



## Review

# Fear of cancer recurrence: A qualitative systematic review and meta-synthesis of patients' experiences

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## HIGHLIGHTS

- Qualitative data complement quantitative findings and can expand our current knowledge about fear of cancer recurrence.
- FCR is described as a complex experience involving emotional, perceptual, conceptual, bodily and behavioral dimensions.
- Survivors often refer FCR when speaking of their cancer experience, ranging on a continuum from adaptive to maladaptive.
- Vivid metaphors of conflict and vulnerability emphasizing fragility and helplessness are commonly used by survivors.
- Psychotherapists may use our results as a kind of map of the aspects and varieties of FCR experience.

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## ABSTRACT

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 FCR were extracted, then analysed 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.

## 1. 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

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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.

## 2. Methods

### 2.1. 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.

### 2.2. 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 "berry-picking" 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).

### 2.3. 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](http://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).

Fig. 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](http://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](http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42016036688)).

### 2.4. 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

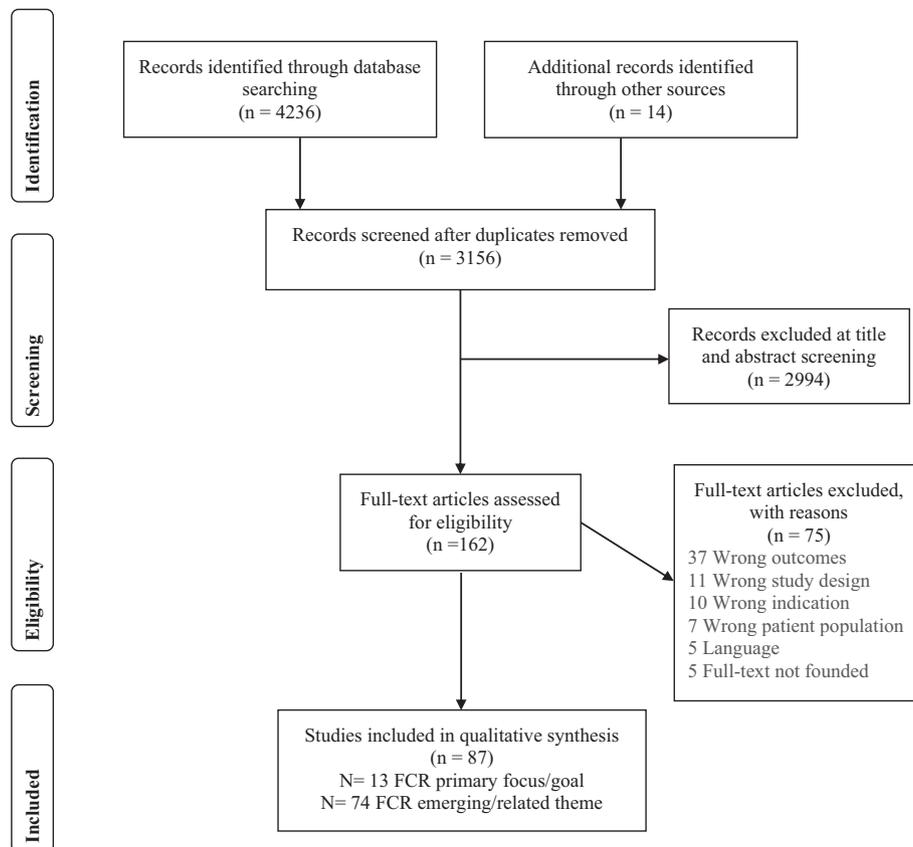


Fig. 1. PRISMA flow diagram of the study review.

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 1), 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).

### 2.5. 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 online 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).

### 2.6. 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

**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	
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 <sup>a</sup>	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%)

<sup>a</sup> Not 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”.

( $n = 74$ ). 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-behavioural; 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.

### 3. 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.

#### 3.1. 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

**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%)

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).

### 3.2. 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/news-paper/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.

### 3.3. 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.

### 3.4. 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.

### 3.5. 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.

### 3.6. 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.

#### 3.6.1. 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).

#### 3.6.2. 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).

### 3.7. 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/time line*; 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).

### 3.8. 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).

### 3.9. 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.

#### 3.9.1. 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).

#### 3.9.2. 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 *paralyzing* or *blocking* any action tendency: “I was just so paralyzed by fear” (Berman, 2013); “it's just almost crippling” (Mutsaers et al., 2016).

### 3.10. 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).

## 4. 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 of 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 from 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 formed the multidimensionality 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.

#### 4.1. 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.

#### 4.2. 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 analysed. 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.

## 5. 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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## Contributors

All authors contributed to the conception and design of this project. Susana N. Almeida conducted the literature searches and with Eunice R. Silva proceeded to the selection and assessment of the studies. Célia Sales and Robert Elliott were consulted in the final phases of inclusion of studies to further analysis and synthesis. Susana N. Almeida first analyzed the data, which was then discussed, revised and audit by Robert Elliott. The first draft of the manuscript was done by Susana N. Almeida and all authors reviewed it and contributed to its final version.

## Conflict of interest

All authors declare that they have no conflict of interest.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.cpr.2018.12.001>.

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