

Review

# Fear of cancer recurrence: a theoretical review and its relevance for clinical presentation and management

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## Abstract

**Background:** There is increasing recognition of the unique physical and psychosocial concerns of the growing population of cancer survivors. An emerging literature demonstrates that *fear of cancer recurrence (FCR)* is a problematic long-term and late effect for cancer survivors. In fact, FCR is a top concern, and this article provides a necessary synthesis of the extant research evidence and theory.

**Methods:** Literature searches were conducted using databases including MEDLINE and PsychINFO using specified search terms including ‘fear of recurrence’ and ‘worry about recurrence’. A comprehensive narrative review summarizes early empirical findings on FCR including current definitions, assessment tools, clinical presentations, quality of life impact, prevalence, trajectory and risk factors. This paper also critically reviews the relevant theoretical frameworks to best understand these findings and considers multiple psychosocial treatment models that may have relevance for addressing FCR in the clinical setting.

**Results:** There is evidence of substantial prevalence and quality of life impact of FCR. Several theories (e.g. self-regulation model of illness, a family-based model, uncertainty in illness theory, social-cognitive processing theory, terror management theory) directly or indirectly help conceptualize FCR and inform potential treatment options for those with clinically significant distress or impairment resulting from FCR.

**Conclusions:** Further investigation into FCR is warranted to promote evidence-based care for this significant cancer survivorship concern.

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## Background

In the USA, there are nearly 14.5 million cancer survivors [1]. This number is expected to increase rapidly in coming decades owing to a growing and aging population, improved early detection and advances in treatment. With more recent attention paid to the life-after-treatment phase of the cancer care continuum comes the knowledge that many cancer survivors experience multiple physical and psychosocial long-term and late effects of treatment (e.g. fatigue, pain, anxiety, etc.). An emerging literature is showing that *fear of cancer recurrence (FCR)* is a problematic long-term and late effect observed post-treatment. This is a well-founded concern, as one third of all individuals with a cancer diagnosis die of cancer within a 5-year period [1]. While some degree of FCR is to be expected and adaptive (e.g. maintaining medical follow-up, engaging in healthy lifestyle change), in excess, FCR can impair quality of life. The purpose of this article is threefold: (a) to provide a review of the early empirical findings on FCR, (b) to present several theoretical frameworks within which to better understand FCR, and (c) to consider multiple psychosocial treatment models that have relevance for addressing FCR.

## Methods

Literature searches were conducted using databases including MEDLINE and PsychINFO using specified search terms including ‘fear of recurrence’ and ‘worry about recurrence’. Additional articles and references were selected to provide further background or details regarding theories or treatments where needed.

## Results

### Definition and measurement

A systematic review identified existing FCR assessment methods as ‘assessing fears (or worry or concerns) about previous forms of cancer returning, developing a new primary of a previous or entirely new form of cancer, metastases or disease progression’ [2]. FCR has been operationalized with reference to ‘fear/worry’, ‘distress’, ‘troublesome thoughts’ and ‘cancer-specific concerns’ [3]. Targeted measures assess FCR quite literally in terms of the degree of worry or fear one has about ‘cancer coming back’ or being diagnosed with another type of cancer. In contrast, more global measures capture FCR as a subset of

worry [4] with attention to symptom checking (e.g. concern that pain may indicate a recurrence), apprehension over future screening or diagnostic tests, anticipated physical health consequences of a recurrence (e.g. need for additional treatment, poor health, dying), and anticipated psychosocial consequences of a recurrence (e.g. emotional distress, the inability to fulfill important social roles). Importantly, while FCR shares variance with measures of negative affect, it is distinct from general psychological distress; observed correlations between FCR and negative affect have been small to moderate in magnitude, even among the more targeted measures of FCR [5]. Therefore, it would be inappropriate to rely on measures of general psychological distress to assess FCR.

One well-validated and oft-cited tool with demonstrated specificity and sensitivity for determining FCR is the Fear of Cancer Recurrence Inventory (FCRI) [6]. The FCRI is a 42-item, multifactorial construct measuring cancer-related triggers, severity, psychological distress, coping strategies, functioning impairments, insight, and reassurance [6]. The nine-item FCRI severity subscale has demonstrated psychometric properties [7] and established sensitivity and specificity for a cutoff score of 13 [8].

Other commonly cited measures include the Fear of Progression Questionnaire [9] and the Cancer-Related Health Worries Scale [10]. The Fear of Progression Questionnaire, which is not unique to cancer and is utilized with general chronic illness, is comprised of five factors including affective reactions, family, occupation, autonomy, and coping with anxiety, while the Cancer-Related Health Worries Scale is a single construct derived from four items. For a systematic review of fear of cancer recurrence self-report measures, refer to Thewes *et al.* [7]. Critiques of current assessment attempts have pointed to three major issues. First, the majority of studies collect FCR at one time point in a cross-sectional design [3]. Second, most FCR questionnaires have been reported in few studies with limited published psychometric data [2]. Compounding this issue is the lack of consistent use of a clinical cutoff score, overreliance on data from breast cancer survivors, and lack of consensus on conceptualization of FCR as a single or multifaceted concept. Third, there has been little attention paid to the cross-cultural validity of FCR measures [11].

### Triggers

In developing a measurement inventory for FCR, Simard and Savard [6] identified seven situations that may trigger FCR including conversations about cancer, knowing someone who is ill, media references to cancer, attending funerals or reading obituaries, appointments with health professionals, examinations and procedures, and feeling sick. Similarly, physical symptoms such as aches, pain, and fatigue [12,13] and the anniversary of the diagnosis can also be triggers [3].

### Prevalence and trajectory

There are no established criteria regarding the frequency, duration and severity of symptoms that would constitute clinically significant FCR, but there are some preliminary descriptive statistics. Savard and Ivers [14] reported prevalence rates of clinically significant FCR of 44–56% with highest levels at a peri-operative baseline, but persisting over time. Similarly, in a systematic review of 15 studies, Koch and colleagues [3] reported that FCR is experienced by most cancer survivors and is stable over time. At low levels, FCR was prevalent among 82% of long-term (at least 5 years post diagnosis) breast cancer survivors in Germany, with 11% experiencing moderate levels and 6% reporting high levels of FCR [15]. Although the majority of studies suggest FCR is stable over time, a couple of studies contradict this finding by reporting a decrease in FCR over time [16,17]. For example, Taylor and colleagues [16] reported that FCR decreased with time since diagnosis in a sample of ( $n=51$ ) African-American breast cancer survivors. Similarly, Thewes, Bell and Butow [17] reported a significant association between FCR and time since diagnosis in a sample ( $n=218$ ) of young, early stage breast cancer survivors at least 1 year post diagnosis.

In studies involving other types of cancer, there is similar variability in the reports of FCR. For instance, among those with head and neck cancer approximately 8 months post diagnosis, 60% reported FCR ‘occasionally’ or more frequently and 12% endorsed FCR ‘often’ or ‘all of the time’ [18]. Another study of patients with head and neck cancer reported significant levels of FCR in 35% of the sample that was maintained over time [19]. In a sample of patients with cancer measured at three different time points within 1 year, FCR was first classified as ‘low’ (15%), ‘moderate’ (67%) and ‘high’ (18%) initially. These percentages remained stable over time, and time since diagnosis was not significantly correlated with FCR [20]. In a study of men on average more than a decade post-diagnosis from testicular cancer, 31% of the participants reported FCR ‘quite a bit’ or ‘very much’ [21]. In terms of trajectory, there is also evidence of increasing anxiety as medical follow-up approaches and a subsequent transient decline following news of sustained remission [22].

Two tentative conclusions can be drawn from this literature. The first, although perhaps counterintuitive, is that the degree of FCR does not appear to be proportional to prognosis or survival statistics. For instance, across all types of head and neck cancer, the 5-year survival rate is approximately 50%, and yet, only 12% of participants in the head and neck study endorsed FCR as more often than not. By contrast, the 5-year survival rate for men with testicular cancer is approximately 95%, and yet, 31% of the participants in the testicular cancer study reported FCR more often than not. In the later study, the average participant was more than 11 years post diagnosis ( $SD=4.2$

years). Hence, the second tentative conclusion that can be drawn is that FCR does not necessarily resolve or even diminish with the mere passage of time; instead, it can be stable for years. In sum, these results would suggest that FCR represents a prevalent and persistent unmet psychosocial need for cancer survivors.

### Clinical presentation

When FCR ceases to be adaptive and becomes distressing, it can manifest as an anxiety disorder, trauma or stressor-related disorder, somatic symptom disorder and subclinical distress or may exacerbate pre-existing psychological conditions. Common clinical diagnoses observed in the context of FCR include post-traumatic stress disorder (PTSD), generalized anxiety disorder (GAD) and adjustment disorder. Whether an exacerbation of an existing disorder or trigger for a new one, those with clinically significant levels of FCR are more likely to have a current diagnosis of a psychiatric disorder [8].

For a small, but significant minority of patients, cancer diagnosis and treatment are considered traumatic events capable of producing symptoms consistent with PTSD. While being diagnosed with cancer is not automatically conceived as a trauma, discrete events that occur during the course of cancer diagnosis, treatment, and survivorship could certainly qualify as traumatic [23]. While the literature on comorbid cancer and PTSD is focused on cancer as the traumatic stressor, a PTSD framework may be particularly relevant for cancer patients who have experienced prior trauma, given that a history of trauma increases likelihood of development of PTSD symptomatology. This is most salient for those whose cancer may be a trigger of a prior trauma (e.g. gynecological cancer in a woman with history of sexual trauma, Hodgkin's disease for agent orange-exposed veterans). Traumatic stress symptoms include recurrent and intrusive thoughts, behavioral-cognitive avoidance and numbing, alterations in mood and cognition and increased arousal [24]. Individuals with cancer-related PTSD may experience awareness of feelings about cancer that have not been dealt with; distress when returning to treatment location or receiving follow-up care; avoidance of cancer-related thoughts, conversation and media; sleep difficulties; irritability and hypervigilance to somatic symptoms. Kangas, Henry and Bryant [25] reviewed distinctive features of PTSD in cancer. They noted that the 'threat' posed by cancer may actually be multiple stressors at various time points during the cancer experience, and the sometimes lengthy duration of the stressor(s) may contribute to more intense reactions [25]. FCR may be relevant to these unique features of PTSD reactions to cancer. While to date there is no evidence of a causal relationship between FCR and post-traumatic stress symptoms, Skaali and colleagues [26] reported higher rates of cancer-related intrusions and

avoidance among testicular cancer survivors who reported greater levels of FCR. Even so, more research is needed to examine the relationship between FCR and PTSD.

While a PTSD-like framework is one way to conceptualize FCR, this is not without limitation, as discussed elsewhere [27,28]. For example, one limitation is the potential to confuse treatment side effects with PTSD arousal symptoms (e.g. sleep disturbance); however, clinicians should not automatically assume that these symptoms are not diagnostically relevant. Other arousal symptoms, such as hypervigilance (while less likely to be confused with treatment side effects), can present differently in people with FCR than it does in people with other trauma histories. In many cases, this hypervigilance is to physical symptoms and contributes to catastrophic misinterpretation that cancer has returned—that is, the focus is often on an internal stressor and future-oriented threats, unlike other cases of PTSD that occur from external and discrete events with an immediate threat [25]. Alterations in cognition and mood may include beliefs about having caused one's cancer or excessive feelings of guilt about not receiving regular follow-up medical care. Furthermore, intrusive thoughts, although they may include 're-experiencing' of cancer treatment, may also be future-oriented worries about what may happen if the cancer recurs. These worries may be vivid and may encompass a fear of reliving the trauma all over again; hence, they may be simultaneously re-experiencing the trauma and catastrophizing.

In light of the future-oriented and catastrophic nature of FCR, worry may be of particular importance as it relates to the presentation, measurement and treatment of FCR. Worry in the context of GAD often contributes to sleep disturbance, tension and difficulty concentrating—symptoms common among those with FCR. Worry can be considered a form of coping with an anticipated threat (e.g. recurrence), but it reaches a pathological point when it feels uncontrollable and excessive [28]. Those who report FCR often report the chaining characteristic of worry (e.g. cancer will recur and they will die shortly after). This pattern of worry may not allow for adequate processing of future-oriented concerns, thus impairing appraisal of coping responses and contributing to maintenance of fear. While FCR worry is not 'generalized' but is rather specific, it is still plausible that a propensity to worry would be a risk factor for FCR and play a critical role in the maintenance of FCR (e.g. refer to case study [29]). Thewes and colleagues [30] found that 36% of breast cancer survivors with clinical levels of FCR met criteria for GAD.

Given the strong relationship between somatic symptoms and psychological symptoms in an oncology population, FCR may also be characterized by somatic symptom disorder or illness anxiety disorder given the concordance between distress and disruption in daily activities and a subsequent over-reliance or under-reliance on medical follow-up. Research indicates that those with higher levels

of FCR have greater frequencies of emergency room visits [31], unscheduled medical visits, self-examination or conversely reduced participation in cancer screening [11]. Although research on the comorbidity of cancer with somatic symptom disorder and/or illness anxiety disorder is still needed, extrapolations can be made with caution from existing research on hypochondriasis. One study investigated hypochondriasis in breast cancer survivors and found that 43% of those with clinical levels of FCR met the diagnostic criteria [30]. Clinically, FCR can manifest with persistent thoughts of physical symptoms and health anxiety. This can be exacerbated when the symptom is pain, a specifier of somatic symptom disorder. With regard to illness anxiety disorder, FCR can also manifest as health-related checking or avoidance that can result in excessive care seeking (e.g. requesting scans beyond what is clinically indicated) or care avoidance (e.g. repeatedly cancelling or no-showing appointments or failing to engage in requisite care to address symptoms and reduce actual risk of recurrence). Because changes in the diagnostic system have subsequently occurred, further investigation into whether similar patients would meet criteria for somatic symptom disorder or illness anxiety disorder is needed.

In summary, for purposes of diagnosis and treatment planning, the clinical presentation of FCR can range from an adaptive stance, to subclinical transient reactions, to disorders of stress, adjustment or anxiety. Although not studied, it is quite conceivable that one's history of anxiety may be very influential in how FCR manifests.

### Quality of life

Existing literature demonstrates a significant relationship between FCR and quality of life (QoL). Among breast cancer survivors, FCR positively correlated with distress and negatively correlated with well-being [32]. Additionally, Myers and colleagues [33] found a negative correlation between FCR with all areas of QoL (physical functioning, social functioning, role limitations, mental health, vitality, bodily pain and general health perception). Relative to worries about health, womanhood and death, worries about the impact that recurrence would have on one's roles had the strongest relationship with reduced QoL among those with breast cancer. There is also evidence that higher levels of FCR are related to poorer QoL among breast [15,34], prostate [34,35], testicular [26], colorectal [26], urogynecologic [26], lung [26], head and neck [36], pancreatic [37] and hematological cancer survivors [36].

### Risk factors

In the context of a disorder, one common risk factor for FCR includes a history of prior mental health problems. This includes a history of trauma and possible pre-

existing PTSD, GAD, as well as other anxiety disorders and mood disorders [26]. For example, among survivors of gynecologic cancer, anxiety, post-traumatic stress and functional and emotional well-being accounted for over 40% of variance in FCR [38]. Furthermore, personality characteristics, such as neuroticism [34], are related to greater degrees of FCR, while psychological variables including greater mental health QoL, self-esteem, healthy coping [26] and sense of coherence [39] are related to lower levels of FCR. In addition, Mellon and colleagues found that survivors and caregivers who derived less meaning from the cancer experience had higher levels of FCR [40].

Physical health variables are also related to FCR. Physical health QoL, fatigue, neurotoxic side effects, somatic complaints [26] and pain [41] are associated with increased report of FCR. Additionally, greater cancer severity is linked with greater levels of FCR among both cancer survivors [42] and their caregivers [34]. Lastly, positive margins [33] and receipt of chemotherapy [14,33] were identified as additional risk factors for FCR.

Various sociodemographic factors have been linked with FCR. For instance, younger age is a frequently reported risk factor for FCR among those with breast [32,34,40,42], colorectal [31,43], gynecologic [33], uterine and prostate cancers [40], although not among survivors of testicular cancer possibly because its limited age range of diagnosis [26]. Racial and ethnic background also appear to be relevant to level of FCR, for example, Janz and colleagues [44] found that low acculturated Latinas experienced the most worry about recurrence, followed by more acculturated Latinas, then Caucasians and lastly African-American women. Although not measured explicitly, the authors hypothesize that communication style, coping style and social support may account for cultural variability [44]. Overall, fears were 'low to moderate' in a study of African-American breast cancer survivors [16]. In a sample of survivors with varied cancer sites, survivors of color (5% African-American, 5% Latino, 4% Native American) perceived less risk of recurrence than white survivors; however, the vast majority of the sample (86%) identified as white [45]. There are mixed findings of education level as a risk factor, for example, Skaali et al. [26] found that testicular cancer survivors with education at the high school or lower level was associated with increased report of FCR; however, others have reported no connection between education level and FCR among breast [34], colorectal, uterine and prostate cancer survivors [40]. Other socioeconomic variables, including unemployment and financial difficulties, have been linked with FCR [26]. Lastly, findings suggest that women with fewer social supports are more likely to report greater FCR and that feeling understood by significant others helps patients monitor their thoughts about recurrence [33,44,46].

## Theories and formulations of fear of recurrence

There are a number of theories relevant to understanding FCR, including the self-regulation model of illness [47], self-regulatory executive functioning model [48], a family-based model [40], uncertainty in illness theory [49,50], social-cognitive processing theory [51] and terror management theory [52]. These theories have addressed FCR directly or represent novel applications of a theory to the FCR construct. The theories reviewed in the succeeding texts have several overlapping components (refer to Figure 1). First, there is a consensus that cues trigger FCR cognitive schemas. These cues can be internal (e.g. physical symptoms and side effects) or external (e.g. cancer-related media, medical follow-up, etc.). Second, these cues are interpreted through an appraisal process (e.g. pain may be interpreted as either a reminder of the cancer or a possible symptom of cancer recurrence) that can lead to more or less adaptive coping responses. Third, the appraisal and processing of FCR cues can be further influenced for better or for worse by the social environment. In an effort to provide a framework for researchers and clinicians, a review of the aforementioned theories follows.

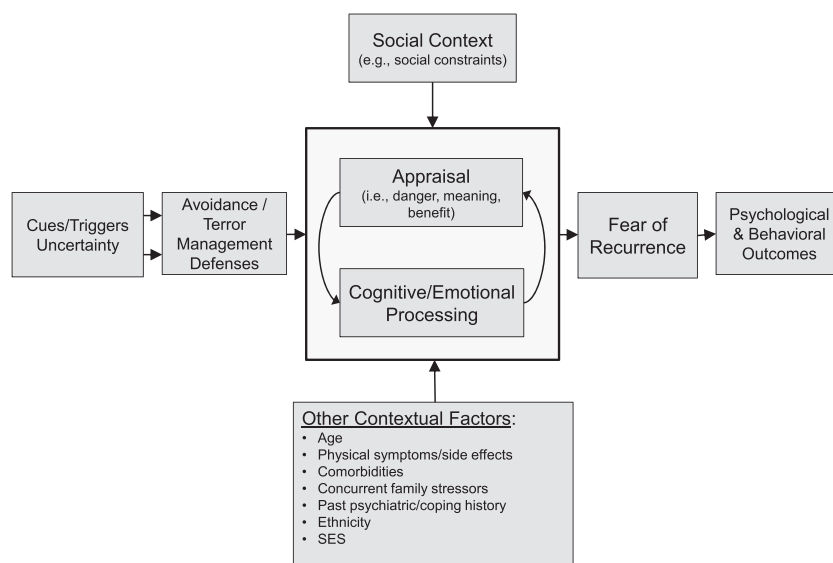
### Self-regulation model of illness

Lee-Jones et al. [47] suggest that FCR may be understood through Leventhal's common sense self-regulation model of illness [53]. As such, FCR varies based on one's illness representation where internal and external stimuli activate

cognitive responses associated with FCR. They also suggest that one's predispositions, past coping styles and family concerns could contribute to the degree of FCR. One unique contribution of this model is the focus on consequences of FCR. For instance, behavioral consequences include symptom checking (e.g. hypervigilance to symptoms and attribution of symptoms to cancer instead of a common cold or muscle strain), potential for overutilization of the medical system (e.g. requesting scans, emergency department visits) and limited future planning (e.g. not shopping for clothes or planning vacations). Psychological consequences include symptom misinterpretation, somatic hyperarousal and potential for onset of panic attacks. While research is needed, the authors propose that some patients may benefit from psychoeducation on recurrence rates and their interpretation. In addition, cognitive behavioral therapies may hold promise for addressing symptom checking and panic resulting from FCR.

### Self-regulatory executive functioning model

An alternative to the previously mentioned model is the self-regulatory executive functioning model (S-REF), which posits that anxiety disorders are 'caused, maintained and exacerbated by maladaptive information processing styles' [48]. The S-REF model is more process versus content oriented. According to S-REF, one may become more reactive and attentive to relevant information, and this may trigger intrusive thoughts followed by worry/rumination. Research currently supports the role



**Figure 1.** Proposed conceptual model of key components of FCR theories. Cues and triggers and uncertainty are often avoided or sometimes filtered through terror management defenses. Appraisal and processing of FCR cues not filtered out by defenses can be further influenced for better or for worse by the social environment and other contextual factors. FCR contributes to psychological and behavioral concerns (e.g. worry, post-traumatic stress disorder-like symptoms, panic attacks, hypervigilance/symptom checking, overutilization of medical system)

of maladaptive metacognitions, but not attentional biases in FCR among survivors of early stage breast and prostate cancer. Those with clinically significant FCR had greater positive beliefs about worry (e.g. worrying will help them be prepared for recurrence) and greater beliefs about the uncontrollability and danger of worry (e.g. worrying will cause the cancer to recur) than those with non-clinically significant FCR [48].

### Uncertainty in illness theory

Fear of cancer recurrence may also be understood in the context of uncertainty in illness theory, which suggests that cognitive processing allows one to construct meaning from an illness experience [50]. The theory was originally developed to address acute illness but later reconceptualized to address uncertainty of illnesses that are chronic or pose a risk for recurrence [49]. This is particularly relevant to an illness like cancer where there is no certain predictability about whether or not it will recur. Uncertainty in illness theory is another information-processing model that explains how illness-related stimuli are appraised, leading to responses that span the spectrum from post-traumatic stress responses to adaptation and meaning generation. Uncertainty, defined as the 'inability to determine the meaning of illness-related events' [49], when appraised from a mechanistic, linear and deterministic paradigm is more likely to lead to post-traumatic responses. In contrast, when appraised from a probabilistic paradigm, uncertainty is understood to be a natural condition of life and is more likely to lead to perceptions of opportunity and meaning. Consistent with this formulation, uncertainty of recurrence and the emergence of long-term physical treatment side effects are common among breast cancer survivors, and somatic symptoms (e.g. pain) and hearing of another's cancer are the two most common triggers of uncertainty [13]. As in the other theoretical models, social resources can influence the appraisal of uncertainty.

### Family-based model of fear of cancer recurrence

The family-based model of FCR [40], which draws on McCubbin and McCubbin's resiliency model [54], was developed to understand some of the risk factors that influence FCR in both survivors and their family caregivers. Research using this model identified that personal factors, such as a partner's younger age, other health problems, concurrent family stressors and appraisal of the meaning of cancer were influential on both survivor's and partner's experience of FCR [40]. There is some evidence that family caregivers report higher levels of FCR than survivors. Moreover, there appears to be a bidirectional relationship between survivors and family regarding coping with FCR. While there are some risk factors that are not alterable, this model suggests that stress management and

cognitive reappraisal of the meaning of cancer could be potential avenues for addressing FCR.

### Social-cognitive processing model

As highlighted in the aforementioned theories, there is a social component related to the processing of the illness experience. The social-cognitive processing model argues that the social environment can either enhance or inhibit cognitive processing of the cancer experience [51]. Social constraints are negative social responses to attempts to discuss the cancer experience. Whether overt (e.g. criticizing, directives to stop worrying) or covert (e.g. looking uncomfortable), they may lead to avoidance of thinking or talking about cancer, which, in turn, may inhibit cognitive processing and exacerbate emotional distress [55]. Cognitive processing, from the PTSD literature, refers to attempts to assimilate or accommodate a stressful or traumatic experience into mental models (also referred to as schemas) of self, others and the world [51]. Through this process, one may develop meaningful interpretations and emotional acceptance, which may alleviate trauma-related distress [51]. Cancer survivors commonly talk with members of their social network about their emotional reactions to cancer and other stressors [56]. When survivors report that they are not free to express themselves, because of social constraints, they often show signs of impaired adjustment and greater overall psychological distress. For example, women who perceived their friends and family as less receptive to discussing the breast cancer experience reported greater distress [55,57]. While the evidence demonstrating an inverse relationship between social constraints and psychological adjustment among cancer survivors is strong, there is little research to date looking at social constraints in the context of FCR. One recent study did find support for the social-cognitive model for FCR among gynecologic cancer survivors, for example, holding back (in terms of talking about cancer) was related to increased FCR and, in turn, increased cancer-specific stress [33]. Additionally, the social-cognitive processing model would appear to hold a great deal of promise given the relevance of PTSD for some patients presenting with FCR.

### Existential psychology/terror management theory

In *existential psychotherapy*, Irvin Yalom argued that awareness of certain "givens of existence" (p. 8), including the inevitability of death, produces significant anxiety, which, in turn, motivates the use of defense strategies to manage this anxiety [58]. Yalom and colleagues applied this clinical perspective to developing supportive interventions specifically tailored to people living with advanced cancer. *Experimental existential psychology* seeks to empirically evaluate the influence of existential factors on human behavior. One product of this line of research is terror management theory (TMT). Similar to Yalom's assertions, TMT

posits that the natural human instinct for self-preservation combined with a self-awareness of mortality creates the potential for debilitating levels of anxiety—that is, terror—that need to be managed or defended against in order to function. Over the last 30 years, TMT has empirically characterized the *proximal* and *distal defenses* people employ when reminded of our mortality [59]. Proximal defenses are implemented very shortly after a mortality salience to remove death thoughts from one's consciousness and include self-distraction, thought suppression and rationalizing. Distal defenses are implemented over time and incorporate a belief in a particular worldview that provides meaning and symbolic immortality to what could otherwise be perceived as meaningless and finite existence. In more recent years, TMT has been applied to health generally (i.e. the terror management health model; [60]) and to coping with cancer-related concerns specifically [61]. Going forward, TMT may offer a more informed framework for conceptualizing FCR triggers (referred to as mortality salience in TMT), healthy and unhealthy defenses and the sometimes unhelpful behavior observed from members of survivors' support networks.

### Managing fear of recurrence

To date, there has been limited investigation of psychosocial interventions for the management of FCR. However, FCR is a top concern among cancer survivors and warrants new research on evidence-based treatment. The theoretical perspectives and symptom presentation of FCR discussed in the preceding texts prompts consideration of the following modalities as potential treatment options to further evaluate.

#### Education

Several of the previously mentioned theories indicate that education on recurrence rates and their interpretation could be beneficial for managing FCR, and there is an education component to several of the interventions reviewed in the succeeding texts. Janz and colleagues [62] found that breast cancer survivors who reported receiving insufficient information about risk of recurrence or who believed they had a higher risk of recurrence, regardless of the accuracy of this belief, subsequently reported a decrease in emotional well-being over time. Therefore, educating patients about their individual risk of recurrence and studying tools available for helping women better understand their risk is warranted [62]. While education on recurrence risks will be most accurate coming from one's providers, technology and social media have led to an unprecedented level of access to information. Patients engage in a wide range of information seeking and participation in online forums and blogs, and there are more ways than ever to access and share information related to the cancer experience. While some

online tools and forums may decrease anxiety and fear, an abundance of information can be overwhelming, inaccurate or personally inapplicable for patients. To date, it is unknown how FCR is impacted by access to technology and social media; however, it is possible that particularly for patients who are prone to anxiety and worry, it could exacerbate FCR. In general, patients should rely on more verified sources of information, such as their providers and resources to which they are referred.

#### Cognitive behavioral therapies

When conceptualizing FCR in the context of anxiety disorders, it only follows that empirically supported treatment for anxiety, such as cognitive behavioral therapy (CBT), would be indicated. For example, where FCR resembles a trauma-related disorder, including PTSD, prolonged exposure therapy or cognitive processing therapy may be effective at reducing symptoms. Foa and Kozak propose that fear can be alleviated by first activating fear and then providing new information that is incompatible with the fear [63]. Prolonged exposure therapy focuses on repeated activation of trauma memories and confrontation of fear. Through this intervention, clients create and repeatedly work their way through a hierarchy of feared and avoided stimuli (an example of a fear hierarchy: hair loss, nausea, sharing bad news with family, fear of the dying process). Clients share a verbal account of their trauma memory and do so repeatedly with increasing detail of external and internal cues, and they listen to recordings of their account in between sessions to maintain the exposure. Cognitive processing therapy (CPT) is based on information processing model of PTSD, and it combines exposure therapy with cognitive therapy techniques aimed at challenging beliefs and meaning attributed to the trauma and the future (e.g. recurrence, death). To date, there are no studies exploring the benefits of prolonged exposure therapy or CPT for a PTSD-like presentation of FCR; however, considering the theoretical evidence supporting the role of cognitive processing and appraised meaning in FCR, these treatments hold promise.

For others where FCR presents as a salient worry within a GAD, CBT-based worry management therapy may be of value. This cognitive behavioral approach may include relaxation, cognitive reframing and imagery exposure. To date, there has been one case study looking at CBT for the treatment of FCR in the context of GAD. The authors documented a clinically significant reduction in FCR in a 60-year-old breast cancer survivor with a prior history of GAD, where FCR became the central worry [29]. Furthermore, coming from the self-regulation model of FCR, Lee Jones and colleagues [47] note cognitive behavioral therapies, including having patients note precipitants of their anxiety, challenging irrational thoughts and seeking support to manage anxiety, in addition to the use of exposure

therapy, could address compulsive symptom checking behaviors and panic if these present with FCR.

While the previously mentioned CBT approaches have not been extensively researched directly as treatments for FCR, several interventions with CBT components have or are being investigated. Uncertainty management—based on the uncertainty in illness model—consists of CBT and psychoeducation provided via telephone, audio tape and a self-help manual. The intervention includes building active emotion-focused coping responses to threats of recurrence and behavioral self-help materials to improve management of treatment side effects (refer to [64] for a more detailed description of the intervention). Treatment outcome data indicated that the uncertainty management intervention resulted in improvements in cognitive reframing, cancer knowledge, social support, knowledge of symptoms and side effects and coping skills when compared with a control condition involving usual care [64]. Women regularly used the intervention components to deal with triggers of breast cancer recurrence and long-term treatment side effects, and most women found the strategies very helpful [65].

Several other interventions are under investigation. Metacognitive therapy [66], based upon the self-regulatory executive function model, has been suggested as way to specifically address unhelpful metacognitions in persons with FCR [17]. The Conquer Fear intervention uses metacognitive and acceptance and commitment therapy components such as attentional training, detached mindfulness, value clarification, psychoeducation and relaxation training; however, outcomes have not yet been reported [67]. The BREATH intervention, a strength-based internet program that incorporates psychoeducation with CBT techniques to target emotional recovery and FCR, is currently being evaluated for efficacy with female breast cancer survivors from the Netherlands [68].

Beliefs about medicine and illness have been found to be related to FCR in some cancer survivors; therefore, interventions aimed at ‘changing maladaptive illness and medication beliefs that fuel the fear’ may be particularly useful in addressing FCR [69]. Additionally, addressing personal or culturally laden beliefs about illness and medication could be a key component infused with other approaches to enhance culturally informed interventions.

### Cognitive-existential therapies

As reviewed in the preceding texts, the family-based model of FCR and uncertainty in illness theory both suggest that appraising meaning in the cancer experience facilitates adaptive coping, and those who have not derived meaning may be at risk for FCR. These models suggest that cognitive reappraisal of the meaning of cancer could be potential avenues for addressing FCR. More broadly, existential and cognitive processing theories suggest that the disruption of world views caused by trauma

may lead to distress but that restructuring beliefs/life priorities and finding meaning may lead to the experience of positive change. Subjective appraisal plays a large role in adjustment to cancer; hence, the use of cognitive reframing techniques might assist in decreasing FCR and increasing post-traumatic growth [55]. Cognitive-existential group therapy aims to help patients grieve losses, use cognitive reframing, enhance problem solving and coping skills, increase hope and examine priorities for the future in a supportive environment [70]. Early sessions include patient narratives and grief work, which may be beneficial in a similar manner as cognitive processing therapy. Threat of death, FCR and living with uncertainty are included among other topics for group discussions [70]. A randomized controlled trial found a trend for reduction in anxious preoccupation, but a FCR-specific measure was not utilized [71]. Lebel and colleagues [72] created another cognitive-existential group treatment and found reductions in FCR, cancer-specific distress and uncertainty and improvements in QoL and coping among a small sample of breast and ovarian cancer survivors. These results were sustained at a 3-month follow-up assessment. This provides preliminary evidence for efficacy of cognitive-existential group treatment, and additional research including a randomized control trial is pending.

### Supportive therapies

The role of the social environment, including social constraints, is a key component of each of the theories reviewed in the preceding texts. In particular, social-cognitive processing theory argues that trauma survivors often have the innate ability to resolve their own PTSD-like symptoms so long as they have the opportunity to express themselves without social constraints. The logic seems to follow that cancer survivors would have the same ability to resolve their own FCR symptoms given the right social conditions. For instance, cancer survivors experiencing FCR who report high levels of social constraints stand to benefit from new emotional outlets. Supportive counseling, support groups and instruction on therapeutic writing can offer survivors’ opportunities for expression that take place outside their social network. Levine, Eckhardt and Targ [73] found that a 12-week unstructured psychoeducational support group (90 min each session) emphasizing coping, communication, body image, sexuality, grief, anger, anxiety management and problem solving led to significant decrease in PTSD including hyperarousal, re-experiencing and avoidance symptoms (refer to [74] for a description of the intervention). Second, couple therapy interventions (e.g. emotion-focused therapy for trauma [75]) can be tailored for survivors and their spouses/partners to help promote both healthy emotional expression and tolerance for discussing distressing topics. Finally, the group-based supportive-expressive therapy developed by Spiegel, Bloom and Yalom [76] originating



from the work Yalom's writings on group and existential therapies [58,77] may have an application for FCR. Although supportive-expressive therapy has been primarily studied in the context of metastatic breast cancer—where the focus on death is more explicit—the overarching focus on existential issues certainly is relevant for many cancer survivors experiencing FCR, where the ultimate fear, although not always explicitly stated, is often death and dying. In particular, the focus on processing difficult emotions and finding meaning in the context of a supportive group environment may prove beneficial.

### Mindfulness and acceptance and commitment therapies

The concept of mindfulness, originally developed within Buddhist belief systems, has been the focus of considerable medical and psychological research over the last two decades. Mindfulness is 'receptive attention to and awareness of present events and experience' [78]. The practice of mindfulness meditation has been associated with improved physical and psychological health outcomes [79]. Empirical evidence has been growing to support therapeutic modalities that explicitly utilize mindfulness concepts and techniques [i.e. mindfulness-based stress reduction (MBSR), mindfulness-based cognitive therapy and acceptance and commitment therapy (ACT)]. Specific to cancer, Lengacher and colleagues [79,80] reported that a randomized controlled trial of MBSR [81] in women with early stage breast cancer not only reduced participants' reports of depression and anxiety but also FCR in particular compared with participants in the usual care condition. Similarly, in another randomized controlled trial conducted with a heterogeneous sample of cancer survivors, MBSR led to a significant reduction post-traumatic avoidance and general stress symptoms, as well as an increase in positive states of mind [82]. Utilizing similar concepts and adding a movement therapy component decreased FCR and increased mindfulness attitude in a randomized, controlled pilot study of the Mindful Movement Program with breast cancer survivors [83]. ACT has not been studied exclusively with outcomes of FCR in cancer populations, although outcomes related to the use of its components are pending in the aforementioned Conquer Fear intervention [67]. Additionally, studies show it holds promise, as when compared with treatment as usual, women in an ACT treatment demonstrated greater improvements in mood and QoL in a sample of women with late-stage ovarian cancer [84]. Given these findings, translational research may look

to ACT as a suitable intervention for FCR. For cancer survivors experiencing clinically significant levels of FCR, providing instruction on mindfulness meditation to 'cultivate' trait mindfulness may represent an appropriate intervention in its own right or it could be implemented as an adjuvant approach designed to augment the effectiveness of other treatment modalities (e.g. CPT).

### Conclusions

While in its early stages, the existing research on FCR offers preliminary insight into its measurement, clinical presentation, risk factors and QoL impact. Furthermore, a number of theories are emerging to help guide clinicians in understanding and managing FCR in a clinical setting. However, understanding this important clinical concept is largely shaped by cross-sectional research on white, female, breast cancer survivors, indicating that there may be other facets of FCR yet to be articulated and examined. For example, one would imagine real differences in presentation and severity given that differences exist in cancer recurrence based upon sociodemographic characteristics such as gender. Using more robust measures on a more diverse patient population (with regard to demographics and disease) may allow for better understanding and subsequently the ability to better address the impact of FCR with patients in psychotherapy. In the absence of clearly defined, clinically significant levels of FCR, future qualitative research may aid in gathering subjective reports from patients, caregivers and providers about functional impairment and behavioral changes. Once consensus is built on what determines a clinically significant level of FCR, measurement, research and treatment may be improved. Furthermore, longitudinal research will allow the testing of mechanisms that drive or alleviate FCR. Cancer does impact not only the survivor but also loved ones and family, in some instances to a greater degree [40], hence having a larger effect on society and signaling the need for more research. There is limited research on the economic and healthcare system sequelae of FCR, although with some indication of increased healthcare utilization and reduced use of preventative screening, one can hypothesize that it would have a large impact. A body of intervention research to address the psychological comorbidities of cancer survivors already exists, but a more specific focus on FCR that may be central to distress and randomized control trials to demonstrate intervention efficacy are warranted.

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