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# Fear of Progression

Peter Herschbach and Andreas Dinkel

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## Abstract

Fear of progression (or fear of recurrence) is an appropriate, rational response to the real threat of cancer and cancer treatments. However, elevated levels of fear of progression can become dysfunctional, affecting well-being, quality of life, and social functioning. Research has shown that fear of progression is one of the most frequent distress symptoms of patients with cancer and with other chronic diseases. As a clear consensus concerning clinically relevant states of fear of progression is currently lacking, it is difficult to provide a valid estimate of the rate of cancer patients who clearly suffer from fear of progression. However, recent systematic reviews suggest that probably 50 % of cancer patients experience moderate to severe fear of progression. Furthermore, many patients express unmet needs in dealing with the fear of cancer spreading. These results underline the necessity to provide effective psychological treatments for clinical levels of fear of progression. A few psychosocial interventions for treating fear of progression have been developed so far. Our own, targeted intervention study showed that dysfunctional fear of progression can be effectively treated with a brief group therapy.

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P. Herschbach (✉)

Roman-Herzog-Krebszentrum (RHCCC), Klinikum rechts der Isar Technische Universität München, Trogerstraße 26, 81675 Munich, Germany  
e-mail: p.herschbach@lrz.tum.de

A. Dinkel

Klinik und Poliklinik für Psychosomatische Medizin und Psychotherapie, Klinikum rechts der Isar Technische Universität München, Langerstraße 3, 81675 Munich, Germany  
e-mail: a.dinkel@tum.de

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## 1 Introduction

There is sound evidence today that about 30 % of all cancer patients suffer from some form of mental disease (Mitchell et al. 2011; Singer et al. 2010; Vehling et al. 2012). The most prevalent diagnoses are depression, anxiety, and adjustment disorders.

These diagnoses are based on a thorough assessment of cancer patients, using some kind of structured clinical interview for diagnosing mental disorders. These measures are related to the current psychiatric classification systems, i.e., DSM or ICD, which were primarily developed for the assessment of (more or less) physically healthy patients with psychological problems. However, there are some limitations of the psychiatric model in medical illness, and the criteria of mental disorders might not generally apply to cancer patients. The psychological symptoms of cancer patients, and other medical patients, sometimes do not fit the usual descriptions and the criteria of common mental disorders. As Gurevich et al. (2002, p. 259) noticed, “the personal tragedy of serious medical illness is not necessarily captured within the bounds of psychiatric illness”.

In the field of psycho-oncology, one way to resolve this dilemma was to introduce the concept of distress. This is a broadly defined umbrella term that encompasses a wide range of psychological problems, ranging from severe psychopathological symptoms to mild forms of irritation. According to the US-American National Comprehensive Cancer Network Clinical Practice Guideline, distress is “a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, and emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis” (see NCCN

Guideline Distress Management 2013). Distress can be measured by self-report, which is one methodological advantage compared to the interviewer-based assessment of mental disorders.

There are plenty of studies that demonstrate the relevance and frequency of various distress symptoms. In our own work, we found that the fear of the cancer spreading was one of the most frequent and important problems of patients. In a sample of 1.721 patients with different cancer diagnoses, about one-third of the patients acknowledged that being afraid of disease progression was a serious or very serious problem to them. Indeed, this was the problem which received the highest severity rating of all problems that were listed in the distress questionnaire (Herschbach et al. 2004).

In the following, we will provide a description and definition of fear of disease progression; report on its prevalence, course, and correlates; and refer to the psychological treatment of clinical levels of fear or progression.

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## 2 Fear of Disease Progression

It is not unusual for physically ill patients to suffer from fears that are related to various aspects of the illness itself. We referred to these kinds of illness-related fears as *fear of progression* (FoP; Dankert et al. 2003).

FoP should be differentiated from the psychiatric concept of anxiety disorders. A central and common characteristic of neurotic anxiety disorders (such as generalized anxiety disorder, panic disorder, and agoraphobia) is that these problems are unreal or irrational. In the context of cancer, however, patients are confronted with real threats; their reactions are neither irrational nor inappropriate. Yet, patients can experience long lasting and exaggerated realistic fears that affect their well-being and quality of life.

Thus, we define FoP as patients' fear that the illness will progress with all its biopsychosocial consequences, or that it will recur. This is a reactive, non-neurotic fear response patients are fully aware of. The fear is based on the personal experience of a life-threatening or incapacitating illness. Like other anxieties, FoP is experienced in emotional, cognitive, behavioral, and physiological qualities. Basically, FoP is an appropriate response to the real threats of diagnosis, treatment, and course of illness. In our view, the level of FoP can range between functional and dysfunctional ends. Elevated levels of FoP that become dysfunctional, i.e., affecting coping, treatment adherence, quality of life, or social functioning, are in need for treatment.

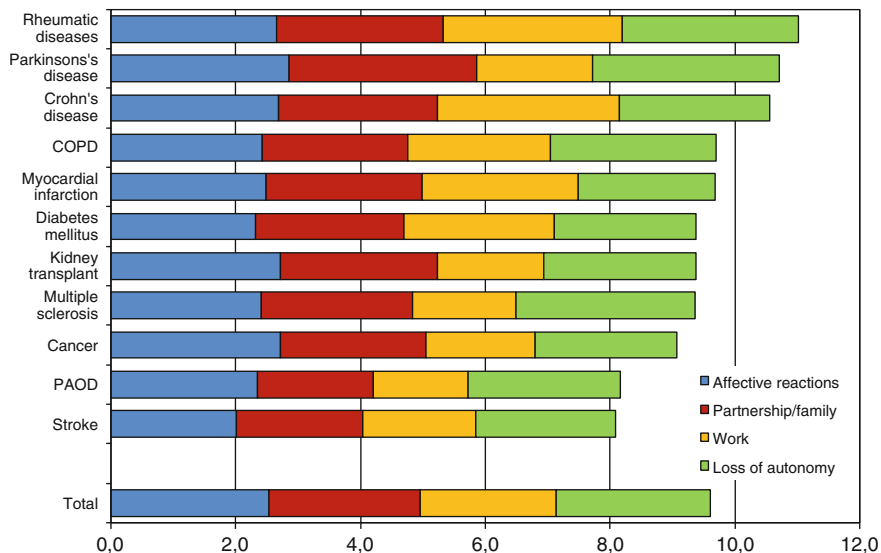
### 2.1 Excursion: Fear of Progression Versus Fear of Recurrence

The fear of chronically or severely ill patients about the illness getting worse is not a new phenomenon. It seems plausible that this kind of fear is inextricably linked with the experience of severe physical illness. However, it is only in recent years that this kind of fear received more systematic attention in research.

Northouse (1981) provided one of the earliest empirical accounts of cancer patients’ fear that the illness might recur. More than a decade later, Lee-Jones et al. (1997) summarized the available, still sparse literature on that topic, and developed a cognitive-behavioral model to explain the exacerbation and maintenance of recurrence fears in cancer patients.

These authors, as well as others, coined the term *fear of recurrence* when speaking of realistic, illness-related fears of cancer patients. So, is there any difference between the two concepts, *fear of progression* and *fear of recurrence*?—Basically, the two concepts are nearly identical.

Our own research on illness-related fears has not been restricted to cancer patients. As our early work revealed, FoP was evident in patients with cancer, rheumatoid arthritis, and diabetes mellitus (Dankert et al. 2003). Furthermore, we discovered that the content of patients’ illness-related fears was quite comparable across the studied diseases, with slight nuances concerning predominant fears within each disease group (Dankert et al. 2003). Thus, we conceptualized FoP as a generic concept. To be applicable across a wide range of chronic diseases, we used the term *fear of progression*. This label allows adequately including various diseases with a different disease course, e.g., constantly progressing or remitting-recurring. A further study with more than 800 patients who belonged to 11 disease groups confirmed that FoP is widespread across different diseases (see Fig. 1). Although the disease groups were not directly comparable, owing to differences in the composition of the samples, the results suggested that FoP is a serious concern in rheumatic diseases and some neurologic diseases, too (Berg et al. 2011).



**Fig. 1** Fear of progression in different diseases according to subscales and total score of the Fear of Progression Questionnaire (FoP-Q), adapted from Berg et al. (2011) Abbreviations: COPD—chronic obstructive pulmonary disease; PAOD—peripheral artery occlusive disease

The concept of *fear of recurrence* was mainly developed in the field of psychoncology. From early days on, it was mainly used to refer to cancer patients in remission, or disease-free cancer patients, who were worried about the cancer coming back (e.g., Northouse 1981). Today, fear of recurrence is defined as “the fear or worry that cancer will return, progress or metastasise” (Crist and Grunveld 2013, p. 978). Another frequently cited definition is usually traced back to the work of Vickberg (2003), although she did not provide this definition verbatim in her paper. It states that fear of recurrence is “the fear that cancer could return or progress in the same place or in another part of the body” (see Koch et al. 2013; Thewes et al. 2012a, b). It is obvious that despite the different labeling, the two constructs *fear of progression* and *fear of recurrence* share relevant defining features and are, basically, comparable. Therefore, we included studies using either one of these two concepts in the writing of this chapter.

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### 3 Assessment of Fear of Progression

As fear of progression has to be distinguished from anxiety disorders, traditional anxiety measures, such as the State-Trait Anxiety Inventory (STAI; Spielberger et al. 1983) or the Beck Anxiety Inventory (Beck and Steer 1993), cannot adequately measure FoP. During the past few years, several self-report measures have been developed that focus specifically on FoP. Recently, Thewes et al. (2012b) provided a systematic review on all current multi-item self-report questionnaires and subscales that assess FoP in cancer patients. They identified 20 multi-item assessment tools, 6 of which being subscales of more comprehensive instruments. Ten measures were classified into the group of brief instruments with 2–10 items. Most of these measures had only limited reliability and validity data available. The remaining four measures fell into the group of longer tools with more than 10 items. These latter measures were judged as reliable and valid. One of these longer self-report measures that had proven reliable and valid is the Fear of Progression Questionnaire (FoP-Q). Actually, the FoP-Q received the highest total quality rating of all instruments, together with the Concerns about Recurrence Scale by Vickberg (see Thewes et al. 2012b).

The FoP-Q is a multidimensional self-reporting questionnaire that was developed in our research group, using samples of patients who were suffering from cancer, rheumatic diseases, and diabetes mellitus (Herschbach et al. 2005). The questionnaire contains 43 items that are rated on a five-point scale, ranging from *never* to *very often*. The items relate to the five dimensions *affective reactions*, *partnership/family issues*, *occupation*, *loss of autonomy*, and *coping with anxiety*. The total score is calculated as the sum of the subscales’ mean scores, *excluding* the coping subscale. The questionnaire (total score) has high internal consistency (Cronbach’s  $\alpha = 0.95$ ), as well as high test–retest reliability over one week ( $r_{tt} = 0.94$ ) (Herschbach et al. 2005).

Apart from this full version, Mehnert et al. (2006) developed a unidimensional short form, using a sample of breast cancer patients. This abbreviated version, FoP-Q-SF, comprises 12 items pertaining to four of the five subscales (excluding coping). The short form showed adequate reliability ( $\alpha = 0.87$ ); correlational analyses with other psychosocial measures suggested validity. Furthermore, a version for partners of chronically ill patients has been developed and validated, recently, based on the 12-item short form (Zimmermann et al. 2011).

Moreover, the Fear of Progression Questionnaire was translated into two further languages. Shim et al. (2010) provided a Korean version of the full FoP-Q, based on research with a heterogeneous cancer sample. Kwakkenbos et al. (2012) adapted the short form and developed a Dutch version of the FoP-Q-SF, using a sample of patients with systemic sclerosis. Thus, the FoP-Q and the FoP-Q-SF proved to be applicable and useful measures of fear of progression, or fear of cancer recurrence.

Most researchers acknowledge that FoP is an adequate response to the suffering from cancer that, nonetheless, might become dysfunctional. Therefore, it would be highly desirable to identify patients who experience heightened, clinically relevant levels of FoP. However, to date none of the available self-report measures, including FoP-Q and FoP-Q-SF, provides a validated cut-off for the classification of dysfunctional FoP. One reason for this unsatisfying condition is the lack of established external criteria. To date, we do not have a well-established definition of a clinical state of dysfunctional FoP, analogous to the definition of common mental disorders. Consequently, there is no clinical interview to assess and diagnose dysfunctional FoP. Furthermore, it does not seem appropriate to use one of the common anxiety measures as a gold standard, and to conduct sensitivity and specificity analyses of FoP measures in order to establish a clinical cut-off score. Therefore, most researchers who need to define clinical FoP use cut-off scores that are based on statistical considerations, taking into account the distributional characteristics of the measure. Alternatively, cut-off scores are defined on the basis of theoretical considerations.

This shortcoming of the current state of research on FoP has far reaching consequences. As Thewes et al. (2012b) point out, the lack of diagnostic criteria limits comparison between studies, the development of specific interventions, the evaluation of the criterion validity of measures, as well as the development of screening tools indicative of clinical states of FoP.

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## 4 Frequency and Correlates of Fear of Progression

Research on FoP in cancer patients has grown rapidly during the recent years, and the research literature has accumulated. In fact, there are already three systematic reviews on different aspects of FoP in cancer (Crist and Grunveld 2013; Koch et al. 2013; Simard et al. 2013), which underlines the massive interest and efforts put on this topic. Most of this research was conducted with breast cancer patients.

For instance, only 2 of the 17 articles that were included in the systematic review by Koch et al. (2013) included patients who were not diagnosed with breast cancer. In the most comprehensive systematic review, so far, Simard et al. (2013) included 130 papers. The majority of the studies that they had reviewed focused on a specific cancer site, primarily breast cancer (42 studies). However, research also focused, among others, on patients with prostate cancer, ovarian, hematological, or colorectal cancer. Most of the research on FoP was conducted in the United States, but there are also several studies from the UK, Canada, or Germany (see Simard et al. 2013).

In the following, we will briefly refer to the main empirical results on prevalence and correlates of FoP.

## 4.1 Prevalence and Course

FoP is an appropriate, rational response to the diagnosis of cancer and its treatment. Accordingly, nearly all patients acknowledge feelings of FoP, ranging from very mild upset to severe worries. In Table 1, we present the responses of cancer patients to the items of the Fear of Progression Questionnaire-Short Form (FoP-Q-SF) in women with breast cancer and in a sample with mixed cancer diagnoses. The results show that the vast majority experiences fears and worries. Breast cancer patients, as well as patients with other diagnoses, stated that they are mainly bothered by thoughts about the cancer spreading, worries about severe medical treatments, worries about the next physical examination, and fear of pain.

As there is no clear consensus on clinically elevated FoP, different definitions were applied to define dysfunctional FoP. This limits the comparability of the available data concerning the prevalence of clinical levels of FoP. Prevalence was reported to amount to 47 % in women newly diagnosed with gynecological cancers (Myers et al. 2013), or 56 % in a sample of patients with first-ever cancer diagnosis (Savard and Ivers 2013). Dysfunctional FoP is also high in cancer survivors: 24 % (Mehnert et al. 2009) to 70 % (Thewes et al. 2012a) in breast cancer survivors, 35 % in head and neck cancer survivors (Ghazali et al. 2013), and 31 % in testicular cancer survivors (Skaali et al. 2009).

In their review, Simard et al. (2013) found that, across different cancer sites and assessment strategies, on average 49 % of cancer survivors reported moderate to high degree of FoP, and on average 7 % reported high degree.

Several researchers found that FoP is quite stable over time, with slight decreases in the first months after diagnosis (Savard and Ivers 2013) or during rehabilitation (Mehnert et al. 2013). Simard et al. (2013) report that of 22 longitudinal studies on the course of FoP, eight studies showed that FoP decreased after diagnosis or cancer treatment and then remained stable. The other studies reported no change, or even increase over time. Thus, these results clearly underscore that FoP is a constant companion of cancer patients.

**Table 1** Responses to the items of the Fear of Progression Questionnaire-Short Form (FoP-Q-SF) in two different samples; mean (*M*), standard deviation (*SD*), and percent of patients (% Positive) experiencing the item at least seldom (scoring at least 2 in the FoP-Q-SF item)

	Breast cancer patients; cancer registry ( <i>N</i> = 1.083) <sup>a</sup>			Mixed diagnoses; inpatient rehabilitation ( <i>N</i> = 482) <sup>b</sup>		
	<i>M</i>	<i>SD</i>	% Positive	<i>M</i>	<i>SD</i>	% Positive
I become anxious if I think my disease may progress	2.71	1.12	85.0	3.02	1.06	92.6
I am nervous prior to doctors' appointments or periodic examinations	3.28	1.34	86.9	3.22	1.06	91.1
I am afraid of pain	2.93	1.25	85.0	2.95	1.07	92.1
The thought that I might become less productive at my job disturbs me	2.14	1.39	49.1	2.10	1.31	51.2
When I am anxious, I have physical symptoms, e.g., rapid heartbeat, stomach ache	2.91	1.30	81.4	2.88	1.20	85.9
The possibility of my children contracting my disease disturbs me	2.81	1.54	67.0	2.86	1.42	85.2
It disturbs me that I may have to rely on strangers for activities of daily living	3.08	1.34	84.0	2.88	1.25	85.2
I am worried that at some point in time, because of my illness I will no longer be able to pursue my hobbies	2.38	1.22	69.0	2.46	1.18	75.4
I am afraid of severe medical treatments in the course of my illness	2.80	1.26	82.2	3.08	1.10	91.4
I worry that my medications could damage my body	2.83	1.31	79.7	2.86	1.19	85.0
I worry about what will become of my family if something should happen to me	2.88	1.31	81.0	3.01	1.33	82.0
The thought that I might not be able to work due to my illness disturbs me	2.09	1.32	50.4	2.20	1.24	59.0

*Note* Item wording of the FoP-Q-SF is taken from Herschbach et al. (2005)

<sup>a</sup>Mehnert et al. (2006)

<sup>b</sup>Herschbach (unpublished data)

## 4.2 Correlates and Consequences

Research has looked at many potential variables that might correlate and predict FoP. Among potential demographic characteristics, the strongest evidence is for younger age to predict FoP (Crist and Grunveld 2013; Koch et al. 2013; Simard et al. 2013). In contrast to many research results from the field of psychiatry which typically report an association between gender and distress, there is no clear evidence that women experience higher FoP. Similarly, the evidence concerning marital status and FoP is mixed (Crist and Grunveld 2013; Koch et al. 2013;



Simard et al. 2013). Some studies suggest that having children is associated with higher FoP (Mehnert et al. 2009, 2013), but there is also contrasting evidence (Thewes et al. 2012a).

Although some studies reported significant associations among cancer type, disease stage, and treatment-related factors, especially chemotherapy, and FoP, these variables did not predict FoP in most multivariate analyses (Simard et al. 2013). With regard to physical symptoms, there is strong evidence that more frequent or higher number of somatic symptoms are related to higher FoP (Koch et al. 2013; Simard et al. 2013). Thus, the evidence to date suggests that medical and treatment-related factors are of only minor relevance for patients' FoP, except for the presence of somatic complaints.

On the whole, mixed evidence exists for the influence of psychological factors (Koch et al. 2013; Simard et al. 2013). Some results suggest that FoP is higher among cancer patients with high neuroticism, or with low optimism, or with low social support (see Simard et al. 2013), but these results need further replication as they were investigated in only a few studies, so far.

FoP is significantly correlated with distress, depression, anxiety, and traumatic stress symptoms (Simard et al. 2013). These associations are moderately high, showing that FoP is distinct from more general distress or common psychopathological conceptions of emotional disorder.

With regard to the consequences of FoP, there is strong evidence that FoP is related to reduced quality of life and social functioning (Simard et al. 2013). Furthermore, there is some evidence that FoP is related to health care use and health behaviors after cancer diagnosis. Higher FoP was predictive of more unscheduled visits to the general practitioner (Thewes et al. 2012a) and visits to the emergency department (Lebel et al. 2013). Among breast cancer patients, higher FoP was associated with higher frequency of breast self-examination but, interestingly, a lower participation rate in formal medical surveillance, e.g., mammograms or ultrasound. The authors of this study suggest that this behavior pattern is consistent with a cognitive-behavioral model of general health anxiety which postulates that high anxiety is associated with both excessive threat monitoring and avoidance behaviors (Thewes et al. 2012a).

Taken together, despite many research efforts, our knowledge concerning the most potent and relevant predictors of FoP is still limited. The results show that FoP is common and long lasting, and that FoP has a negative impact on patients' lives. However, apart from two or three variables for which there is a quite consistent results pattern, there is mainly mixed evidence regarding the predictive relevance of demographic, illness/treatment-related, and psychological factors.

### **4.3 Couple and Family Perspective**

A very recent trend in research on FoP is the inclusion of partners and family caregivers. One study with relatives of cancer, rheumatoid arthritis, and migraine patients showed that 49 % of the relatives suffered from clinical levels of FoP

(Zimmermann et al. 2012). Studies that included cancer patients as well as their caregivers revealed that FoP was even higher among the family caregivers than in the patient group (Hodges and Humphris 2009; Mellon et al. 2007).

Furthermore, as might be expected, FoP is not only influenced by individual factors, but also by partner effects. One study showed that caregivers' FoP is higher if the patient is in poor physical health (Kim et al. 2012). Another investigation revealed an effect for age; survivors with younger caregivers, as well as caregivers with younger survivors experienced higher levels of FoP (Mellon et al. 2007). Furthermore, one longitudinal study showed that patients' FoP 3 months after diagnosis of head/neck cancer predicted caregivers' FoP at 6 months after diagnosis. No effects of family caregivers' FoP on patients' level were found (Hodges and Humphris 2009).

Thus, these results remind us that cancer is a family affair, and that it is fruitful to adopt a family perspective on FoP. Obviously, this research is only at the beginning, and more research that takes a dyadic, relational approach is needed. Notably, the fact that caregivers express levels of FoP higher than patients should motivate research to develop treatment approaches that also include or are specifically targeted at family caregivers.

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## **5 Psychological Treatment Approaches**

### **5.1 Clinical Relevance of Dysfunctional Fear of Progression**

Like other researchers, we conceptualize FoP as an adaptive response that can become dysfunctional. As already shown, the prevalence of FoP is rather high among newly diagnosed cancer patients and among cancer survivors. However, are there any empirical hints that justify the assumption that these are really clinically relevant states?

In our view, there is convincing evidence that FoP in cancer patients can reach levels that are in need of treatment. First, as stated above, FoP is often experienced as the most severe distress symptom (Herschbach et al. 2004). Second, FoP is among the most important concerns cancer patients would like to discuss during their consultation with their oncologist. Research with head and neck cancer patients showed that about 40 % of the patients indicated FoP as their main concern (Kanas et al. 2013; Rogers et al. 2009). Third, FoP is a main reason for the uptake of psychological treatment. As Salander (2010) reports, anxiety, and worries caused by the disease represented the leading cause for consulting a psychologist. Interestingly, one study showed that FoP was only seldom the main reason for visiting a general practitioner (Heins et al. 2013). Finally, research has shown that FoP is the most commonly identified unmet psychosocial need of cancer patients, during treatment as well as in the post-treatment phase (Ames et al. 2009; Harrison et al. 2009).

These results corroborate the necessity to identify patients who are suffering from dysfunctional FoP, and to develop and provide appropriate treatments for patients who are experiencing clinically relevant FoP. In the following, we will present, in some detail, a group-based treatment approach that was developed in our research group.

## 5.2 The Munich Approach

The psychotherapeutic treatment of realistic problems—such as FoP—does not have many predecessors in the professional literature (see Moorey 1996, for an exception). Usually, psychotherapeutic interventions are theoretically related to and developed for neurotic or psychosomatic disorders. Thus, it seemed inevitable to develop a special psychotherapeutic intervention for dysfunctional FoP in physically ill patients.

This new intervention was developed with the guideline that the intervention would be applicable in an inpatient rehabilitation setting. Therefore, it seemed most appropriate to design a brief group-based intervention. The group-based intervention is based on the principles of cognitive-behavioral psychotherapy (CBT). The main general characteristics of this intervention are directiveness and specificity, both aiming at confronting patients with their recurrence fears and supporting patients learning to cope with them. The goal was to learn to manage FoP, in order not to become overwhelmed in daily life. One further treatment goal was to strengthen patients' self-awareness regarding the elicitation and experience of fear. The treatment followed the well-established concepts of cognitive restructuring and worry exposure. Educational elements and homework assignments were also included.

Eventually, this approach comprised four sessions of group psychotherapy (Waadt et al. 2011). Each of the sessions lasted 90 min. The intervention was manualized with regard to structure and content; session topics and interventions were predefined. The session topics are self-awareness and self-assessment, fear exposure, and behavior change and problem-solving. Home-work assignments, diary keeping, and relaxation exercises were used as accompanying interventions.

In the beginning, patients are supported in identifying key personal triggers of FoP, and to describe their subjective experience of FoP. Patients are instructed to differentiate cognitive, behavioral, emotional, and physiological characteristics of their fear response. Patients are educated that experiencing FoP is an adequate response to the real threat of being ill, and that it is necessary to differentiate between functional aspects of FoP and dysfunctional fear levels. The actual cognitive exposure intervention is called “To-Think-the-Fear-to-an-End” (*Zu-Ende-Denken* in German). This intervention resembles the worry exposure, which is used in the treatment of generalized anxiety disorder (Hoyer et al. 2009). Patients are to choose a personally relevant situation that elicits high levels of FoP. In the next step, patients are asked to imagine this situation and to elaborate on all

aspects and possible consequences—a task that was usually avoided in daily life, before participation in the group psychotherapy. One such scenario might be loosing one’s hair during chemotherapy. An example of a therapeutic dialog with a female patient suffering from the fear of loosing her hair is presented in box 1.

**Box 1: Example of cognitive exposure of FoP**

Therapist: How will you notice that you start losing your hair?  
 Patient: I will find hair on my pillow... and in the basin, after hair combing.  
 Therapist: What will happen in the worst case, what do you think?  
 Patient: I will also lose my eyebrows.  
 Therapist: What will be the consequences in your every day life?  
 Patient: I will feel unfeminine. I will stay at home. I would not go out because people will see that I am a cancer patient. It will be embarrassing for my child, in school when others ask her about her mom.  
 Therapist: How would you like to react? What do you think would be a competent response, a response you feel well with?  
 Patient: I'd like to face my cancer, feeling confident, not to hide at home.  
 Therapist: How could you prepare for this situation?  
 Patient: I will cut my hair gradually beforehand...I will try wigs and headscarves... I will show myself only to good friends first.

It is assumed that confronting the patient with the possible consequences leads to an increase in perceived control and a reappraisal of the feared consequences. The consequences might get clearer, and the patient might develop helpful ways to deal with the feared consequences. Clearly, the real threat is a real threat is a real threat—however, the cognitive confrontation can demystify diffuse worries to some extent. This helps the patient to find strategies to cope with the actual threats of the disease.

At the end, patients are asked to think about personal changes in coping with FoP as well as changes they would like to implement in their daily lives. Patients are encouraged to choose specific goals that they would like to reach in the next 4 weeks after the end of the group intervention.

As mentioned initially, this group-based intervention was developed for use in inpatient rehabilitation (Waadt et al. 2011). This is a time-limited setting where patients receive multidisciplinary, multimodal therapeutic treatment. It seems reasonable to make necessary adaptations to the treatment protocol, depending on the specific circumstances. For instance, we developed a slightly modified protocol for use with cancer patients who are treated in our outpatient department. Here, we provide a six-session group therapy. We included an introductory session, and we added one more exposure session.

In routine clinical practice, it is essential to inform patients beforehand about the treatment rationale, as this kind of therapy is not suited for all cancer patients. There are patients who feel heavily burdened by clinically elevated FoP but who refrain to join this CBT-based group treatment. Typically, these patients cannot believe that they might tolerate the confrontation with their recurrence fears. These

patients will very likely drop out of the therapy if they are not adequately informed about the exposure-based treatment. Obviously, alternative treatments should be offered in this case.

### 5.2.1 Evaluation

This brief group-based psychotherapeutic treatment was evaluated in a (partially-) randomized controlled trial. As this treatment approach was conceptualized as a generic intervention, applicable to diverse populations, the trial included patients with cancer and patients with rheumatoid arthritis. In the following, we will briefly summarize the trial and the main results, with a special focus on the cancer patients (see Herschbach et al. 2010a, b).

#### *Study Design and Procedure*

This was a multicenter, longitudinal (partially-) randomized controlled study. Patients were sampled consecutively during the study, which was conducted in three rehabilitation clinics. Cancer patients were approached in two clinics, arthritis patients came from one clinic. In Germany, admission to inpatient rehabilitation is not necessarily a sign of exacerbation or dramatic worsening of symptoms. Many patients with acute or chronic illness get inpatient rehabilitation treatment in order to re-establish vocational capability, to prevent work disability, or to increase vocational and community participation.

To be eligible for the study, patients had to be at least 18 years old and had to suffer from dysfunctional FoP, i.e., they had to score above a predefined cut-off. The cut-off score for dysfunctional FoP was derived in a separate investigation, conducted before this intervention study, with  $N = 130$  arthritis and  $N = 150$  cancer inpatients. These patients filled in the short form FoP-Q-SF. In addition, they indicated whether they felt in need of treatment for FoP and would participate in a psychotherapeutic intervention (“yes”/“no”). As there were no external criteria to validate the cut-off score, we followed the conventional strategy of using the median score in a first step. Next, we stratified the sample according to their self-reported treatment need. Thirty-eight percent of the arthritis patients and 36 % of the cancer patients scored above the median and felt in need of treatment. About 10 % in both groups scored above the median and did not express a need for treatment, and about 30 % scored below the median but said they were in need of treatment. These results qualified the median score as a pragmatic cut-off for dysfunctional FoP. The consequence of this approach, which leads to a corresponding rate of treatment need in the two diagnostic groups, was the use of two different median scores. Thus, the predefined FoP-Q-SF cut-off scores for this intervention study were  $Md = 38$  for the arthritis patients and  $Md = 34$  for the cancer patients.

Patients were randomized into two interventions. Patients in both intervention groups received four sessions of group psychotherapy, each lasting 90 min. The intervention groups were specific to each diagnosis. Groups were designed for a maximum of 10 participants. Both group interventions were conducted as a manualized treatment. The CBT intervention was highly manualized with regard to

structure and content. Topics and interventions were predefined, as already described above. The second intervention was a supportive-experiential group intervention (SET). It was manualized with regard to structure, but less prescriptive regarding content. It was based on a client-centered concept and was characterized by nondirectiveness and unspecificity. This intervention aimed at facilitating the expression of personal experiences and emotions, it did not specifically focus on the management of FoP. In each session, the patients decided which topic they would like to discuss. They were supported in reflecting the issues they had selected with regard to FoP. Patients from both intervention groups received two booster phone calls 6 and 9 months after discharge from the clinic. The groups were led by psychotherapists who had at least 3 years of clinical experience and/or who had accomplished or were in the final phase of their therapeutic training.

Originally, the SET intervention was conceptualized as the control condition. However, to exclude that improvement in outcomes was related to overall improvement through the rehabilitation program, a treatment-as-usual control group was sampled after the completion of the intervention phase. These patients did not receive either of the two interventions for reducing FoP. The control group was sampled 1 year after the intervention phase in the same clinics; the same research staff conducted the recruitment using the same eligibility criteria.

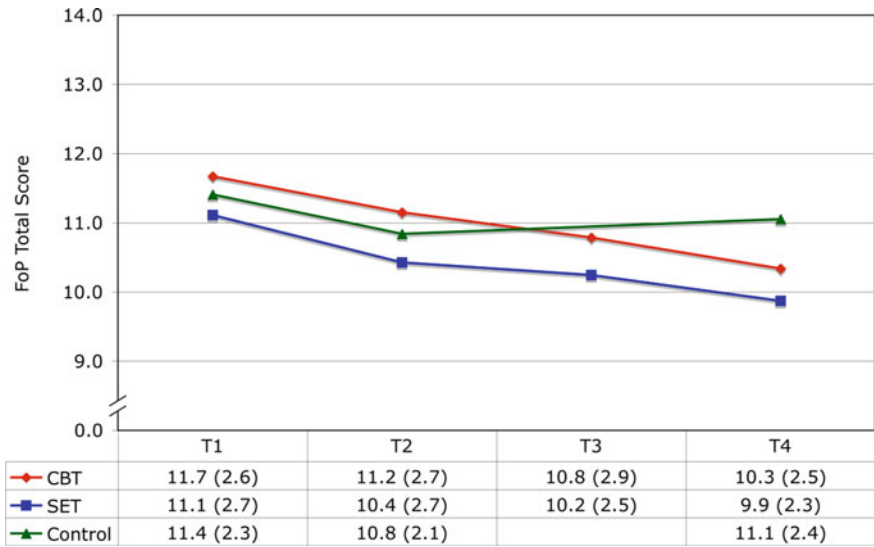
Of 457 cancer patients screened, 210 patients were eligible. Of those, 174 (82.8 %) agreed to participate and were assigned to one of the two interventions. In addition, 91 patients were recruited for the control group, resulting in a total sample of  $N = 265$  patients. Although patients were not randomly assigned to the control group, our procedure resulted in no relevant systematic differences between the intervention groups and the control group in the measured variables.

FoP was the primary outcome of the study and was assessed using the FoP- $Q$  (full version). Secondary outcomes were anxiety, depression, health-related quality of life, and life satisfaction. Patients from the intervention groups provided data on all outcome measures prior to the initial group therapy session (T1), shortly before discharge from the clinic (T2), 3 months (T3), and 12 months (T4) after discharge. Patients from the control condition only reported on T1, T2, and T4, and they only provided data on the primary outcome FoP.

## 5.2.2 Results

The mean age of the cancer patients was 53.7 years ( $SD = 10.2$ ), 83 % were women. Not surprisingly, breast cancer was the most frequent diagnosis (58.9 %). 13.1 % of the patients had metastases. The mean illness duration was 19.2 months ( $SD = 30.6$ ).

The results revealed that, compared with treatment-as-usual (TAU), both group therapies were effective in reducing dysfunctional FoP, but only among cancer patients. The effect size were 0.54 for the CBT intervention, 0.50 for the SET intervention, and 0.14 for the TAU group (Herschbach et al. 2010a). As is shown in Fig. 2, the FoP total score significantly declined from pre to post intervention, and continued to decline until 12 months after discharge. In contrast, FoP declined



**Fig. 2** Course of fear of progression in different intervention groups during 12 months; total score of the Fear of Progression Questionnaire (FoP-Q) (see Herschbach et al. 2010a) Abbreviations: CBT—cognitive-behavioral group therapy; SET—supportive-experiential group therapy

in the TAU group during inpatient stay, but had reached the initial level after 12 months. There was no effect of intervention type on any secondary outcome.

In a secondary analysis, we aimed to uncover treatment effects beyond the mere reduction of FoP at the group level and, thus, investigated the long-term response to group therapy using the Reliable Change Index (RCI) as response criterion. The results showed that 39.5 % of the cancer patients experienced reliable (though not necessarily clinically significant) improvement 12 months after group therapy. The rate of reliable improvement did not differ according to intervention type. Higher educational level emerged as a significant predictor of reliable change after 12 months (OR 2.53, 95 % CI 1.33–4.81;  $p = 0.005$ ) (Dinkel et al. 2012).

Furthermore, an economic cost-effectiveness evaluation with about 60 patients from the CBT and the SET group, respectively, revealed that group CBT, compared with SET, is cost-effective without the need for additional costs to payers (Sabariego et al. 2011).

In the light of our very brief four session treatment, the effect size as well as the proportion of over one-third of patients who showed a reliable improvement 12 months after the group interventions can be regarded as very promising.

One of the patients who had participated in the CBT intervention provided a vivid account of the helpful experience of this intervention: *“Through ‘Thinking-the-Fear-to-an-End’ I am not so fearful anymore, I became calmer...The exercise was a ‘transformation’. The greatest fear was that I would have to go to a nursing home if the cancer recurs. This is quite unlikely at the moment... However, in case*

*it recurs—I have registered at a nursing home... I do not like to go there but it is an option.”*

However, there was no difference in the effectiveness between our newly developed, highly structured CBT intervention, and the less directive SET intervention (except for the economic cost-effectiveness analysis). The reasons are unclear. Yet, there seems to be more than just one single way to reduce dysfunctional FoP in cancer patients.

### 5.3 Further Treatments

To date, our trial (Dinkel et al. 2012; Herschbach et al. 2010a, b) is the only one that investigated a psychotherapeutic treatment approach that specifically targeted dysfunctional FoP. Apart from this empirical study, there are conceptual publications and trial descriptions on specific interventions for elevated FoP. These protocols describe interventions that are primarily based upon a CBT framework (Butow et al. 2013; Humphris and Ozakinci 2008). Apart from that, there are a few interventions that did not specifically focus on elevated FoP but included it as a secondary outcome. For instance, Lengacher et al. (2009) investigated the effects of mindfulness-based stress reduction (MBSR) for breast cancer survivors. They found that a six-week MBSR program, compared to standard care, reduced FoP from pre to post intervention. However, results on the long-term effects are currently lacking.

Finally, it should be noted that there is one intervention study that focused on couples. This study investigated the effects of a couple-based skills program for women recently diagnosed with breast or gynecological cancer and their partners on FoP and other individual and dyadic outcomes. The effects of the couple-skills intervention were compared to couple cancer education. The results showed that the skills intervention was superior compared to the education intervention in reducing FoP, but only in the short-term. The effect was not maintained over the follow-up period of 16 months (Heinrichs et al. 2012). Thus, this research provides initial evidence for short-term effectiveness of a couple-based intervention in reducing FoP levels in women with cancer. Undoubtedly, as cancer and FoP are also a family affair, more research on the development and evaluation of dyadic and family interventions seems necessary.

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## 6 Conclusion

Many researchers and clinicians have realized that it is necessary and promising to pay special attention to cancer patients' fear of progression. The recent years witnessed a marked increase in research on fear of progression. Several assessment tools were developed, with some instruments reaching high quality ratings. Research revealed some relevant predictors, correlates and consequences of fear of



progression. A few psychosocial interventions for treating fear of progression were developed. Results on the efficacy of such interventions are sparse; some trials are under way, some research showed that dysfunctional fear of progression can be effectively treated, as we did show in our own intervention study.

So, what are the main future tasks in research on fear of progression in cancer patients? In our view, the priorities are first, to reach consensus on the definition and measurement of clinical levels of fear of progression; second, to better understand the relevance of illness-related and personal/social factors for dysfunctional fear of progression; and third, to develop, further elaborate and evaluate individual and family-oriented psychological treatments for clinical fear of progression. Accumulating knowledge on these topics should help to provide even better psychosocial care to our patients.

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