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FEAR OF PROGRESSION IN SELECTED CHRONIC DISEASES – A REVIEW OF STUDIES

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Summary. The aim of the review is to find the leading ways of addressing the issue of fear of progression. In order to avoid a rather fluent use of this term, due to the history of its creation, the necessary definitional distinction was used, according to the searched publications. The results show two main trends in the recognition of fear of progression in scientific research. The fear of progression construct is most often used in relation to cancer and sometimes omitted in the case of other chronic diseases. Expanding research on this issue is one of the conclusions and recommendations suggested in the discussions of publications included in the review, especially due to the practical implications of this knowledge for people working with the chronically ill and creating policy in health care.
Key words: chronic disease, psychooncology, fear of progression, multiple sclerosis

Introduction

Laskowska and Sanna (2018) define fear of disease progression as "patients' fear of a disease worsening or relapse after a period of improvement or resolution of symptoms" (p. 131). This type of fear includes concerns about the further course of the disease, such as the possibility of recurrence or metastasis, and the accompanying consequences. The term fear of progression (FoP) is sometimes used interchangeably with fear of recurrence (FoR), which originally referred to patients who

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had recovered from cancer but had concerns about recurrence. Fear of progression is a broader phenomenon in terms of definition and applies to various diseases – not only cancer. It is worth noting that this fear is considered characteristic of the remission stage. Due to the above definitional scope, the use of the terms FoR and FoP in the scientific literature has been somewhat separated. The review aims to analyze the ways in which fear of progression (FoP) is perceived in psychological research, to compare conclusions and research proposals found in the discussion of the results, and to identify the leading research methodology on this phenomenon. This review focuses on the issue of FoP as defined by Herschbach et al. (2005) and Laskowska and Sanna (2018), in selected chronic diseases. Articles containing the term fear of recurrence in the abstract and keywords were not analyzed due to the fact that FoR is a common psychosocial problem among cancer survivors, in this context also known as fear of cancer recurrence (FCR) and is relatively well researched.

Fear of progression – the emergence of the concept

Anxiety disorders are widespread among chronically physically ill patients. Most research on anxiety is based on psychiatric diagnostic and measurement categories. The criteria for individual anxiety disorders have been developed for the mentally ill and usually do not include people with chronic somatic diseases who are struggling with a real and continuous threat (whose reactions are not irrational). Moreover, psychosocial stress screening studies using somatic disease-specific questionnaires report that the patient's specific fear for life is the fear that the disease and its consequences will progress. This type of anxiety has been referred to by researchers as fear of progression (Herschbach et al., 2005). There is much empirical evidence that FoP is felt by a significant proportion of patients with chronic diseases. Thus, the fact that there is no systematic research in this area is astonishing. As the authors point out this may be due to terminological confusion, resulting in not distinguishing mental disorders, such as anxiety disorders, from specific fear of progression. Dankert et al. (2003) sought to answer questions about patients' main fears, the life circumstances in which they occur, and their triggers. They examined 65 people using interviews, the analysis of which showed that the leading fears of cancer patients are fear of death and unpredictability, while in patients with chronic arthritis the fear of dependence on someone else. Therefore, they developed the Fear of Progression Questionnaire (FoP-Q) and tested its psychometric properties in patients with cancer, diabetes and rheumatic diseases. (Herschbach et al., 2005). Finally, the scale includes five factors (Cronbach's *alpha* > .70), including: affective reactions (13 items), partnership/family (7), occupation (7), loss of autonomy (7) and coping with fear (9). The questionnaire is characterized by high internal consistency (Cronbach's *alpha* = .95) and high test-retest reliability within a week (*rtt* = .94). A study published a year later by Mehnert et al. (2006) aimed to validate a 12-item

abbreviated version of the Fear of progression questionnaire short form (FoP-Q-SF). 1,083 patients with breast cancer were recruited for the study from the database of the Hamburg Cancer Registry. Reliability estimates were high (Cronbach's *alpha* = .87) and the obtained correlations indicate that the short version of the questionnaire is a reliable and relevant tool that can be recommended for use in both research and clinical care.

Method

Advanced research using the Ebsco platform was carried out around two phrases: fear of progression and the name of the disease to which a given review step applies. For this reason, literature that did not contain the term fear of progression in the keywords and abstract and included something similar in content, e.g. fear of relapse, fear of disease, fear of pain, was not taken into account. This distinction narrows down the amount of available research material and indicates a certain definitional confusion around the above term. As a review by Sharpe et al. (2022) fear of progression, although it is a concept broader than FoR or FCR, has rarely been studied outside the context of cancer, although it also applies to non-cancer diseases. The review cited above aimed to find qualitative studies on FoP and to determine the relationship between FoP and anxiety, depression and quality of life in quantitative studies in chronic non-cancer diseases. In 25 qualitative studies, subjects reported concerns about disease progression and relapse, including, for example, death or being a burden to loved ones. In 11 quantitative analyses, FoP was moderately associated with quality of life and strongly associated with anxiety and depression. The researchers conclude that the data suggest that FoP in non-cancer diseases is similar to FCR and is an important construct related to suffering and there are far fewer reports on it. For this reason, the review of studies exclusively for FoP in non-cancer chronic diseases is an attempt to broaden the view on this construct, to highlight the small amount of research and to find gaps in this area of science worth filling with new research reports.

Results

The conducted review indicates two main tendencies to recognize the fear of progression in scientific research. The first of them, and at the same time the least used in the case of chronic diseases, is the recognition of FoP as the main research topic. This fact indicates a large disproportion in the number of such conceptualizations of FoP in chronic (non-cancer) diseases in relation to neoplastic diseases. The second tendency is to use FoP as one of several correlated variables that may be related to the "main" issue under study. In this case, it is treated in two ways: (1) as a construct not differentiated from other (non-specific) types of fear, and thus – poorly found in the literature under the term FoP, but very similar in content; (2) as a directly named

construct as defined by FoP. In order to present examples of the above division in a clear way they have been described separately in selected chronic diseases. The indicated ways of presenting FoP are shown in the diagram below.

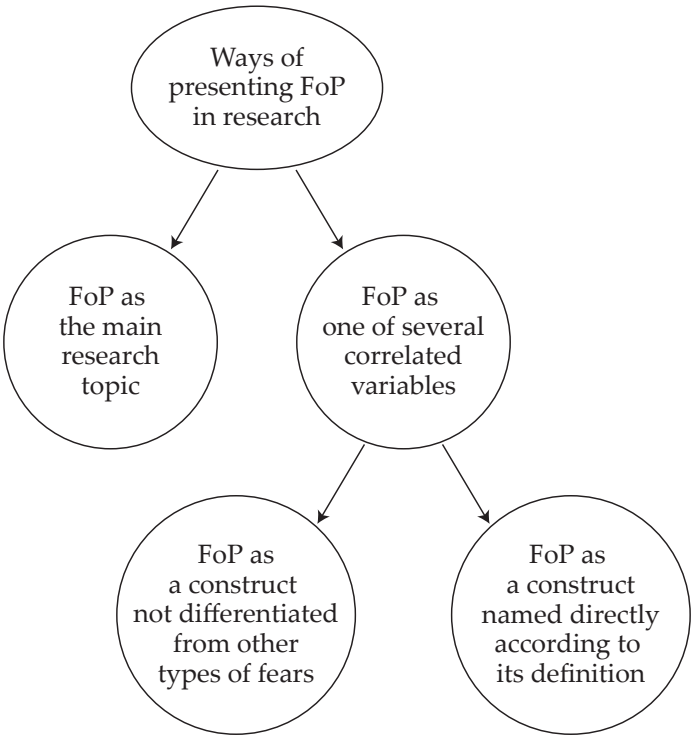

Figure 1. Scheme of presenting FoP in research
Source: own work.

Multiple sclerosis

People with MS struggle with the unpredictability of the disease both in the progression or exacerbation of symptoms and in the emotional, social, occupational and physical aspects of disease progression (Werfel, Durán, Trettin, 2016). Due to the above aspects they constitute a group of people for whom the examination of the fear of disease progression is invaluable. Nevertheless, the conducted review indicates a small – in relation to cancer – amount of research in this area. The publications cited below show the most common way of presenting FoP in scientific research, more as one of the variables correlated in the study than the "main" research problem. The study by Nielsen et al. (2022) belongs to the latter category of FoP, which aims to identify important aspects of wisdom and self-management

skills in dealing with fear of progression (FoP), which researchers have defined as a widely under-diagnosed real fear for life in response to uncertainty and as a significant risk factor for depression and anxiety in patients with multiple sclerosis. The results of the above studies show that fear of progression (FoP) is a common undiagnosed and untreated problem in MS and emotional regulation, self-observation and self-efficacy are key elements in coping with FoP. An earlier study by Nielsen et al. from 2018 showed no effect of gender, age and duration of the disease on the level of FoP. There were also no changes in the mean level of FoP-Q depending on the type of MS (relapsing-remitting, secondary progressive, primary progressive), which indicates that the development of FoP is independent of the type of MS and the duration of the disease. Analysis of the results showed moderate to high correlations between progression anxiety and depression, while hierarchical regression analysis predicting depression showed a model in which 70% of the depression variance was explained by various predictors, but the most important of them was the affective response (FoP-Q subscale), items concern fear of various areas of life, triggers and forms of expressing fear. A positive β coefficient indicates the frequent coexistence of anxiety and depressive patterns of response which suggests a close relationship between fear and depression and, importantly, shows that FoP is a significant predictor of depression. The inverse relationship suggests that the better the patient copes with this type of anxiety the less severe the depression. A study by Ghojazadeh et al. (2014) aimed to assess the impact of family support, quality of life and knowledge about multiple sclerosis on FoP in MS. Sixty-five patients with multiple sclerosis participated in the questionnaire study. The following were used: Multiple Sclerosis Knowledge Questionnaire (MSKQ), Progression Anxiety Questionnaire – short version (FoP-Q-SF), Beck Anxiety Inventory (BAI), Beck Depression Inventory (BDI), World Health Organization Quality of Life Questionnaire (WHQOL-BRIEF). Depression, anxiety, disease knowledge and three quality of life subcategories (environment, social relationships, and mental health) were highly correlated with fear of progression. Fear (BAI) was positively predictive of fear of progression (FoP-Q-SF), however knowledge about MS and mental health (WHQOL subscale) were inversely correlated with fear of progression ($p < .05$), meaning that knowledge about MS and lack of burden of mental disorders leveled FoP. As the researchers conclude, the obtained results can be used to manage and create policy in health care.

Rheumatoid arthritis

Rheumatoid arthritis (RA) is an autoimmune systemic connective tissue disease characterized by inflammation of the synovium of many symmetrical joints. This leads to irreversible damage to the tissues that form the joints. Due to the fact that it is a chronic and progressive disease it contributes to a significant reduction in functional capacity and deterioration of the quality of life, and in the absence of

treatment – disability. Successful therapy can lead to remission or low disease activity. In addition to the destruction and deformation of joints, damage to various internal organs may occur as a result of a chronic inflammatory process, which shortens the life of patients (Targońska-Stępniak, 2019). The publications quoted below refer thematically to the fear of progression, although not in a direct way. In order to show the gap in the use of the term fear of progression as the main research problem in RA, it is necessary to look at the ways of presenting this variable. Namely: as an indirect issue or too general to be able to conclude that it is a specific FoP. For example, to assess the main concerns and beliefs of people with RA and their impact on treatment outcomes Palominos et al. (2018) systematically reviewed the literature (articles published up to May 2017 describing patients' concerns and/or beliefs). Out of 474 publications, 84 were analyzed (number of patients with RA – 24,336. Concerns were reported in 38.4% of articles (N = 32/84), most of which were related to pharmacological therapy (50.0%, N = 16/32) and fear of disability (28.1%, N = 9/32). In the above review, the researchers divided the main types of fear found in 32 articles on fear in a very broad sense: fears related to pharmacological therapy (N = 16) and fear of future consequences of the disease and disability (N = 9), including fear of pregnancy and parenting, fear of falling, fear of exercise-related injury/fear of exercise that increases RA symptoms, fear of disturbing other people, fear of infection, fear of being judged negatively by others because of appearance (which were reported in 2–3% of articles). This review suggests that FoP is also one of the sub-types of fears that RA patients may experience. It was the second most frequently reported category in articles about fear. Due to the fact that mental distress is a common complication in RA, studies by Östlund et al. (2014) focused on emotions related to limitations in patients with early RA in a qualitative dimension. The described emotions have been categorized e.g. into sadness, fear, anger, shame. Examples of fear descriptions were found in relation to deteriorating health and fumble fear, which resulted in the individual withdrawing from activities motivated by distrust of their own body. As the researchers point out the emotions related to disability, and thus those closest to FoP, should be addressed both in clinical settings to optimize interdisciplinary interventions and in research to expand knowledge. Another way of perceiving fear of progression in a very broad context is the use of a fear variable in the study, measured on the basis of psychiatric criteria for anxiety disorders and not related to FOP. Isik et al. (2007) aimed to investigate the prevalence of fear and depression in RA. The study included 82 people with RA and 41 healthy controls. Psychiatric examinations of all subjects were performed according to DSM-IV criteria. Subsequently, the Hamilton Anxiety Scale or Hamilton Depression Scale was completed by people who were diagnosed with anxiety or depression. The overall incidence of anxiety, depression and mixed anxiety-depressive disorder was 70.8% in the RA group and 7.3% in the control group. 41.5% of people with RA were diagnosed with depression, 13.4% with anxiety and 15.9% with mixed

anxiety-depressive disorder. The duration of the illness was positively correlated with the degree of depression and negatively correlated with the degree of anxiety. According to the research suggestions the incidence of fear, and mainly depression, increases in people suffering from RA. This indicates a greater focus on depression as a more common factor, however, it was the level of fear of progression and not fear in general that turned out to be a significant predictor of depression among patients with multiple sclerosis. Research by Gossec et al. (2015) aimed to describe the most common fears and beliefs about the disease in patients, e.g. with RA. The questionnaire created by the researchers (25 items on fears and 19 on beliefs about illness) contained items to be scored from 0 to 10. 226 patients were analyzed, including 161 with RA. Of the 25 items, the 6 most frequently reported fears were: "fear of suffering again" (66.7% rated it as ≥ 7/10), "fear of losing control and autonomy" (61.4%), "fear of being a burden to relatives" (59.6%), "fear of losing all joint mobility" (58.9%), "fear of spreading the disease to other joints" (58.6%) and "fear of the consequences of my illness for my professional activities" (58.6%). Again, the disclosed "types" of fear also correspond to FoP in terms of content, but this is more a matter of randomness in similar nomenclature than a deliberate recognition of the fear of progression in RA as a research problem. Another situation of this type is illustrated by Kotsis et al. (2012), which did not distinguish FoP from other anxiety symptoms, but emphasized the importance of fear of the consequences of the disease ("concerns about the consequences of arthritis"; "patient anxiety"; "fears about bodily symptoms"). The aim of the study was to compare psychological stress in psoriatic arthritis (PsA) and rheumatoid arthritis (RA) and to check whether the relationship between psychological variables and health-related quality of life (HRQOL) was similar in the above forms of arthritis. The incidence of moderate and severe depressive symptoms (PHQ-9 score ≥ 10) was 25.1% in RA patients. Depressive symptoms and concerns about the consequences of arthritis were independent correlates of health-related quality of life. In the case of RA, the only study that included progression anxiety as the main research issue is the study by Khanbabaei et al. (2019). It aimed to assess the effectiveness of acceptance and commitment therapy (ACT) in terms of stress and fear of disease progression. They were conducted in 30 people with RA by purposeful sampling and randomly assigned in the experimental and control groups. The intervention included 8 half-hour sessions per week in the experimental group. The results indicate a significant difference between the two groups in the average severity of depression and stress levels. The fear scores, however, did not differ significantly between the two groups. Post hoc tests showed a significant difference between stress, depression and FoP, indicating the effect of ACT therapy on stress levels and on FoP in patients with rheumatoid arthritis. The above conclusion indicates a certain legitimacy of using ACT therapy to improve the quality of life of people with RA and – probably – with other chronic diseases in which the level of FoP makes it difficult for patients to function on a daily basis.

Table 1. Ways of addressing the issues of FoP in chronic diseases

	Author and year of publication	Title
FoP 1	1. Khanbabaeiu et al. 2019	The effectiveness of acceptance and commitment therapy (ACT) on the psychological distress and fear of disease progression in patients with rheumatoid arthritis.
FoP 2b	1. Nielsen et al. 2022	The role of wisdom and self-management skills for coping with fear of progression among patients with multiple sclerosis with moderate disability: Results from a cross-sectional study.
	2. Nielsen et al. 2018	Facing the Unknown: Fear of Progression Could Be a Relevant Psychological Risk Factor for Depressive Mood States among Patients with Multiple Sclerosis.
	3. Ghojazadeh et al. 2014	Fear of Disease Progression in Patients with Multiple Sclerosis: Associations of Anxiety, Depression, Quality of Life, Social Support and Knowledge.
FoP 2a	1. Palominos et al. 2018	Fears and beliefs of people living with rheumatoid arthritis: a systematic literature review.
	2. Gossec et al. 2015	The Most Frequent Fears and Beliefs of 226 Patients with Rheumatoid Arthritis or Spondyloarthritis, Using a Novel Questionnaire.
	3. Östlund et al. 2014	Emotions related to participation restrictions as experienced by patients with early rheumatoid arthritis: a qualitative interview study (the Swedish TIRA project).
	4. Kotsis et al. 2012	Anxiety and depressive symptoms and illness perceptions in psoriatic arthritis and associations with physical health-related quality of life.
	5. Isik et al. 2007	Anxiety and depression in patients with rheumatoid arthritis.

Discussion

The number of articles that may, according to the assumed criteria, be included in this review points to several problems related to the issue of fear of progression. The first of them is a certain ambiguity as to the use of this term and the content visible in some publications in which researchers refer to the fear of progression in an unconscious way – talking about certain features of fear in general, when their subjects are chronically ill people, at the same time classifying them as people with intense symptoms of anxiety or depression measured with tools such as the Hamilton Anxiety Scale. In this way, some of the cases that may indicate a specific type of fear, which is FoP, are not distinguished from general anxiety, which makes FoP difficult to grasp. The second problem worth discussing is the fact that there are only a small number of studies in the group of chronically ill patients, in which FoP is the main research issue, and not one of the variables correlated with another leading subject of research. The discussed issues indicating the shortage of research in non-cancerous chronic diseases are illustrated in the table below.

Since multiple sclerosis and rheumatoid arthritis are diseases with a long history of research it is all the more surprising that there are publications on research on FoP in Covid-19 (Ding et al., 2022) and no such articles in the case of such widespread and well-known chronic diseases for years. It is worth noting that FoP may be an important research topic in future experimental and quasi-experimental studies on the effectiveness of various therapeutic strategies. Herschbach et al. (2010) studied the effectiveness of brief psychotherapeutic group interventions in reducing the dysfunctional level of FoP. These interventions included either cognitive behavioral group therapy or supportive group therapy. Preliminary measurements showed that chronic arthritis patients had higher levels of FoP than cancer patients and the results revealed that, compared to the absence of specialized intervention, both group treatments were effective in reducing dysfunctional FoP, but only in cancer patients. As the researchers conclude dysfunctional FoP can be effectively treated with short group interventions and the applied interventions should focus on specific features of the disease. This reflection may suggest a certain direction of research, answering the question of what therapeutic interventions will be more effective for – in this case, patients with RA – or with another chronic disease, when we focus on the mentioned "specific features of the disease".

Measurement methods

FoP in the above-mentioned studies was assessed using the Fear of progression-questionnaire (FoP-Q) or its shortened 12-item version (FoP-Q-SF). It will not be surprising that quantitative research outweighs qualitative research in terms of numbers, however, it is interesting and worth considering the presence of a large number of publications in this area, as for qualitative research. Several of the studies

cited above answered the research questions based on the interview method, e.g. in order to distinguish several types of fears, some of which seemed to be equivalent to FoP in their content. For example, "fear of the consequences of the disease" as a separate type of anxiety examined qualitatively fits into part of the definition of fear of progression: "fears about the further course of the disease, such as the possibility of recurrence or metastasis and the accompanying consequences" (Laskowska, Sanna, 2018, p. 113).

Disease remission stage

The specificity of not only cancer but every disease is dynamism, which requires the patient to cope with a situation that is constantly changing, if only because of the progress in treatment, its side effects or the conditions and diagnostic capabilities of given hospital facilities (Wrona-Polańska, 1999). Effective treatment translates into remission of the disease which is considered its next stage. At this stage the person is still under the care of the clinic and performs regular check-ups. The longer the period of remission lasts the more intensively patients think about the future in the context of health and plan to live without disease (Pilarczyk, 2010). At this time a person begins to gradually return to life "before the disease", usually returns to the social roles he had previously performed, which – if only because of the need to help with everyday activities – were changed both in the family and in the professional environment. The patient may also experience Damocles syndrome, which is characterized by constant vigilance, recurring thoughts about the cancer and a persistent fear that the disease may return. This syndrome intensifies before control examinations (Zielazny, Zarzeczna-Baran, Wojtecka, 2013). The period of remission is therefore a time of dilemmas and possible contradictions: the joy of remission and the fear of recurrence. Kozaka (2015) describes the anxiety characteristic of the remission stage. Due to less frequent visits to the doctor patients are afraid of the loss of security they felt during treatment and feel anxiety due to the possible recurrence. They have a sense of losing the protection of treatment. As the author mentions the period of remission can also be a time when the level of hypochondria may increase and the level of vigilance and fear before the check-up visit may increase. As the above examples suggest remission is a complex time, however, in relation to the number of studies on people in the "active" phase of the disease – just after diagnosis, before/after surgery, it seems to be slightly neglected in terms of research, and patients experiencing remission are somehow left with their problems themselves as a group in which "nothing bad" happens anymore. None of the above-mentioned studies on FoP listed the stage of disease remission as a significant variable, and as follows from the definition of FoP, it is "patients' fear of worsening of the disease or its recurrence after a period of improvement or resolution of symptoms" (Laskowska, Sanna, 2018, p. 131), which suggests a certain logical inseparability of remission for FoP to be considered.

Summary and conclusions

1. Despite the terminological distinction between fear of recurrence and fear of progression scientific psychological research still uses the concept of fear of recurrence/progression in cancer and the lack of research in this area in other chronic diseases.
2. Fear of progression, in the case of research on chronically ill patients, is most often recognized as one of several variables correlated with others such as quality of life, and rarely constitutes the main research problem in itself.
3. FoP is most often measured using a questionnaire. Studying it in a qualitative way can broaden the knowledge about this construct. From the individual narratives of the respondents an image of FoP may emerge which we do not notice when they fill out the questionnaire. The information obtained by analyzing the content can be an application function of scientific research. Its example can be social benefits, such as; the creation of a new theoretical model that facilitates the development of therapeutic scenarios for the clinical level of FoP or their individual equivalents for given diseases, and expanding the knowledge of specialists working with patients.
4. Despite the fact that many chronic diseases have alternating stages of remissions and relapses the moment of remission as a complex psychological situation, in which many difficulties may arise, is not included in research as an important factor that receives attention.

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LĘK PRZED PROGRESJĄ W WYBRANYCH CHOROBACH PRZEWLEKŁYCH – PRZEGLĄD BADAŃ

Streszczenie. Celem przeglądu jest odnalezienie wiodących sposobów podejmowania problematyki lęku przed progresją. Aby uniknąć dosyć płynnego posługiwania się tym pojęciem ze względu na historię jego powstania, zastosowano konieczne rozróżnienie definicyjne, według którego poszukiwano publikacji. Wyniki przedstawiają dwie zasadnicze tendencje do ujmowania lęku przed progresją w badaniach naukowych. Konstrukt *fear of progression* jest używany najczęściej w stosunku do chorób nowotworowych, a niekiedy pomijany w przypadku innych chorób przewlekłych. Poszerzenie badań nad tym zagadnieniem jest jednym z wniosków i zaleceń sugerowanych w dyskusjach publikacji uwzględnionych w przeglądzie, zwłaszcza ze względu na implikacje praktyczne tej wiedzy dla osób pracujących z chorymi przewlekle oraz kreujących politykę w opiece zdrowotnej.
Słowa kluczowe: choroba przewlekła, psychoonkologia, lęk przed progresją, stwardnienie rozsiane

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