to improve (Dinkel et al., 2012).

Clients were doing significantly better by the end of therapy, with no cases of reliable deterioration, but most were still presenting clinical levels of emotional suffering, remaining in the clinical range on PQ, PQ-FCR and CORE-OM. The PQ showed to be the most sensitive measure to change, reinforcing previous psychometric analysis (Elliott et al, 2015). These results might point to some degree of relief from distress with presenting problems rather than specifically to a dissolution of the anxiety related to the real threat of a cancer recurrence. It would be relevant in future research to assess other variables that could also help explain this result, such as the presence and severity of physical symptoms, a factor related to higher levels of FCR (Simard et al., 2013).

Because EFT is a new approach to address this specific cancer-related concern, exploring aspects of the therapeutic process through the HAT form data helped us to assess if it was a suitable approach for FCR as well as to identify what people found most helpful. Participants essentially described their own internal processes as helpful, mostly valuing internal realizations during therapy sessions and positive feelings coming from it, as well as verbal expression of experiences and work on parts of self. Awareness/insight/self-understanding, exploration of feelings/emotional experiencing, relief, empowerment and reassurance/support/safety were precisely some of the core categories Timulak (2007) found in his meta-analysis of client-identified helpful events in psychotherapy. Given that chair-work is a major and salient component of EFT work, it was not surprising that people identifying this as helpful. Chair-work for working with different parts of self has been shown to reduce self-criticism and anxiety and depression symptoms in clients (Elliott et al., in press). Observing specifically the accounts directly related to FCR, we found these are aligned with EFT's emotion change principles: awareness, expression, regulation, reflection, and transformation (Greenberg, 2011). Participants valued becoming more aware of their fear of recurrence (including of the

impact it has in their lives), as well as expressing and differentiating their fears. Through two-chair work, some people also referred the usefulness of “being face to face” and “talking with” their fear, coming to important realizations such as “fear isn’t my enemy/fear is my ally” (*Sophie*) or linking it to traumatic experiences: “I realize[d] that what I’m going through is the fear I felt at the time of my surgery that is being activated again” (*Tom*). These two examples reflect the possibility of fear of cancer recurrence being both an adaptive emotion (connecting the adaptive need of protection/prevention) and a maladaptive one (connected to past traumatic events) (Elliott et al., 2004). Overall, EFT seemed to be an acceptable psychotherapy for helping patients dealing with FCR.

This study has several limitations, some also constituting eventual potentialities. The sample size was restricted and limited to the work of only two therapists, thus limiting the generalizability of the findings. However, the diversity of patients regarding cancer diagnosis, stage of disease, age, and level of education points to the possible usefulness of EFT for this cancer-related problem in a wide range of patients. In addition, the identification of patients from the larger sample was only based on the PQ items, not fully guaranteeing the specific relevance of FCR for each patient; some of the excluded patients could also have FCR as a relevant issue in their therapy even if this was not mirrored in the PQ. The fact that we couldn’t find significant differences in pre-post PQ, PQ-FCR and CORE-OM between the subsamples Main and Minor FCR might reflect this also. More importantly, we did not use a specific or valid measure for assessing FCR (such as the Fear of Cancer Recurrence Inventory – FCRI, Simard & Savard, 2009), which could be relevant for better distinguishing dysfunctional forms of FCR and providing a better understanding of pre-post FCR changes. It is also worth noting that there are not yet validated questionnaires for measuring FCR in Portuguese, which may be important in future investigations. In the face of this, we could equate the PQ-FCR items to existing

brief FCR questionnaires (Thewes et al., 2012), including the single-item measure recently developed by Rudy and colleagues, which has shown promise as an assessment tool of FCR (Rudy, Maheu, Körner, Lebel, & Gélinas, 2020). Considering that the study was done in a naturalistic, practice-based context and that the researchers/therapists were careful not to burden the participants, the psychological assessment in general was limited. We also acknowledge the limited number of HAT forms collected which restricted the analysis done.

Conducting this study in a regular clinical practice and without extraordinary resources suggests the possibility of using this psychotherapy approach effectively in cancer hospital settings in routine practice. At the same time, this limited the assessment procedures that could be used, preventing deeper exploration of the results found and their meaning. The great variability in the number of sessions held per person can also make more difficult to replicate this study. The allegiance of most of the research team to the psychotherapy model studied (including the two therapists), has also to be considering in evaluating the results. Moreover, as 35% of the participants were under psychiatric medication, it is also not clear the role it might have had in the results found. Some other challenges were identified while working with this specific population: doing therapy in the same hospital where the patients were treated for their cancers was itself a cause of anxiety (and of avoidance) for some patients, interfering with therapy compliance; in some patients, experiencing physical symptoms or functional impairments related to the disease and/or treatments, sometimes difficult to distinguish from somatic complaints of anxiety; and having to deal with the real threat of recurrence and death related to cancer, which brought high levels of vulnerability and connected to deep existential issues in patients. The effectiveness of EFT in this particular population, both in terms of having a specific cancer-related problematic and in terms of nationality/culture, can also expand

the use of EFT to populations yet understudied, contributing as well to increasing the diversity of choice in psychotherapy in Portugal. In conclusion, based in this exploratory study and both in the quantitative and qualitative data, we see EFT as a promising treatment for high levels of FCR, one that might provide an alternative to other well-established treatments (i.e., cognitive-behavioral). Deep empathic work combined with active tasks (such as two-chair work) can help people go through their intense fear experience and transform it, connecting to more adaptive emotions, which was validated by the qualitative data. The existential concerns the cancer experience can bring to people may be also properly addressed by this humanistic-experiential therapy. Further research is needed to replicate these preliminary results and to expand our knowledge related to the applicability of EFT to fear of cancer recurrence.

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Chapter 5

Developing an emotion-focused therapy model for fear of cancer recurrence: A case-level task analysis (Study 3)

Abstract³

Fear of cancer recurrence (FCR) involves anxiety about the possible return or progression of the disease. It is common among people surviving cancer, covering a range of adaptive and maladaptive responses including clinical presentations of FCR, for which different psychological interventions have been developed, most within the cognitive-behavioural paradigm. Recently, emotion- focused therapy (EFT) has been proposed as an alternative and has been the subject of research focusing on the cancer population and cancer- related issues, including FCR. In this study, we looked closely at a successful case from a larger exploratory study, carrying out a discovery- phase task analysis aimed at identifying the main components of EFT–FCR. We found that this approach generally followed the usual structure of an EFT intervention, with four distinct phases. However, we identified some specific secondary processes (e.g., hypervigilance and catastrophising) and clarified the nature of the core pain in this presentation as existential (e.g., fear of dying).

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Introduction

Fear of cancer recurrence (FCR), that is, the fear, worry or concern of cancer coming back or progressing (Lebel et al., 2016), is a major issue for people surviving a cancer diagnosis (Simard et al., 2013). Recognized as a multidimensional construct since the first theoretical formulations (Lee-Jones et al., 1997), FCR is a highly diverse experience, described by survivors as affecting their perceptions, emotions, body, cognitions and behaviour (Almeida et al., 2019). Understandably present after a serious and potentially life-threatening disease, FCR is a form of health anxiety (Lebel et al., 2020) with similarities to other anxiety problems (e.g., social anxiety and generalised anxiety). Like cancer-related distress more generally (Riba et al., 2019), FCR ranges on a continuum from adaptive to maladaptive (Lebel et al., 2016). Thus, FCR can support patient self-care and health-oriented behaviours or, conversely, it can impact negatively on a person's quality of life and well-being. Maladaptive FCR can manifest, for example, in persistently high levels of preoccupation or worry about cancer and death, or hyper-vigilance to bodily symptoms; furthermore, these difficulties can interfere with daily functioning and planning for the future (Mutsaers et al., 2016, 2019).

Different psychological interventions are available for people presenting with significant FCR-related distress, the most common being cognitive behavioural approaches, either in traditional or contemporary versions (see Hall et al., 2018; Tauber et al., 2019 for systematic reviews and meta-analyses). Examples of these interventions range from psychoeducation and preventative interventions (Dieng et al., 2016; Pradhan et al., 2021) to mindfulness-based interventions (Lengacher et al., 2009), cognitive-existential (Lebel et al., 2014) or acceptance and commitment therapy (Arch & Mitchell,

2016). In general, these interventions have been shown to be effective, with small but robust effects at postintervention, largely maintained at follow-up (Tauber et al., 2019).

Emotion-focused therapy (EFT) is a humanistic-experiential approach to psychotherapy (Elliott et al., 2004), empirically validated for different psychological difficulties, such as depression, complex trauma or anxiety (Elliott, 2013; Greenberg & Watson, 2006; Paivio & Pascual-Leone, 2010; Timulak & McElvaney, 2015). Individual EFT has also been used effectively with cancer populations, albeit in only a few studies. Six women with breast cancer showing comorbid anxiety and depression improved significantly after an EFT treatment (Connolly, 2016). A hospital-based exploratory outcome study with 17 patients with different cancer diagnoses and presenting with FCR, among other cancer-related concerns, also found significant pre- and post-outcome differences, both for client-generated and standardized measures (Almeida et al., 2022).

Although EFT can be considered a transdiagnostic approach (Timulak & Keogh, 2020), there is still a need for understanding how EFT works with different difficulties or populations, refining its practice. Specifically regarding EFT–FCR, there is not enough information about the change process or the helpful factors in therapy, which can be researched by methods such as task analysis of significant therapy events or microanalytic research of sequences of client–therapist in-session interactions (Elliott, 2010). The goals of this study were, first, to identify the EFT components used with a good-outcome client who presented with high levels of FCR, and second, to develop a rational-empirical model of how successful EFT–FCR can unfold over therapy. We addressed these questions via case-level task analysis.

Methods

Although task analysis has been used for more than a century (for an history of cognitive task analysis, see Militello & Hoffman, 2008), its application to psychotherapy originated in the 1970s with Laura Rice and Leslie Greenberg (Greenberg, 1983, 2007; Rice & Greenberg, 1984) and provided the basis for the development of EFT, which was based on task analyses of the different therapeutic tasks (e.g., empty-chair work for unresolved relational issues). In psychotherapy research, task analysis aimed at discovering and validating the specific/detailed steps by which clients address and resolve particular emotional processing difficulties, that is, successfully complete relevant therapeutic tasks (Pascual-Leone et al., 2009). Usually, a complete task analysis consists of two phases: (a) a discovery phase, in which both rational and empirical methods are used to build a model of how a given therapeutic task is effectively performed; and (b) a validation phase that will test and validate the discovered model (Greenberg, 2007). In this study, we conducted an adaptation of the task analysis methodology, in its discovery phase, using a good-outcome single-case study. In general, task analysis involves examples of a particular task being collected and studied. Here, however, we decided to broaden our scope by examining an entire EFT treatment to discover how a particular client used it to achieve change in her FCR, creating a case-level form of task analysis of a successful therapy. Specifically, we aimed at identifying the most relevant elements of EFT for FCR with this client, along with the sequence by which these elements unfolded, leading to the creation of a rational-empirical model of the change process in EFT–FCR.

Participants

Client

The client, whom we will call *Louise*, was part of an exploratory outcome study involving 17 persons with a cancer diagnosis who presented with FCR, among other cancer-related difficulties, and who received an adaptation of EFT (Almeida et al., 2022). This research observed all relevant ethics requirements, including approval by the hospital ethics committee and informed consent from the patient for participation in the study and research purposes. *Louise* was a 55-year-old White European woman who had had breast cancer 6 years before, for which she received a mastectomy, radiation treatment and chemotherapy, along with psychotherapy from the first author. At the time of the study, 5 years after her initial treatment, she was still on hormone therapy when she sought further psychotherapy. The major difficulty that brought *Louise* to therapy was an overwhelming fear of her cancer coming back, expressed by intense levels of anxiety, frequently related to bodily signs and symptoms (e.g., whenever she felt something in her body or was physically sick, she was terrified thinking it was cancer again) and to what she saw as her inappropriate health behaviours, which she believed could lead her to a cancer recurrence (mostly “bad” eating and sleeping). Her high levels of anxiety resulted in some panic episodes in the previous months, as well as a general difficulty regulating her own emotions (besides the panic attacks, she was also feeling she was talking and eating too much). Since she had been free of disease for some years already and had thought that she had coped well with her cancer process, she was also quite puzzled by her own feelings and behaviours; as a result, one of her major goals in therapy was to understand her own reactions and present distress.

Her therapy extended over 15 sessions, mostly every 2 weeks, with sessions occurring in the cancer hospital in which she had previously been treated. In accordance

with the research protocol, the client completed a client-generated weekly outcome measure (PQ-Personal Questionnaire; Elliott et al., 1999; Portuguese version: Sales et al., 2007; *Louise's* items are shown in Table 6) and a standardized general clinical distress measure (CORE- OM; Evans et al., 2002; Portuguese version: Sales et al., 2012), every five sessions, as well as a postsession questionnaire (HAT- Helpful Aspects of Therapy Form; Llewelyn, 1988; Portuguese version: Sales et al., 2007). Based on her outcome results, *Louise* showed clinically significant change on the PQ (Elliott et al., 2016; ≥ 1.5 pre- and postpoints): at pretest, her score was 5.4, slightly above the average for clients beginning therapy in outpatient settings; at posttest, her score was 3.2, in the nonclinical range; her pre- and postchange therefore substantially exceeded the reliable change value of 1.5. Similarly, she showed reliable change on the CORE-OM (pretest – 24; post-score – 13; reliable change value: 5; see Barkham et al., 2006). By the end of therapy, *Louise* described feeling less anxious, having better emotional regulation and understanding her own process and fully attaining her goals for therapy. Therefore, *Louise* was considered a good-outcome case.

Table 6. *Louise's* Personal Questionnaire items.

1. Fear that the disease comes back
2. Eating voraciously
3. Guilty— I should not do this, I have not the right to have these risky behaviours
4. Difficulty in going to sleep
5. Talk too much (I get tired)
6. Irritability and lack of patience
7. I do not work well (I am a fraud)
8. Remorse (burning my stomach)

9. Tightness in my stomach (imprecise anguish)
10. Sadness for having had the disease (added at third session)
11. Conscious of mortality (added at fourth session)
12. Fear of starting things (added at seventh session)

Therapist

Louise's therapist was the first author, a clinical psychologist in her mid 30s; she had worked in a Portuguese cancer hospital for around 10 years when she saw this client. During this period, the therapist was completing her formal training in EFT and was supervised by the second author, one of the developers of EFT, who also assessed treatment integrity and audited research processes.

Analysis

Rational model construction

Following our adaptation of standard therapeutic task analysis (Greenberg, 2007; Rice & Greenberg, 1984), we began by constructing a rational model for the expected course of EFT for FCR, based first on the general model of the phases of EFT, as presented by Elliott and Greenberg (2021); for further details, we also drew on the EFT Model for Social Anxiety (Elliott & Shahar, 2017). In addition, the first and third authors worked from their extensive clinical experience of working with people with cancer. This model specified four phases of work:

1. making contact and beginning to explore FCR experiences;
2. initial work with presenting secondary FCR processes (e.g., anxiety episodes);
3. deepening: working on and resolving primary existential processes (e.g., fear of death);
4. consolidation: maintenance (e.g., continuing intermittent support) or ending.

Data preparation

For the case study, transcriptions of all of *Louise's* therapy sessions were prepared; each session was divided into session episodes (defined as segments of the session organized around a common task or topic; Elliott, 1993), which also included identifying EFT markers and therapeutic tasks. This stage of the research was developed by the first author and audited by the second author, a specialist in qualitative methods in psychotherapy. To construct the rational-empirical model, a mapping exercise iteratively worked between the initial rational model and the data generated from *Louise's* sessions. Whenever necessary, adjustments or alterations to the original model were made, so that the final model mirrored *Louise's* therapeutic process as closely as possible.

Results

As noted, the rational-empirical model of EFT for FCR we started from followed the adaptation of the current EFT treatment phase model (Elliott & Greenberg, 2021) to work with social anxiety processes, requiring us to make adjustments and refinements to the initial model to make it better fit FCR. The proposed Model of EFT for FCR, described below, is also presented in Table 7.

Phase 1: Making contact and beginning to explore fear of cancer recurrence

- a. Alliance Formation. In Phase 1, the main goals were creating a safe environment and an emotional bond to work productively and effectively with the client, as well as clarifying and exploring the client's main difficulties. *Louise* stated clearly that her different complaints converged with or related to FCR, as she concluded

at the end of Session 1 (minute 43): *It all started to be channeled, everything always in the same direction...the illness doesn't spare me, the illness is there again.*

- b. Narrative work. The narrative work, which occurred in different forms across her therapy, began at this stage with *Louise* recalling traumatic events, such as the cancer diagnosis and several episodic memories from her cancer trajectory, as well as identifying some cherished beliefs that were violated by the cancer experience (an EFT marker for the creation of meaning task). The rupture she felt before versus after her cancer clearly involved grief and trauma, as can be seen in this account from Session 1: *And I've never had again that feeling of being a winner, "I'm going to make it", thinking, I was already ill and didn't know, and I've never had that again after the illness, of "I'll now be able to"...never again.*
- c. Empathic exploration/focusing. Using mainly empathic exploration (Elliott et al., 2004) and experiential focusing (Gendlin, 1981) allowed the client to access, deepen and symbolise her experiences of FCR, which, in turn, led the client to begin to approach what seemed to be her core pain (i.e., the thing that hurts the most), the fear of dying. Here is an example of this from Session 2 (minute 16):

T: What does that side [of you] tell you, because there's a side of you that frightens you in some way, or...what does that side tell you? That it might be...

C: That the second time I don't make it.

T: The second time you don't make it.

C: That's it! Or very difficultly (T: very difficultly) because I don't rule it out: [that] I'll still get away with it, if there's another time, I'll still get away with it!

Phase 2: Initial work with presenting secondary anxiety processes

- a. Narrative retelling/systematic unfolding of fear/FCR episodes. In Phase 2, the experiences of FCR were progressively explored in more depth through narrative work and systematic unfolding, in which the therapist guides the client through specific difficult or puzzling experiences. While doing this, *Louise* evidenced strong experiential avoidance, which she realized had been an important coping mechanism until recently. In Session 3 (around minute 20), *Louise* revealed how difficult it was to access her painful emotions:

C: Some time ago I was sent an e-mail, one of these colleagues, an email that there's a movement now where people must, what was it like? Talk about the thing, let themselves be sad and I shook it off, I said, "I don't want that!"

T: I don't want to let these difficult things come.

C: Because I focused backwards [crying voice].

T: What's it like to be letting it come for a bit?

C: It's horrible [mixture of laughter and crying], it's horrible!!!

- b. Emotion regulation. Also fundamental at this stage was helping the client deal with emotion dysregulation or potentially dysregulating experiences in therapy. *Louise* tended to oscillate between over-regulating her emotions, such as overly describing experiences in a nonemotional or externally focussed mode or using laughter (as can be noticed in most of the excerpts presented) for distancing from the painful emotions, and becoming under-regulated, as when experiencing panic attacks. The main strategies used with *Louise* in therapy were helping her take a

breath, grounding, using therapist presence/pacing and experiential teaching, which helped her approach her most difficult emotions using two-chair work.

- c. Two-chair work for conflict splits. Throughout this phase, presenting secondary processes were worked with mainly through two-chair work (which started in Session 6). These included different conflict split markers regarding FCR, revealing the critic/coach/guard aspects of self, related, for instance, to body checking or hypervigilance (i.e., anxiety splits, which involve one part of the person scaring another part); the attribution to others own feelings/perceptions, such as feeling blamed for not being sufficiently involved in professional activities (i.e., attributional splits, in which feelings about self are projected on to others); as well as self-interrupting deeper emotions (i.e., self-interruption splits, which involve part blocking or silencing another part), frequently through self-critic processes (e.g., *Louise* found herself “stupid” or “ungrateful” for having certain feelings “after so much time” and “since having survived”).

Progressively reducing the avoidance or interruption of her emotional experiences, *Louise* started to express herself more freely, as can be seen in Session 4: “I’m no longer a woman with cancer who refuses to say, ‘This is very bad’; [now] I’m saying it.” In Session 6, in two-chair work for self-criticism, *Louise* criticized herself for being more active in her job recently and experienced being “a poor thing” after the illness, revealing a kind of self-pity (a secondary reactive emotion), eventually leading to a vulnerable sense of a fragile or diminished self (a maladaptive primary emotion). The dialogue between the critic and the experiencer evolves to a point where the experiencer comes to a better understanding of the negative impact the cancer diagnosis had in her life/self and assertively expresses her needs, at this point appearing as a partial resolution (minute 39):

T: What about that part that says, "You're always going to be an underdog and you're not going to get out of it?"

C: I don't know, I don't believe it, I don't want to be an underdog.

T: Tell them that.

C: I don't want to always be an underdog.

T: "I'm not that, I don't want to be."

C: I'm not, I wasn't before, I wasn't an underdog, I wasn't, I became [that] after the illness.

T: "I became like that, I was weakened."

C: I became like this, I'm not the one that's like this, I became like this.

T: "I became like that," that's not an intrinsic thing or...

C: No, it's not (T: It's not) I want to believe that it's momentary, that's what I want it to be, transient, not momentary because it's been a long time, but transient

T: Okay, "Transient, this is not what I am, it doesn't define me, therefore..."

C: It's not what I am, I didn't have these fears before, I didn't have the disease either, I wasn't afraid that any day I'd go there and that's it, I wasn't afraid of that.

T: "I wasn't, now it's as if I..."

C: I wasn't afraid to talk about death, I wasn't afraid to talk about [it], I wasn't, and now I am. But I wasn't afraid to talk about these things, it was a natural thing (T: Most natural thing); of course, I didn't want to die, I never wanted to, I always thought that, as I say, I was going to be very old and grumpy like my grandmothers and, but I was calm about it, I could talk about it, and I never could anymore (...)

In a subsequent dialogue, in Session 7 (minute 26), the coach/critic/guard part expresses its fear that it is afraid of *Louise* returning to her old life before diagnosis, in which she now recognizes that she neglected herself:

C: And this side is very distressed because I have the feeling that this voracious eating or whatever is like before, it's dangerous for my health, it's dangerous.

T: Okay, so it's this side that says, "just stop it or don't get into this stuff because it can..."

C: It makes you very tired (T: very tired), it also doesn't do you any good and it gives you (T: gives you) uncontrolled (T: gives you uncontrolled) sleep.

T: Of sleep, of food.

C: And that's dangerous. (T: That's very dangerous) That's my old life.

T: Okay, and it connects to what's happened before and you don't want that, we don't want that, nobody wants that.

C: Nobody wants that.

T: Okay, it's clearer what that side, it leads to...

C: Is the old fears.

T: And it brings the old fears, "I'm very afraid."

C: Or rather, it brings the fear of going back to the beginning.

T: You can say, [pointing to the other chair] before you then move on here, can you say, "I'm afraid that when you do this..."

C: The lack of control (T: the impact that that...), the lack of control, the panic - so the lack of control, the overeating, the not sleeping, not resting, because that was, that's what led to the illness.

T: "That's what led to the illness, and I don't want you to get sick again."

C: Exactly.

Phase 3: Deepening: Working with and resolving primary existential processes (fear and sadness)

In Phase 3, more consistently present from Session 8 onwards, we found that chair work for conflict splits deepened to meet and transform primary maladaptive processes, making way for adaptive (useful) needs and emotions.

- a. Two-chair work (with focusing) on deeper primary maladaptive emotions. Using two-chair work and focusing, *Louise* progressively identified the multiple physical and psychological losses derived from her cancer experience, including what she called the “loss of the illusion of eternity.” *Louise* grasped how this had left her with a sense of a defective, weak and vulnerable self. Existential issues (i.e., dying/death, isolation, meaninglessness and responsibility; cf. Yalom, 1981) were found to make up *Louise's* core pain. Finding more distant sources of existential pain in her childhood and young adulthood (when dealing with the loss of her mother), *Louise* realized these had been there essentially since her cancer diagnosis, but most of the time covered, suppressed or distanced, as this statement in Session 9 (minute 24) shows:

C: It bothered me a lot since I got sick, it bothered me a lot, the idea of nothing, the nothingness, the disappearing; very very bad, very difficult, and I, for many years, didn't think and now I think [about it] [laughs].

Fully recognizing the fact of her own mortality and how her current difficulties related to that, *Louise* felt the need to face her existential fear and sadness, which carried some clarity and underlying relief (Session 10, minute 36):

C: At least I can see better what's going on (T: a little better, ah, a little clearer), basic, I didn't think it was so basic and so primary; I like being alive and I really like living and I'm afraid of walking through nothingness.

Nonetheless, she was still finding it challenging (same session, minute 37):

C: This doesn't have a solution, but it doesn't have a solution. (T: It doesn't have a solution, ah, defi-) How does one live, how does one, how does one learn to live with this, without having all those manifestations around?

- b. Reprocessing work re: trauma and cancer. Reprocessing work also continued mainly through the trauma retelling and meaning recreation therapeutic tasks. *Louise* reviewed several difficult cancer-related episodic memories, accessing, expressing and reprocessing aspects of those experiences she had not before, such as sadness and anger for having had the disease. This allowed her to build some meaning bridges, significant connections involving her different cancer-related experiences, helping her to better understand her present situation, but also to link her present experiences to previous traumatic experiences, as she clearly stated in Session 11 (minute 4):

C: Basically, what I already had, was the first time when I was a little girl with the history of the universe and then when my mother died, that was a direct confrontation without much of a chance, there was no remedy. Then I had it again and I gained about 20 kg at that time. This week I've been thinking about (T: mm-hm, mm-hm, there was that too) the manifestations, the manifestations were the same [as in my cancer experience].

- c. Compassionate self-soothing chair work. At this stage, as *Louise* started unveiling her existential anguish, the therapist proposed some compassionate self-soothing chair work. At the end of Session 9, in work with her deep emotional suffering, *Louise* provided soothing to an imagined vulnerable friend, as seen in this excerpt, which, in the end, brought her some hope and comfort:

C: It'll pass, these things will pass (T: This will pass), just hang in there and it will pass.

T: Ah hang in there, is that it? That's it, hang in there, it's not easy, but just hang in there, it will pass (C: It will pass), you will come out of this?

C: Because I too in my life can't do that easily.

T: But tell her that, tell her!

C: It will pass, people have it too, I have it too, everyone has it, problems, bad phases (T: problems, more difficult phases), I just must learn to get out of the phase.

T: "You must learn to get out of it" – How can she learn to get out of it?

C: To get out of the phase by analyzing (T: That and what's happening), eat the elephant one bite at a time (T: one bite at a time, ok, so instead of trying to solve the whole problem) all at once, one at a time.

In the following session (Session 10), in another chair work for compassionate self-soothing, *Louise* found it harder to get to a place of self-comfort when she moved to the soother chair (around minute 20): "I'm feeling that thing, that voice of fears and that thing in my chest growing, that red, purple thing." Using the focusing task, which helped her to clearly point to her deepest pain, *Louise* was progressively more able to find comfort inside herself, coming to this declaration at the end of the session (minute 41):

C: There's the fears deep inside and there's a certain peace of "This is no big deal after all," this is what it is.

T: Okay, it is what it is, okay?

C: And you're going to have to deal with it.

Approaching the transformation of her maladaptive emotion scheme, *Louise* was able to access primary adaptive emotions, such as sadness for having had the disease and existential fear and sadness, which she was able to express and be with.

d. Cyclic/complicated processes for anxiety/traumatic processes.

One of the differences/adjustments we found from the initial rational model is that *Louise* oscillated between the tasks of Phase 2 and Phase 3 in most of the middle sessions of her therapy. We realized it was difficult for the client to get past her experiential avoidance/self-interrupting processes, even in the late phases of therapy, while she was, at the same time, progressively more capable of identifying and dealing with her core pain. It was also reflected, for example, in the progress and setbacks in two-chair work (from secondary to primary processes and back again). As such, we found the model needed to better reflect the fluidity and complementary work between these two phases.

Phase 4: Consolidation: Maintenance or ending

In Phase 4, *Louise* found herself ready to end therapy, “because it disappeared that thing that made me come here” (Session 14, minute 26). She felt she had solved her initial puzzlement and showed actual changes in her previously dysfunctional behaviours, such as not having panic attacks and feeling what she considered to be a normal and proportional fear of certain situations. Overcoming experiential avoidance and dealing with deeper painful emotions were also considered important accomplishments, as referred to in Session 13 (minute 22):

C: So, it comes the sadness but it also comes more of a, more normal, more normality (T: ok), it's both things (T: ok); it comes the sadness because I actually face it, it was a big bummer.

T: Sure, because you look more at it, to what happened and to what it brought you.

C: Yeah and because I really look at it, I really do.

This ending of therapy excluded the other element of the rational model (Maintenance), although we think this might be a real possibility in other cases, considering the practical experience in the field on the part of the research team.

Table 7. Rational-empirical model of emotion-focused therapy for fear of cancer recurrence.

<p>Phase I: Making contact and beginning to explore FCR</p> <p>a. Alliance formation: Bonding and clarification of therapy goals</p> <p>b. Narrative work for developing a coherent cancer narrative:</p> <ul style="list-style-type: none"> • Cancer trajectory and impact on life projects; possible identification of cancer-related traumatic events. • Account of FCR experience(s). <p>c. Empathic exploration/focusing for accessing, deepening and symbolizing experience of FCR; differentiation of specific fears and validation of fear</p>
<p>Phase II: Initial work with presenting secondary anxiety processes</p> <p>a. Narrative retelling/systematic unfolding of specific fear/FCR episodes</p> <p>b. Emotion regulation work: dealing with dysregulation; helping the client to approach potential dysregulating experiences (Leads into:)</p> <p>c. Two-chair work for conflict splits: anxiety; attributional; self-criticism; and self-interruption</p>
<p>Phase III: Deepening: Working with and resolving primary existential processes (fear and sadness)</p> <p>a. Two-chair work (with focusing) on deeper primary maladaptive stuck emotions (e.g., depression, abandonment, vulnerable and resentment/protest) and/or sense of defective/weak/bad self (e.g., for having had cancer) moves to core existential pain (e.g., dying/death; isolation; meaninglessness; and responsibility)</p> <p>b. Reprocessing work: trauma; meaning protest (regarding cancer and death); from fighting to grieving; connecting sadness/shared human experience; meaning construction</p>

- c. Compassionate self-soothing chair work for repairing core pain/old injuries
- d. Cyclic/complicated processes related to anxious and traumatic processes: cyclic movements between Phase II and Phase III

Phase IV: Consolidation: Maintenance or ending

- a. Providing ongoing support for cancer process (e.g., periodic tests/medical appointments) as needed (or)
- b. Ending: Tapering off frequency of therapy; helping client consolidate change and carry this forward in their life; preparing for and processing the end of therapy

Discussion

This client's therapy involved common aspects of EFT for other anxiety presentations, generally following the expected phases of intervention in the initial rational model: (1) *Louise's* therapy started with the development/strengthening of the therapeutic alliance and empathic exploration of her cancer-related experiences, including FCR; (2) it progressed with work around secondary emotional processes, such as emotional avoidance and secondary anxiety splits, until it reached; (3) the primary maladaptive processes, which allowed the identification, deepening and transformation of her core pain; and (4) the consolidation of the changes achieved led the therapy process to its completion. However, our analysis provided considerable detail about how these broad stages unfolded.

The centrality of the relational and empathic aspects of EFT, documented here, points to the importance of a unique and safe relationship of the client with someone who genuinely cares and sees, understands and accepts their experience. This is emphasized by different psychological interventions with cancer patients (Boulton et al., 2001; Carlson, 2015; Krenz et al., 2014; MacCormack et al., 2001). Secondary processes in *Louise's* case involved strong experiential avoidance and self-interrupted emotions, found in previous research (Connolly, 2016) and generally understood as typical perpetuating emotional difficulties in women with breast cancer (Aguirre-Camacho et al., 2017). Emotional and behavioural avoidance have been conceptualized in EFT as ways for the person not to feel core, chronic painful feelings and may involve avoiding all feelings (Timulak & Keogh, 2020). For *Louise*, this was also related to what has been termed the guilt of the (cancer) survivor (Glaser et al., 2019), as she felt she had no right to feel sad/angry/fearful, given that she had survived cancer, unlike other patients. During other

periods of the cancer trajectory, such as through treatment, connecting with “negative feelings” was also viewed by the patient as contradicting the widely held push to think positively, which, for patients with cancer, has long been considered an unfair burden (Rittenberg, 1995) and even a kind of tyranny (Holland & Lewis, 2000).

Given that FCR was identified as the main problem for *Louise*, our data nicely illustrate the complexity of the lived cancer experience (Iskandar et al., 2021), impacting different areas of life (personal, professional, family), for a long period of time, and connecting to past experiences and to the prospect of future life. Cancer experience thus often includes a succession of multiple stressful and potentially traumatic events, namely diagnosis, treatment and post-treatment/survivorship stages (Cordova et al., 2017), which may be exacerbated by precancer psychological vulnerabilities (Connolly, 2016). In *Louise's* therapy, this indicated the importance of her reprocessing her cancer-related traumatic experiences, with events extending from her strong emotional response after hearing the cancer diagnosis to the impact of an interaction with a nurse during a chemotherapy session. This latter situation implicitly triggered a fear related to a possible recurrence in the future, but also led to the need of reprocessing other noncancer previous traumatic events related to her existential condition (e.g., first childhood experience with the immensity of the universe). Fully emotionally processing all these different major and minor events may be somehow more difficult during periods of intensive treatment, making the phase of post-treatment more suitable for revisiting and completing this internal work. Although we found aspects similar to other anxiety presentations, the identified core pain in EFT for FCR was related to existential pain (fear and sadness), which was in line with what was found in participants of Connolly's study (Connolly, 2016), but differed from what has been considered central in social anxiety (shame/fear; Elliott, 2013) or in generalized anxiety (loneliness, shame and fear/ terror; Timulak &

McElvaney, 2015). Death anxiety has been argued to be a transdiagnostic construct relevant for various psychological conditions (Iverach et al., 2014), and it might also be a central factor in the FCR experience (Berlin & von Blanckenburg, 2022), although there is still a need to further investigate this theory, taking into account the possible multiple manifestations of FCR and death anxiety (Sharpe et al., 2018).

Another difference from the initial rational model was the cyclic movements between secondary and primary processes we found in *Louise's* therapy, confirming the idea of a non-linear “saw-toothed” pattern of emotional progress in psychotherapy (Pascual-Leone, 2009, 2018). It is also possible to relate it to the demands of facing the existential givens (Yalom, 1981), which can be hard for patients and health professionals, including psychotherapists (see Sharpe et al., 2018, for a reflection on some barriers to the study of death anxiety and FCR). Using a single case for a task analysis limits the generalization of the conclusions we arrived at, bearing in mind that FCR may be very different for different people (Almeida et al., 2019). At the same time, considering that this is a new field of research for EFT, in spite of its overlap with other anxiety difficulties, this study provides a basis for future research, for example via further exploratory case studies and the validation step of task analysis (Greenberg, 2007). Another limitation is the allegiance of most of the research team to EFT, which is also important to consider when generalizing from these results.

Although the PQ has shown clinical utility and robust psychometric qualities, namely strong correlations with standardized outcome measures (Elliott et al., 2016), we also acknowledge the absence of a specific measure for assessing FCR in this study. This also relates to the fact that, in the original larger study, the authors did not define the cancer-related issues to be treated in therapy; instead, FCR emerged as a salient issue for around 60% of the patients (Almeida et al., 2022). In clinical terms, this study can inform

psychotherapists using EFT with clients presenting with problematic FCR. For example, it illustrates how standard EFT humanistic and experiential elements can be combined with attention to particular issues, such as emotional/experiential avoidance and existential concerns.

Conclusion

EFT for helping people dealing with dysfunctional FCR seems to generally follow the common steps of EFT intervention. More specifically, however, this task analysis has highlighted the difficulties a person who has had cancer may have in addressing painful core emotions and moving out of experiential avoidance, which might relate to complex experiences of anxiety and trauma. Dealing with existential issues was also found to be possibly central in this cancer-related issue.

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Chapter 6

General discussion

This section discusses the implications of my study results in three areas: 1) implications for knowledge; 2) implications for practice; and 3) implications for research.

6.1. Implications for knowledge

The various works comprising this thesis have made meaningful contributions to our understanding of the FCR phenomenon and to the EFT interventions, particularly within the context of cancer. In terms of FCR knowledge, the studies in this thesis not only reinforce and deepen existing knowledge but also bring attention to specific aspects of FCR that had been previously overlooked. In terms of EFT, its application to this cancer-related issue highlighted the importance of specific aspects this approach, such as its existential dimension as well as work on traumatic and grieving processes.

6.1.1. Relevance and multidimensionality of Fear of Cancer Recurrence

The qualitative systematic review (Study 1, Chapter 3) underscored the significance of FCR for cancer survivors, aligning with the escalating interest in the literature on this topic and confirming previous quantitative data (e.g., Simard et al., 2013). The multiplicity of descriptions revealed the manifold, intricate, and nuanced nature of FCR experiences, presenting in a continuum from normal to dysfunctional and varying, for instance, in intensity, eliciting triggers or bodily or behavioral responses. While the descriptions provided by participants did not distinctly separate adaptive from maladaptive presentations of FCR, it was evident that FCR is a significant and pervasive experience for patients surviving cancer, identified even when they are not directly asked

about it. A significant proportion of the reviewed studies indicated that participants experienced FCR as a constant or persistent presence in their lives, which is consistent with findings from previous research (Luigjes-Huizer et al., 2022; Simard et al., 2013).

The innovative application of the emotion scheme framework to the systematic review's data, informed by the EFT perspective, highlighted that FCR manifests across perceptions, emotions, body, mind, and behavior, thus validating the theoretical concept of the multidimensionality of the FCR experience (Fardell et al., 2016; Lee-Jones et al., 1997). Within the emotion scheme perceptual-situational domain, it was possible to identify the internal and external cues preceding FCR described by the traditional cognitive-behavioral perspective of FCR as antecedents (Lee-Jones et al., 1997) and different objects of FCR (e.g., recurrence, death, new treatments), which was expanded in our study by including different narrative elements (temporal or qualifiers) and episodic memories related to FCR.

The quality (intensity, vividness, emotional poignancy) of some of these episodic memories, as well as of some metaphorical descriptions, suggest a link to traumatic experiences related to cancer, supporting the possibility of FCR being conceptualized within a PTSD-like framework (Simonelli et al., 2016). Imagery has been found to be a distinguishing factor between clinical and non-clinical FCR (Mutsaers et al., 2016), resembling Clark & Mackay's (2015) suggestion that it plays a key role in PTSD, which serves as a conduit linking experience, memory, and intrusive recollection of traumatic events. Although it remains unclear whether the FCR images reported by participants are necessarily based on previous experiences, it has been recognized that, in cancer-related PTSD, the stressor may be future oriented (Kangas et al., 2002), so the images can translate future-oriented fears. The use of present and future tenses in some descriptions could also indicate a certainty that the cancer will return, another suggestive feature of

dysfunctional FCR (Mutsaers et al., 2016). Regardless the objective probability of a cancer recurrence, the intensity of these vivid descriptions brings this experience to life for participants, who perceive it as a lived reality. The hypothesis of FCR as being linked to traumatic experiences emerged in study 1; nonetheless, it was prominently featured in studies 2 and 3, specifically in the two deeply analyzed case studies (*Tom* and *Louise*), where the resolution of the clinical cases implied working with clients' traumatic experiences when they were found to be a source of their dysfunctional FCR.

In terms of emotions, FCR descriptions included not only fear-related states (such as fear, worry, concern or anxiety), but also undifferentiated distress, depressive states, and positive emotions. Undifferentiated distress may represent the generalized states of anxiety related to FCR, commonly brought by people at the beginning of any relational process (e.g., psychotherapy, interview), eventually containing other emotions that may be symbolized and differentiated during that process. Global distress is recognized as a first stage in an EFT intervention (Timulak & Keogh, 2020; Timulak & Pascual-Leone, 2014). Pleasant emotions were described frequently as emerging after “good news” (i.e., the non-confirmation of a recurrence), when anxiety was dissolved, but they can also function as an antidote for difficult emotions or as a result of the transformative “undoing” process of maladaptive emotional states (Greenberg, 2010).

Distress, anxiety and depression are known to be associated with FCR (Simard et al., 2013). Regarding our deeply analyzed cases, while *Louise* presented mostly with strong anxiety symptoms, *Tom* showed intense depression and anxiety symptoms in the beginning of therapy. In both cases, it was necessary to work through a deep sense of vulnerability and also to work through grieving processes (which we can relate mostly with the emotion of sadness). This finding accentuates the idea that FCR can have

different presentations and include diverse emotions, symptoms, or manifestations, beyond anxiety.

Descriptions of the FCR experience also encompassed a bodily dimension, serving as an additional mode of FCR expression that might reflect its emotional impact. While anxiety can manifest physically, the significance of this component in FCR warrants particular attention, given that the cancer experience can alter both survivors' bodies (e.g., loss of a limb or organ, chronic pain, premature menopause) as well as their relationship with their bodies. The negative impact of cancer on the body image, for instance, is well documented (Davis et al., 2020; Kip et al., 2015; Lehmann et al., 2015; Thakur et al., 2022). The body can also hold traumatic memories, as found in PTSD, and its intrusion and re-experiencing can indicate that those memories are not fully symbolized (Gentsch & Kuehn, 2022). Increased physical symptoms have been associated with higher levels of FCR (Hall et al., 2017, 2019; Simard et al., 2013), especially concerning worry over those symptoms (Cunningham et al., 2021). Hypervigilance or hypersensitivity to bodily sensations or symptoms that might be associated with recurrence are a defining feature of clinical FCR (Mutsaers et al., 2020). However, interpreting bodily signs may be difficult, as anxiety symptoms can be mistaken for signs of disease, and vice-versa, with overlapping symptoms complicating diagnosis (Kariuki-Nyuthe & Stein, 2015). The interpretation of bodily symptoms, namely of anxiety, as a possible sign of cancer was a confounding factor for *Tom*, leading him frequently to the emergency room; for *Louise*, anxiety usually exacerbated any ordinary physical symptom, which made her doubt whether she was with cancer again.

The action tendencies associated with FCR, which primarily fall into avoidant versus approaching behaviors/motivations, may correspond to different coping strategies individuals employ to manage this cancer-related concern. While some coping strategies,

such as excessive reassurance seeking, excessive information seeking, body checking, and behavioural or cognitive avoidance have been deemed maladaptive in addressing FCR (Lebel et al., 2016; Mutsaers et al., 2020), our review data did not conclusively establish which action tendencies were more effective for individuals. Moreover, determining when a particular behavior becomes “excessive” can be subjective, as it hinges on whether it interferes with personal well-being and disrupts life projects and activities.

The FCR dimensions recognized through the systematic review developed in this thesis covered common aspects of any human experience – perception, cognition, emotion, body, and behavior. It systematized and reinforced a more comprehensive view of FCR that is often scattered across separate studies, which tend to focus on specific dimensions. Interestingly, the other two studies composing this thesis, which had a more clinical emphasis, emphasized some of the aspects identified in the review, such as the traumatic and grieving aspects of the FCR experience.

In addition to the dimensions above identified, the emergent significance of the existential dimension was a key finding in understanding and addressing FCR, aligning with the recent and progressive characterization of FCR as an existential concern (e.g., Hall et al., 2018). This notion was hinted at even in earlier research, such as in Raymer’s dissertation from 1993, where participants who reported coming to terms with FCR often referred primarily to the fear of death aspect rather than other factors (Raymer, 1993). Positioned by several authors as an existential concern or an expression of existential distress, alongside constructs like death anxiety or spiritual distress (Hall et al., 2018; Vehling & Kissane, 2018), death anxiety has been identified as a general factor associated with FCR (Berlin & von Blanckenburg, 2022). Additionally, death anxiety predicted a small but statistically significant unique variance in FCR and FoP beyond age,

metacognitions, threat appraisal, intrusive thoughts, and risk perception in a sample of 176 participants with ovarian cancer (Coutts-Bain et al., 2023).

In our studies, fear of death was identified as one of the objects of FCR in the systematic review, but the existential dimension was mainly apprehended through the personal experiences of *Tom* and *Louise* during their psychotherapeutic processes, in which it was particularly salient. While Sharpe (2018) posits that not everyone experiencing FCR is inherently afraid of death or dying, we observed that this fear was pivotal in comprehending and transforming FCR in these patients, which may be supported by the qualitative study of Mutsaers et al. (2016), in which death-related thoughts appeared as a distinctive feature of dysfunctional FCR. We also found other existential dimensions beyond the fear of death in our patients, namely related to existential isolation and to meaning and purpose (Yalom, 1981). Existential concerns are common in cancer survivors (Vehling & Philipp, 2017), despite findings from a systematic review and meta-analysis indicating that death anxiety in patients with cancer is moderate (Soleimani et al., 2020). These concerns often revolve around uncertainty about the future, feelings of uncontrollability, identity issues (Vehling & Philipp, 2017), and also a loss of self, feelings of despair and mental anguish and contemplation of death (Iskandar et al., 2021). Capturing the specific meaning of FCR for each individual, including the meaning and impact of their existential concerns, might be thus crucial, especially for the concern of intervention.

Further exploring the assumption that FCR relates, especially in the most dysfunctional presentations, to existential pain, particularly the fear of death/dying, we highlight the comprehension that FCR might be both a fear (of something specific/known) and an anxiety (more undefined or unknown) (Almeida et al., 2019), which might connect to Kierkegaard's suggestion that individuals tend to redirect the fear of "nothing" (i.e.,

death) toward the fear of “something” (e.g., recurrence, new treatments) (Kierkegaard, 1944), or in May’s words, “anxiety seeks to become fear” (May, 1977, p. 207). In EFT terms, FCR might be considered a secondary reactive emotion, a defensive reaction against or a way of avoiding the more primary fear of death. The term FCR itself can provide a more tangible focus compared to a broader existential fear or fear of death, which can also encompass various fears. For some participants of study 2, the fear of recurrence emerged as the most consciously recognized aspect, while the fear of death, initially implicit and not directly accessible, surfaced only through a deeper exploration of the FCR process. It is also possible that the fear of the unknown, considered a more fundamental fear (Carleton, 2016), might underlie the more undifferentiated experience of FCR and eventually relate to the unknown aspect of the death experience.

Along with the importance of the existential dimension, we recognized its relationship with the traumatic aspects of FCR described above. In both our study cases, the fear of death was experienced traumatically (e.g., *Tom* lived in terror while awaiting surgery, believing he was going to die, although from the medical point of view that was not an expected outcome), thereby establishing a link between the existential and the traumatic aspects of dysfunctional FCR. As Yalom reflects, there is a “difference between knowing and truly knowing, between the everyday awareness of death we all possess and the full facing of “my death”” (Yalom, 1981, p. 120). This new awareness can be experienced traumatically, somehow dividing the person’s world in a “before” and an “after” the traumatic experience (i.e., cancer), which involves the emergence of a new configuration of meaning between these moments (Fischer & Wertz, 1979). These processes can involve also grieving for different cancer-related losses, such as: 1) losses related to identity and selfhood (“no longer being”), such as losing previous health status, bodily/mental integrity, self-image, and the imagined future self; 2) losses of capability

("no longer having/doing"), including declining functional abilities, independence, and the continuation of roles/activities; and 3) existential losses ("no longer be present/connected"), encompassing the prospect of death, loss of relationships/belonging, and loss of life's meaning (Oliveira, 2008 cit. in Oliveira et al., 2012). Surviving a cancer can mean as well struggling with paradoxes, such as with the feeling of being the same vs. not being the same anymore, or the ambivalence of having survived and feeling threatened by a recurrence (Halstead & Hull, 2001).

The complex and multifaceted nature of FCR was thus revealed through our systematic review and clinical studies, showing FCR manifests through various dimensions of the human experience, including the existential dimension. This existential dimension, along with the potential traumatic nature of FCR and grieving processes associated to the cancer experience, may be particularly relevant for people experiencing dysfunctional FCR.

6.1.2. Emotion-Focused therapy for Fear of Cancer Recurrence

Emotion-Focused Therapy (EFT) is a transdiagnostic approach, which has been applied across various clinical presentations and psychological disorders (Timulak & Keogh, 2020). Using the Emotion Scheme concept to examine FCR facilitated the exploration of EFT as a potential intervention for addressing dysfunctional FCR, which was then investigated in the clinical studies. While these were innovative in applying EFT to a novel area within the context of cancer, they were grounded in the established body of knowledge on EFT, particularly its application to anxiety disorders (Elliott, 2013; Shahr et al., 2017; Timulak et al., 2017). However, our research also contributed to expanding the understanding of EFT to the specificities of FCR, including potential adaptations of previous EFT intervention models.

Within the broader framework of EFT, FCR is viewed as an anxiety difficulty, characterized by a dialectical process between a catastrophizing coach/critic/guard (CCG) part of the self (i.e., “scarer”), and a vulnerable part of the self (i.e., “scared”) (Elliott & Shahar, 2017). While the CCG aspect of the self intends to prevent a new danger (i.e., a new/recurrent cancer), by, for instance, instructing the person to frequently check their body to detect any possible signs of disease, it might perpetuate feelings of helplessness in the self, which feels vulnerable to face a new threat. The typical presentation of dysfunctional FCR as “always worried/afraid that my cancer comes back” represents, nonetheless, a secondary process involving constant worry, which exhausts and overwhelms the person, and often displays some avoidant activity (Timulak & Pascual-Leone, 2014). This persistent worry acts as a self-interruption process, inhibiting access to and processing of underlying painful emotions. Experiential and behavioral avoidance, common processes in other anxiety disorders (Elliott & Shahar, 2017; Timulak & McElvaney, 2015), may involve fear of painful emotions, such as fear, anger or sadness. Additionally, the avoidance processes in cancer patients might relate, as discussed in the case of *Louise*, to strong cultural pressures to ‘think positively’ (Holland & Lewis, 2000; Rittenberg, 1995; Willig, 2011) and to ‘feel positive’, which may involve inhibiting ‘negative’/painful emotions.

Different layers of fear and anxiety processes in FCR were thus uncovered in our studies, corresponding to secondary and primary processes. A distinguishing feature between primary and secondary fear is that primary fear, associated with core pain, often has a quality of ‘terror’ and is typically experienced in trauma, while secondary fear is more superficial (Timulak & Pascual-Leone, 2014). *Louise*, for instance, presented initially with secondary anxiety/worry (presented by ruminative tiring thoughts and feelings), which in an advanced phase of her treatment, gave place to deeper fear and

sadness (primary adaptive emotions) related to the perspective of her own death, not accessible in the earlier phases of treatment. According to our case studies, primary fear/anxiety and sadness were therefore the core maladaptive emotions underlying FCR, stemming from heightened vulnerability due to cancer-related traumatic experiences (personal and/or involving others) and the confrontation with the potential of one's own death, which might have been extremely difficult or traumatic and not fully processed emotionally. Loneliness, shame and fear/terror, typical core pains in both General Anxiety and Social Anxiety Disorders (Elliott, 2013; Elliott & Shahar, 2017; Timulak & McElvaney, 2015) may be equally identified, although we found that these ultimately link to existential concerns (Yalom, 1981). Therefore, we found what might be called an “existential core pain”, involving both primary fear and sadness, to be characteristic of dysfunctional FCR.

Previous EFT models for anxiety were foundational for developing an EFT model for FCR, yet we also recognize the importance of considering aspects of the Emotion-Focused Therapy for Trauma (EFTT) model (Paivio & Pascual-Leone, 2010). While EFTT was designed for interpersonal injuries, cancer can be considered a potential complex trauma, given exposure to ongoing traumatic events and not to a unique event (Cordova et al., 2017; Khayyat-Abuaita & Paivio, 2019). Also, in EFTT the therapeutic relationship and emotional processing of traumatic memories are central for the change process (Khayyat-Abuaita & Paivio, 2019), aspects that were found as fundamental in EFT for FCR. Many cancer experiences, as seen in the cases of *Tom* and *Louise*, can be translated into trauma-related emotion schemes, involving perceptual, bodily, symbolic, and action-tendency aspects (Elliott et al., 1998). Similarly, changes in perspectives on the world, others and the self after trauma (Elliott et al., 1998), particularly viewing

oneself as vulnerable, weak or damaged due to cancer, were especially relevant in these patients.

Beyond addressing anxiety and trauma, EFT for FCR also involves working through grieving processes related to the multiple losses experienced throughout the cancer journey, namely at an identity level, as referred to previously (Oliveira et al., 2012). While these grieving processes may differ from those related to the death of a significant other, EFT work similarly involves resolving blocking processes that interrupt the processing of complicated feelings and help access and symbolize adaptive grief around losses (Sharbanee & Greenberg, 2023). According to Connolly's study with breast cancer patients, disenfranchised losses are part of the person's core painful experiences (Connolly, 2016), which need to be (re)processed in order to be transformed and integrated. *Louise*, for instance, reclaimed her cancer-related losses during therapy, in ways she had never done before, as expressed in the beginning of session 3: "something happened to me that I had never felt before, that I don't know, I can't analyze, I can't describe. It was... I don't usually have it. I was sorry for having had all this!".

Considering the aspects worked on in psychotherapy within the issue of FCR, the humanistic, experiential, and existential features of EFT seem to perfectly fit the needs of this population. The relational dimensions, central in the EFT approach and involving a deep and genuine therapeutic bond, moment-by-moment empathic attunement, and goal and task collaboration (Elliott et al., 2004) attend to fundamental needs of cancer patients, such as feeling safe in the therapeutic relationship, deeply heard, understood and cared for (Boulton et al., 2001; Connolly, 2016; Krenz et al., 2014; MacCormack et al., 2001). Feeling understood when experiencing intense and painful emotions, such as those related to cancer experiences, can bring a sense of relief and comfort (Watson, 2019).

The experiential dimension, which includes active tasks like chair-work, promotes the patient's agency over their own internal dynamics, which can be very helpful when dealing with high powerlessness and vulnerability, as may be the case for a patient with cancer. As found in the Study 2 of this thesis (Chapter 4), experiential work has been previously considered helpful for cancer patients (Connolly, 2016) as well as clients in other EFT interventions (e.g., Elliott et al., 2009; Lafrance Robinson et al., 2014; Macleod et al., 2012). Considering the previously referred-to tendency of patients with dysfunctional FCR for experiential avoidance, other experiential tasks such as focusing (Gendlin, 1981) can also be fundamental for helping clients to access and allow their inner experiences, exploring and transforming their FCR emotion schemes (Elliott, Watson, et al., 2004).

The existential aspect of EFT is particularly important for people dealing with FCR. While some interventions for FCR have incorporated the existential dimension (Lebel et al., 2014), most frameworks do not overtly consider or incorporate it (Chen et al., 2018; Tauber et al., 2019), despite recent calls to do so (Coutts-Bain et al., 2023). EFT's existential dimension is mostly based on the notion that a major human motivation is creating meaning, i.e., making sense of oneself and the world through the construction of narratives (Greenberg, 2019). This is a dialectically constructivist process involving synthesis, attending, symbolizing and reflecting a bodily felt sense to generate a coherent narrative (Greenberg & Pascual-Leone, 2001). In fact, meaning construction is integral to much of EFT's work, whether at a micro level (e.g., searching for meaning in a specific situation or feeling) or a meso level (e.g., issues related to identity) (Vanhooren, 2018), and is explicitly addressed in the meaning creation task (Elliott et al., 2004), which will be presented in the next section.

Core needs associated with primary adaptive emotions, such as feeling lovable/connected, valuable, autonomous, safe/protected, or alive, have been articulated as existential (Greenberg, 2019; Pascual-Leone & Greenberg, 2007). In the context of FCR, these needs can be linked to existential concerns, such as the fear of dying, stemming from the experience of having had a potentially life-threatening disease. Thus, the existential aspect of EFT in FCR can have a specific meaning related to the human condition of existence, that might not be found in other clinical presentations.

As described, EFT's relational, experiential, and existential foundations can offer a comprehensive therapeutic approach to the multidimensional phenomena of FCR.

6.2. Implications for practice

The studies composing this thesis were strongly practice-oriented, aligning with our specific research questions and following the scientist-practitioner framework of this Ph.D. Drawing from the conclusions drawn from the various studies, we now reflect on their clinical implications and outline some guidelines and recommendations for practitioners working with cancer patients specifically dealing with FCR issues. We begin with some general considerations, that may be useful to any psychotherapy approach with cancer patients dealing with FCR, before delving into aspects pertinent to the specific use of EFT in these cases, elucidating the main therapeutic tasks identified in our studies.

A critical aspect to consider revolves around the importance of establishing a deep empathic therapeutic relationship between the therapist and the client with cancer. Different studies have found that cancer patients value the relational aspect of therapy, namely the therapist's empathic, caring and supportive attitude (Brandão et al., 2019; Chambers et al., 2015; MacCormack et al., 2001). While this is a fundamental element in any psychotherapy across various populations and disorders, the potentially life-

threatening nature of a cancer diagnosis and the heightened vulnerability that might be experienced throughout the illness trajectory underscore the significance of fostering a delicate yet strongly secure bond between client and therapist. It is acknowledged that the therapeutic relationship between the patient with cancer and their psychotherapist can provide a sense of stability and predictability during a period marked by instability and vulnerability (Sourkes et al., 1998; Strada & Sourkes, 2010), possibly contributing to an effective psycho-oncological care (Flock et al., 2023). A robust and profound therapeutic alliance, central to EFT, facilitates the exploration of the patient's most difficult experiences, frequently delving into themes such as suffering and death.

Assisting patients in addressing these sensitive, existential issues also requires psychotherapists to feel sufficiently comfortable approaching and working with them, starting with not avoiding them. This can help the client overcoming their own avoidance. By supporting someone faced with their mortality, one of the givens of existence, therapists inevitably confront their own existential condition (Yalom, 1981). Being present with the client's existence *and* one's own existence can be both challenging and courageous for the therapist (Vanhooren, 2018). The attitudes toward death and death anxiety among healthcare professionals themselves can constitute significant barriers for clinicians and researchers studying and working with death anxiety (Sharpe et al., 2018). Interventions aimed at addressing death anxiety and enhancing existential well-being in health professionals can assist them in better managing the suffering and death of their patients, potentially reducing burnout (e.g., Melo & Billings, 2017). Therefore, we strongly recommend that therapists working with cancer patients not only pay close attention to the existential aspects of their therapeutic work with patients with FCR but also prioritize working through their own existential issues, which will help them to connect deeply with the client (Vanhooren, 2018). Personal and professional development

work, including supervision and psychotherapy, can be other forms of doing so. Exploring existential themes can also rely on the therapist recognizing a common human condition with the patient, fostering a sense of shared understanding and connection. It is also crucial to acknowledge that cancer patients may actually confront the possibility of premature death, and therapists working with this population must confront this reality as well. While addressing existential issues has the potential to aid in transforming the core pain associated with maladaptive FCR, it is crucial to recognize that not everyone may be ready or able to confront these themes. Respecting the client's boundaries and preferences is paramount, operating within their level of awareness and addressing their immediate concerns (Yalom, 1981). Encouraging the client's curiosity about topics that evoke high anxiety, such as death, can be challenging, and it is important to respect the patient's pace and choices regarding some themes. However, inviting the client to explore these issues as part of their internal experience can facilitate effective emotional work, assisting them in the resolution of their emotional difficulties. Interestingly, for some of our clients in the study (e.g., *Sophie*, unpublished case study) it was surprising to identify "fear of death" beneath their FCR. Nonetheless, the processes of emotional exploration and deepening will allow the person to address whatever their core pain may be, recognizing that existential issues are not the only possible source of distress (core maladaptive pain may stem from other life experiences, such as psychological injuries in childhood).

As pointed out previously, and in line with observations made in other anxiety presentations (e.g., Elliott & Shahar, 2017), therapists addressing dysfunctional FCR must be mindful of the various layers of anxious processes involved. These range from secondary processes, often associated with the presenting symptoms or complaints, to more primary ones that connect with core emotional pain. In our case analysis, we observed an oscillation between these different levels throughout the therapy sessions,

due to what we found to be cyclic/complicated processes related to anxious and traumatic processes (see Table 6, p. 127). This underscores the importance of therapists being able to navigate flexibly between them, while following the EFT main deepening sequence, which implicates assisting clients transitioning from more superficial and less productive emotions to deeper and more useful ones (Elliott & Greenberg, 2021). Effective facilitation of this process may necessitate solid work on self-interruption processes as emotion regulation (see next section on specific therapeutic tasks to do so).

Some foundational aspects of EFT are particularly relevant when addressing this cancer-related issue, specifically the combination and balance between the “following” and “leading” elements of this therapeutic approach (Elliott et al., 2004). On one hand, deeply attuning with the patient’s emotions, “following” their inner experiences namely through the therapeutic relationship, is crucial for helping the client be aware, connect with and explore their own emotional experiences, fostering a sense of deep understanding and support. On the other hand, “leading” the client through specific therapeutic tasks promotes the active participation and agency in the client, enabling them to take ownership of their internal processes, and move away from the victimization world (Elliott et al., 1998) and the identification with the victim (Raymer, 1993). The active role from the client in psychotherapy (Bohart & Wade, 2013) is quite important considering the common experience of powerlessness in patients with various chronic conditions, including cancer (Aujoulat et al., 2007). Also, offering more structure than usual in humanistic psychotherapies within the therapeutic relationship can be exceptionally important for clients with anxiety (Elliott & Shahar, 2017).

Before delving into specific EFT therapeutic tasks, it is important to highlight the significance of helping clients access to all the elements of the Emotion Scheme, which will facilitate a more complete emotional processing of the problematic experiences

(Elliott et al., 2004). This includes connecting with FCR specific triggers or memories, symbolizing the experience (through words, images, metaphors, or other symbols), integrating bodily information, and identifying related action tendencies. These aspects will provide significant information to guide psychotherapy work effectively.

6.2.1. EFT main therapeutic tasks in FCR

When addressing dysfunctional FCR using EFT, certain therapeutic tasks stand out as particularly relevant. Among these, two-chair work for anxiety emerges as central for exploring the different layers of anxious processes associated with FCR. Whether fear/anxiety shows as a secondary emotion (e.g., fear of emotions), or as a primary feeling (e.g., a core trauma-related or existential maladaptive fear), this task plays a pivotal role in exploring, deepening, and ultimately transforming the maladaptive emotion schemes underlying FCR. Following the established structure of the two-chair dialogue for any conflict splits (Elliott et al., 2004; Elliott & Greenberg, 2021), the two-chair dialogue for anxiety involves several steps. Initially, the marker for this task (i.e., an anxiety split) is identified and the therapist sets the task. Subsequently, the two involved aspects of self, the “scarer” and the “scared”, are identified and separated: the "scarer" part representing the anxiety-provoking aspect and the "scared" part (or Experiencer) the anxiety-experiencing self. They engage then in a direct dialogue between these two aspects, during which each is progressively expressed, explored, and deepened. This deepening process leads to the emergence of more differentiated and underlying feelings and needs, eventually resulting in some level of resolution, such as softening and negotiation (Elliott et al., 2004; Elliott & Greenberg, 2021). Two-chair dialogue for fearing cancer recurrence, particularly in its secondary processes, resembles the two-chair worry dialogue, in which the protective nature of the fear is emphasized (Murphy et al., 2017;

Timulak & McElvaney, 2017). Other secondary processes, such as self-criticism for experiencing fear or engaging in unhealthy habits (e.g., overeating or eating in an unhealthy manner) or self-interruption (e.g., *Louise's* feeling of being pleased by experiencing menopause symptoms) can also be addressed through two-chair tasks.

Commencing the task by externalizing the fear, symbolically placing it in the other chair and treating it as something external rather than an internal experience, is also an option that we found to be helpful for some clients dealing with FCR. This externalization might correspond to initial stages of low assimilation (Stiles et al., 1990) and experiencing (Klein et al., 1969) of the problematic experience, in which the client disowns their experience while simultaneously being overwhelmed by it. The client's enactment of their own anxiety process allows them to engage with and fully own their experience, potentially leading to emotional resolution. In our clinical studies, we have observed that for many clients, the FCR feels as uncontrollable and disowned as the cancer itself, evoking strong feelings of helplessness. Also, some patients believe that their negative thoughts and feelings about recurrence risk may somehow increase the likelihood of its actual occurrence, which Hay and colleagues have termed as "cognitive causation" and "negative affect in risk" (Hay et al., 2014). This might also have to be addressed in therapy.

Dysfunctional FCR, like any other high-anxiety experience, can manifest as undifferentiated and overwhelming, also requiring a significant emphasis on emotion regulation work. As illustrated by the cases of *Tom* and *Louise*, clients dealing with FCR, may exhibit both underregulated and overregulated distress. Both clients experienced panic episodes associated with their FCR. Also, both tended to suppress, cover up, or distance themselves from their own emotions, particularly their fears. Various strategies were employed to assist in regulating emotions, either by helping clients in accessing or

containing difficult emotions (Elliott et al., 2004). Employing evocative or vivid language, engaging in focusing tasks, or enacting emotion expression and action tendencies during two-chair work are methods used to facilitate emotional access. On the other hand, employing containing language, engaging in the clearing a space task, and promoting self-soothing activities, mindfulness or relaxation suggestions are potential approaches to help clients contain their overwhelming emotions (Elliott, Watson, et al., 2004).

Another essential set of tasks in addressing dysfunctional FCR involves reprocessing tasks, i.e., trauma retelling, meaning (re)creation and systematic evocative unfolding, which involve re-experiencing or re-examining significant or particularly difficult life events (Elliott et al., 2004; Elliott & Greenberg, 2021). As noted, our systematic review revealed that FCR can be described in trauma-like terms. In the cases of *Tom* and *Louise* that we analyzed, reprocessing difficult or traumatic cancer-related events played a central role in resolving clients' dysfunctional FCR. Their primary maladaptive fear and sadness were rooted in traumatic experiences within the cancer trajectory: *Tom* described a terrifying experience while waiting for surgery, believing that he was going to die, while *Louise* was terrified as she approached the post-treatment period, recalling her close relative's recurrence that ultimately led to death. Both also recalled other connected traumatic experiences, in childhood and before their own cancer experience.

Narrative work entails some degree of re-experiencing significant aspects of traumatic events, enabling the client to differentiate and recognize relevant aspects involved in them (Elliott et al., 2004). During therapy sessions, we observed that these clients had various episodic memories related to cancer, such as diagnosis disclosure and waiting for cancer surgery, which had unprocessed, poignant aspects that benefited from

re-experiencing and re-processing. The intensity of these episodes, along with the ongoing challenges of the cancer trajectory and emotional avoidance, showed as possible obstacles to the full emotional processing of these experiences. Therapy after termination of intensive treatments, as happened in both *Tom* and *Louise's* cases, can be an opportunity to do so.

Meaning (re)creation work was also a significant task in addressing FCR, often closely linked with the trauma retelling work. This process entails the identification and reassessment of *cherished beliefs*, which are benign implicit assumptions about life, the world, the self and others that become threatened by impactful and negative events (Elliott et al., 2004). In a study involving parents of children with cancer, it was observed that beliefs concerning the benevolence of others, the human ability to control negative events, self-worth, happiness in life and the agency in achieving personal well-being were diminished (Zaluski, 2013). The disruption of these beliefs, also known as shattered assumptions (Janoff-Bulman, 1992) can provoke intense emotional reactions. Emotional protest serves as a key indicator (i.e., marker) for therapeutic intervention, alongside feelings of confusion, surprise or incomprehension in response to challenging life events (Elliott et al., 2004).

In our studies with cancer patients, we identified cherished beliefs such as “Young people are not supposed to die” (expressed by *Tom* as: “I’m too young to die”) or “cancer should only happen to bad people”. These beliefs are often rooted in personal experiences, while also being influenced by social and cultural norms (e.g., the expectation in modern Western societies that children should not die, contrary to other historical realities). This suggests that therapists may share some of these beliefs with their clients, underscoring the importance of therapists recognizing and assisting individuals in identifying and reevaluating them. The task of meaning (re)creation is likely the EFT task most directly

associated with the existential dimension previously mentioned as possibly pivotal in clients' FCR, with the other therapeutic tasks potentially complementing the exploration of this dimension.

Reprocessing tasks in FCR also involve assisting clients work through their grieving processes. The cancer experience often encompasses numerous losses across various dimensions, including physical, psychological, and social aspects. For instance, embodied reminders, such as scars (Trusson et al., 2016) serve as live reminders of the cancer experience and of some of these losses. Some patients perceive their own body as having betrayed them, fostering a sense of suspicion inherent in FCR (Thomas-MacLean, 2001). *Louise* recognized and expressed, for the first time, the profound sadness of having lost her breast – a feeling she had never previously articulated. She also identified an ultimate major loss, permeating her entire cancer experience: “the loss of the illusion of eternity”, echoed by other patients as a kind of loss of innocence: the difference between “the knowing” versus “truly knowing” previously referred by Yalom (1981). The reprocessing tasks can help integrate these disrupted experiences in self.

While the traumatic experiences might involve a change on the emotion scheme of the self from “invulnerable” to “vulnerable” (Elliott et al., 1998), resolving dysfunctional FCR can also involve dealing and accepting the vulnerable condition of being human. The compassionate self-soothing task for vulnerability, required when the client expresses anguish, such as finding unmet existential needs (Elliott & Greenberg, 2021) can be another relevant task when addressing FCR. In both cases of *Tom* and *Louise*, both experienced in therapy comforting other vulnerable persons with cancer, which helped them to achieve a self-comforting experience.

6.3. Implications for research

The research methods employed to address our research questions were diverse, allowing for a comprehensive exploration of various aspects of FCR. We integrated both qualitative data and quantitative data across our studies, combining insights from previous research with original naturalistic data. Additionally, we merged theoretical concepts, such as the emotion scheme concept, with practical considerations related to EFT interventions for FCR. Consequently, the findings of these studies provide a solid foundation for further investigation into the efficacy of EFT for FCR and the exploration of our preliminary results.

I will now briefly outline the main global methodological strengths and limitations of our studies, reflecting on future research directions they suggest, in conjunction with the findings previously described. Specific limitations of each of the studies comprising this thesis were discussed in the final sections of their respective chapters.

Globally, our studies were original in their use of standard methods to explore our research goals. For example, we used the emotion scheme concept to categorize relevant information in the qualitative systematic review and employed a single case study in the task analysis discovery phase. Although FCR has been widely studied in recent decades, we expanded knowledge by integrating scattered and diverse qualitative data and exploring a previously unstudied therapeutic approach for individuals with dysfunctional FCR. Consequently, from the perspective of EFT, this research also introduced new possibilities for its application and expanded existing knowledge, such as the potential to deepen EFT's existential features in the context of FCR. Another global strength of our studies consisted of the interplay between qualitative and quantitative data throughout the studies to answer our research questions, both fundamental in psychotherapy research

(Lutz & Hill, 2009). As an example, in Study 2 we used both qualitative data (the HAT form and the illustrative case study) and quantitative data (the outcome data pre-post EFT intervention) to assess the effectiveness of EFT for FCR.

While beginning a thorough investigation usually involves a literature review, our qualitative systematic review provided a comprehensive view of patients' experiences, which was fundamental for later exploring a clinical intervention for FCR. By exclusively using patient's quotes – figuratively referred as the “patients' voices” – we emphasized the importance of the active role of patients in research, decision-making, and the care and management of chronic conditions (Longtin et al., 2010). This approach entirely matched our teams' humanistic view of human beings as active agents in their lives (Cain et al., 2016). Additionally, this qualitative approach supported conclusions from other primarily quantitative reviews, such as the multidimensionality of FCR (Fardell et al., 2016; Lee-Jones et al., 1997), and enriched it by adding relevant qualitative information, such as elements pointing to FCR as a phenomenon within a PTSD framework (Simonelli et al., 2016). Although there are potential identifiable biases and limitations in this study, arising either from aspects related to the primary studies or from our own (secondary) categorization process (see section “Methodological issues”, Chapter 3, p. 58), our assessment and audit process regarding the included studies were quite rigorous and adhered to the most recent standards for reporting qualitative meta-analytic research in Psychology (Levitt et al., 2018), enhancing the validity of our work.

Data from Studies 2 and 3 were derived from an original exploratory study conducted in a natural context, providing insights that closely reflect real-world practice environments. Naturalistic effectiveness studies can be more informative for clinicians, potentially closing the gap between research and clinical practice (Desmet, 2013), a persistent concern in psychotherapy research (Lambert, 2013; Sales, 2009). However, the

absence of control over certain variables, as usual in randomized controlled trials (RCTs), may be seen as a notable limitation. For instance, the lack of a control group in Study 2 makes it harder to attribute changes in FCR solely to the intervention, as other factors may have influenced the outcomes. The absence of a longer follow-up assessment in this study also impedes the capture of potential long-term effects of the intervention on FCR over time. Furthermore, the small sample size in these studies limited statistical power, potentially affecting the generalizability of the findings. The diversity of cancer diagnoses and other demographic characteristics among participants further complicates the interpretation of results. Previous studies found no differences in FCR by cancer type, while being younger has been consistently associated with higher levels of FCR (e.g., Simard et al., 2013; van de Wal et al., 2016). As a result, the ability to draw definitive conclusions from our studies about intervention effectiveness and generalizability is limited. One of our main suggestions for future research is to conduct RCTs with larger sample sizes and longer follow-up periods to rigorously evaluate the effectiveness of EFT for FCR. This kind of research could also include comparative studies, i.e., compare EFT with other psychotherapeutic interventions or treatment modalities to determine its relative efficacy.

Regarding the task analytical work (Study 3), it was unconventional not to focus on a specific EFT task, diverging from typical approaches found in the literature (e.g., Breighner, 2008; Murphy et al., 2017; Sutherland et al., 2014). While we recognize the limitations inherent in a single-case design, this innovative methodological choice enabled a detailed examination of a unique case, facilitating the identification of therapeutic tasks used to address FCR within the context of EFT. However, despite the thoroughness of the analysis, it is unclear whether it captured a discernable common pattern regarding the EFT intervention for FCR. Also, while it served as the empirical

foundation for the discovery-oriented phase of a task analysis, this process was incomplete as it omitted the validation phase (Greenberg, 2007). Strengthening this research, using a larger sample and refining the analysis of specific therapeutic tasks, would allow for the validation of the proposed EFT rational-empirical model for FCR. Testing the model and connecting process and outcomes would concretize the second step of the task analysis validation-oriented phase (Greenberg, 2007).

Process research on the specific mechanisms of change in EFT for FCR would also enhance the understanding of its therapeutic effects (Elliott, 2010). In order to better understand how the intervention actually help the clients with dysfunctional FCR, it would be interesting, for example, to analyze specific therapeutic tasks, such as the anxiety two-chair work, comparing it to other “worry/anxiety” tasks, such as in GAD (Murphy et al., 2017). Process-outcome studies, involving client or therapist processes or investigating the relationship between therapeutic processes identified in the task analysis and treatment outcomes (Elliott, 2010; Llewelyn et al., 2016), would also help refine the therapy model and enhance its effectiveness.

In our studies, no formal assessments of FCR were used, beyond the identification of FCR as a relevant issue on a personalized outcome measure (i.e., Personal Questionnaire). At the time our studies were conducted, there were no Portuguese versions of standardized assessment measures available, although a Portuguese version of the Progression Questionnaire-Short Form (FoP-Q-SF) has since been validated (Silva et al., 2022). Despite this limitation, the PQ has demonstrated strong correlations with standardized outcome measures and sensitivity to changes in clients over the course of therapy (Elliott et al., 2016), aligning with our research purposes. However, the lack of standardized assessment tools makes it challenging to ascertain the level of dysfunctionality of FCR in the participants of our sample and compare intervention

outcomes with other studies. Future research would benefit from integrating standardized measures of FCR to facilitate more robust comparisons and interpretations of intervention effectiveness. Given the existential dimension of FCR identified in our studies, we also recommend, following Vanhooren (2018), incorporating assessments of this aspect in future research.

Concerning the existential issues found in our analyzed cases, further exploration is needed to understand how EFT specifically addresses these in this population. We can say, in line with Vanhooren (2018), that in EFT for FCR, there might be a call for searching for meaning not only at a micro (e.g., meaning of a specific feeling) and meso level (identity-related) but also at a macro level (e.g., existential, or spiritual meaning). Another important aspect would be clarifying what individuals precisely fear about death, as well as how other existential concerns are personally lived, as they vary from person to person. For example, one of *Louise's* core concerns related to what Yalom (1981) considered central in death anxiety: the fear of personal annihilation, such as imagining her body decomposing, which was a major source of terror for her. Research has identified a hierarchical structure of the fear of personal death, distinguishing between the symbolic self-perspective and the physical self-perspective (Jastrzębski et al., 2020). Each perspective includes threats to self-fulfilling existence, threats to well-being and threats of psychical destruction (Jastrzębski et al., 2020). Larripa (2023) work on the existential need in EFT for complicated grief further differentiated global existential needs into the existential need of the self, the existential relational need, and the meta-need.

Additionally, the influence of religious beliefs in the fear of death and dying emerged in *Louise's* case, namely the fear of going to hell. Therefore, religious/spiritual aspects underlying or related to FCR warrant further exploration in future research. A

systematic review on religion/spirituality and psychological well-being among breast cancer survivors found that their psychological well-being depends, to a certain extent, on their belief system (Schreiber & Brockopp, 2012). It is possible that these factors may also represent important resources for the individual (e.g., *God* can be identified as a self-soother). Further examination in this area could provide valuable insights into the nuanced nature of existential distress in cancer patients with FCR and inform more targeted interventions within the EFT framework. It is known that existential interventions facilitate personal meaning and promote psychological adaptation in cancer patients (Vehling & Philipp, 2017).

While it proved to be central in the cases of *Tom* and *Louise*, the hypothesis that dysfunctional FCR is always related to traumatic experiences must also be clarified and tested. A PTSD-like framework has been considered a possible conceptualization of FCR (Simonelli et al., 2016); however, it is not commonly identified in FCR intervention studies (e.g., Lebel et al., 2014; van de Wal et al., 2018). It might be the case that cancer-related traumatic experiences are not always crucial to understand and treat dysfunctional FCR.

A potential limitation that cuts across all three research studies is the allegiance of most of our research team to EFT. While it may have influenced our interpretation of the findings, constituting a bias (Munder et al., 2011), we tried to carefully attend Levitt et al.'s (2018) recommendations to consistently demonstrate our methodological integrity throughout our studies, as well as to describe our prior understandings of the phenomenon under study (e.g., the way EFT usually works with anxiety issues as a way to work with FCR).

Closing this section, we would like to add that our investigation can also contribute for the discussion of whether FCR should constitute a distinct diagnosis,

although not in a conclusive manner. Most experts do not advocate for established diagnosis to categorize FCR experiences, considering it a specific cancer-related problem (Mutsaers et al., 2020). However, Health Anxiety/Illness Anxiety Disorder and Somatic Symptom Disorder have been considered viable alternatives for 25% to 44% of participants in a Delphi study (Mutsaers et al., 2020). Based in our studies and in an EFT understanding of FCR, the excessive worry regarding the possibility of cancer recurrence may also overlap with the broader worry characteristic of GAD, even though Simard & Savard (2015) found that FCR is not a sub-manifestation or a cluster of GAD. Thus, we reiterate the suggestion above described of the possibility of exploring the role of the worry process in the FCR dysfunctional experience. Considering other possible aspects of FCR not so much studied, as the traumatic aspects, we would like to add to the previous referred diagnoses the possibility of FCR as a configuration of a cancer-related PTSD.

In sum, our studies can be seen as a foundational exploration that can pave the way for further investigation into the complex topic of FCR.

6.4. Main contributions

I conclude this PhD thesis by summarizing the main contributions of this work:

- FCR is a complex and multifaceted experience, involving perceptual, emotional, mental, bodily, and behavioral aspects. It can be experienced in different ways by different people and is relevant to presentations from normal to dysfunctional.
- EFT is a viable alternative and effective intervention for helping people deal with dysfunctional FCR. All of the EFT's humanistic, experiential, and existential dimensions are important in addressing this issue.
- Cancer-related trauma, grieving, and existential processes are fundamental aspects when working with people experiencing dysfunctional FCR. There are significant relationships between these aspects, such as the traumatic experience of fearing death.
- The proposed EFT model for FCR suggests an existential core pain associated with dysfunctional FCR, involving primary maladaptive fear/anxiety and sadness. Working through secondary processes involving emotion dysregulation and experiential avoidance is fundamental to transform the maladaptive core pain.
- Future research directions may include: conducting RCT's; continuing the task analytic process (i.e., the validation-oriented phase) on the EFT intervention for FCR as a whole; analyzing specific therapeutic tasks; and exploring and specifying the existential aspects involved in EFT for FCR.

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Appendix A

Quality appraisal criteria used in the review, adapted from Elliott, Fischer & Rennie
(1999)

1. *Explicit scientific context and purpose.* The manuscript specifies where the study fits within relevant literature and states the intended purposes or questions of the study.
2. *Appropriate methods.* The methods and procedures used are appropriate or responsive to the intended purposes or questions of the study.
3. *Respect for participants.* Informed consent, confidentiality, welfare of the participants, social responsibility, and other ethical principles are fulfilled. Researchers creatively adapt their procedures and reports to respect both their participants' lives, and the complexity and ambiguity of the subject matter.
4. *Specification of methods.* Authors report all procedures for gathering data, including specific questions posed to participants. Ways of organizing the data and methods of analysis are also specified. This allows readers to see how to conduct a similar study themselves, and to judge for themselves how well the reported study was carried out.
5. *Appropriate discussion.* The research data and the understandings derived from them are discussed in terms of their contribution to theory, content, method, and/or practical domains, and are presented in appropriately tentative and contextualized terms, with limitations acknowledged.
6. *Clarity of presentation.* The manuscript is well-organized and clearly written, with technical terms defined.

7. *Contribution to knowledge.* The manuscript contributes to an elaboration of a discipline's body of description and understanding.
8. *Owning one's perspective.* Authors specify their theoretical orientations and personal anticipations, both as known in advance and as they became apparent during the research. In developing and communicating their understanding of the phenomenon under study, authors attempt to recognize their values, interests and assumptions and the role these play in the understanding. This disclosure of values and assumptions helps readers to interpret the researchers' data and understanding of them, and to consider possible alternatives.
9. *Situating the sample.* Authors describe the research participants and their life circumstances to aid the reader in judging the range of people and situations to which the findings might be relevant.
10. *Grounding in examples.* Authors provide examples of the data to illustrate both the analytic procedures used in the study and the understanding developed in the light of them. The examples allow appraisal of the fit between the data and the authors' understanding of them; they also allow readers to conceptualize possible alternative meanings and understandings.
11. *Providing credibility checks.* Researchers may use anyone of several methods for checking the credibility of their categories, themes or accounts. Where relevant, these may include (a) checking these understandings with the original informants or others similar to them; (b) using multiple qualitative analysts, an additional analytic 'auditor', or the original analyst for a 'verification step' of reviewing the data for discrepancies, overstatements or errors; (c) comparing two or more varied qualitative perspectives, or (d) where appropriate, 'triangulation' with external factors (e.g. outcome or recovery) or quantitative data.

12. *Coherence*. The understanding is represented in a way that achieves coherence and integration while preserving nuances in the data. The understanding fits together to form a data-based story/narrative, 'map', framework, or underlying structure for the phenomenon or domain.
13. *Accomplishing general vs. specific research tasks*. Where a general understanding of a phenomenon is intended, it is based on an appropriate range of instances (informants or situations). Limitations of extending the findings to other contexts and informants are specified. Where understanding a specific instance or case is the goal, it has been studied and described systematically and comprehensively enough to provide the reader a basis for attaining that understanding. Such case studies also address limitations of extending the findings to other instances.
14. *Resonating with readers*. The manuscript stimulates resonance in readers/reviewers, meaning that the material is presented in such a way that readers/reviewers, taking all other guidelines into account, judge it to have represented accurately the subject matter or to have clarified or expanded their appreciation and understanding of it.