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Fear of progression in chronic diseases
Psychometric properties of the Fear of Progression Questionnaire

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Abstract

Objective: The aim of this study was the development and psychometric testing of a new psychological questionnaire to measure the fear of progression (FoP) in chronically ill patients (cancer, diabetes mellitus and rheumatic diseases). **Methods:** The Fear of Progression Questionnaire (FoP-Q) was developed in four phases: (1) generation of items (65 interviews); (2) reduction of items—the initial version of the questionnaire (87 items) was presented to 411 patients, to construct subscales and test the reliability; (3) testing the convergent and discriminative validity of the reduced test version (43 items) within a new sample (n=439); (4) translation—German to English. **Results:** The scale comprised five factors (Cronbach's $\alpha > .70$): affective reactions (13 items), partnership/family (7), occupation (7), loss of autonomy (7) and coping with anxiety (9). The test–retest reliability coefficients varied between .77 and .94. There was only a medium relationship to traditional anxiety scales. This is an indication of the independence of the FoP. Significant relationships between the FoP-Q and the patient's illness behaviour indicate discriminative validity. **Conclusions:** The FoP-Q is a new and unique questionnaire developed for the chronically ill. A major problem and source of stress for this patient group has been measuring both specifically and economically the FoP of an illness. The FoP-Q was designed to resolve this problem, fulfill this need and reduce this stress.

Keywords: Anxiety; Cancer; Chronic disease; Diabetes mellitus; Rheumatic diseases; Quality of life

Introduction

Anxiety disorders are widespread in patients with chronic physical diseases, such as diabetes mellitus, cancer and rheumatic diseases.

The prevalence rate of abnormal anxiety in cancer populations varies between 0.9% and 49% [1–5]. In studies which apply standardized psychiatric criteria, the range is narrower, from 10% to 30%. Anxiety is not only a problem within early stages of the disease, but also over longer time periods. In breast cancer, approximately 70% of survivors still feared the possibility that the disease might recur 5 years after the diagnosis [6].

According to the findings of Raspe [7], 31% of patients with chronic polyarthritis can be classified as anxious. Chandarana et al. [8] found in 21.4% an increased prevalence of anxiety. The European Research on Incapacitating Disease and Social Support study (EURIDISS; [9]) shows the close relationship between anxiety and fatigue. Soderlin et al. [10], Varni et al. [11] and Suurmeijer et al. [9] also point out the close relationship between anxiety and the ability to function physically.

Patients with diabetes mellitus showed a sixfold increase in the rate of generalized anxiety disorders in comparison to the average population [12]. A study by Lustman et al. [13]

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showed a lifetime prevalence of 41% for generalized anxiety disorders.

Most of the abovementioned findings are based on psychiatric diagnostic categories and measuring instruments. The psychiatric criteria for anxiety disorders (anxious adjustment disorder, generalized anxiety disorder, panic disorder, and phobic anxiety) have been developed for psychiatrically ill persons; they do not generally apply to the chronically physically ill. Such patients are confronted with a continual and real threat; their reactions are neither irrational nor inappropriate.

Studies with a different underlying concept, namely, psychosocial stress screenings with disease-specific questionnaires, come to the unanimous conclusion that one specific anxiety is absolutely central to the patient's life, the fear that the disease will progress with all its consequences, we have called it, fear of progression (FoP).

In previous studies, we have shown that this is true for cancer [14,15] and diabetes mellitus [16,17]. In a recently published study with 1721 cancer patients [15], we used the Questionnaire on Stress in Cancer Patients (QSC-R23), which is a specific cancer distress screening instrument. The sample was very heterogeneous and included different cancer diagnoses and tumor stages. A priority scale of 23 problems showed that the item "being afraid of disease progression" was rated at the top. For 32.2% of the patients this was a "big" or "very big problem".

We found similar results in patients with diabetes mellitus. The subscale "fear of future/depression" of the Questionnaire on Stress in Patients with Diabetes Mellitus (QSD; [16]), which is also a specific distress questionnaire, had the highest stress score, within a sample of 1930 individuals with insulin-dependent diabetes mellitus and non-insulin-dependent diabetes mellitus.

Clinical experience, as well as individual studies, indicate that FoP also plays an important role for rheumatic disease patients [18]. According to Raspe [7], approximately 50% of these patients suffer from fears relating to becoming handicapped or crippled.

There is compelling empirical evidence that FoP is prevalent in the majority of patients suffering from various chronic conditions. It is all the more astonishing that there is dearth of systematic research in this area. This applies to the lack of a conceptual framework that clearly differentiates between psychiatric disturbances, like anxiety disorders, and the specific FoP, which should be considered as an adequate response to an extraordinary life event.

To develop appropriate interventions to reduce FoP, methods that reliably assess patients' distress related to FoP are required. To date, there are no such instruments available to measure this unique aspect of anxiety [5,17,19,21]. Alone in the field of oncology, the Fear of Relapse/Recurrence Scale [20] and the concerns About Recurrence Scale [22] exist.

In the present study, we describe the development of the new Fear of Progression Questionnaire (FoP-Q), as well as its psychometric properties in patients with cancer, diabetes mellitus and rheumatic diseases.

Methods and patients

The development of the FoP-Q was carried out in the Federal Republic of Germany with German patients. The study included four phases: (1) interviews to generate items; (2) item reduction (using the initial version of the questionnaire), construction of subscales and testing for reliability; (3) validation (using the final version of the test) with a new sample; and (4) translation of the final version into English.

Interviews

Literature searches and 60-min interviews were carried out as part of the groundwork for generating items [23]. All interviews were documented in writing. A semistandardized guideline was used to structure the interviews. This guideline entailed awareness of FoP (including physical signals), trigger situations, domains of life affected, relationship to other aspects of stress and coping with anxiety.

The interviews were conducted by PhD level psychologists and physicians MD (male and female) with clinical experience in the relevant disease and with at least one additional psychotherapeutic qualification.

The total sample of 65 patients comprised 23 cancer patients (breast and colon cancer), 25 patients with inflammatory rheumatic diseases and 17 Types 1 and 2 diabetes mellitus patients. The mean age of the patients was 48 years (S.D.=12.6), 69% were female, 78% were married and 78% were employed. The patients were consecutively recruited from rehabilitation clinics (special clinics for recuperation/recovery after operative procedures or acute treatment), where they were also interviewed. They were given an oral and written explanation of the nature of the study and information on anonymity of the data and were informed that participation was voluntary. All patients gave informed written consent to participate in the study.

The initial interview process resulted in the generation of 1025 single-sentence statements. These statements were subsequently condensed into a list of 87 preliminary questionnaire items (for more detailed information of the interview, study see Ref. [23]).

Item analysis and psychometric testing

In the second phase of the study, 411 patients were tested using the initial version of the questionnaire ("reliability sample"). The aim was to reduce the number of items, construct subscales and test for reliability (Cronbach's α). The test–retest reliability was checked with a subsample.

The third developmental phase comprised the use of the condensed version of Phase 2 (43 items; cf. Appendix) in a