

Original Article

Psychological resilience and intolerance of uncertainty in coping with cystic fibrosis



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Received 4 August 2015; revised 22 October 2015; accepted 24 November 2015
Available online 10 December 2015

Abstract

Background: Anxiety and depression are lower than to be expected in a considerable portion of cystic fibrosis (CF) patients. This outcome might be a result of substantial resilience and/or tolerance of uncertainty in coping with adversity. Research into resilience in cystic fibrosis is in its infancy.

Methods: 57 adult CF patients participated in the study during their routine medical checkup. In addition to regular psychological assessment, the Intolerance of Uncertainty Scale (IUS) and the Resilience Scale (RS) were administered. The relative importance of IUS and RS in predicting quality of life in CF was explored. Bivariate correlations and predictive value of variables in multiple regressions on subscales of the Cystic Fibrosis Questionnaire-Revised (CFQ-R) were calculated.

Results: Remarkably, resilience (personal competence and acceptance) was clearly elevated, whereas intolerance of uncertainty was comparable to healthy reference groups. In multiple regressions, personal competence emerged as strongest resilience variable in the prediction of quality of life. **Conclusions:** CF patients in our study seem to be particularly resilient rather than cognitively avoidant. At this stage of research, fostering personal competence in CF patients is most promising in improving quality of life.

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Keywords: Cystic fibrosis; Quality of life; Psychological well-being; Resilience; Intolerance of uncertainty

1. Introduction

Survival rates in cystic fibrosis (CF) have increased considerably during the past decade [1] and increasing numbers of patients grow into adulthood and even old age [2]. However, regular checkups at specialized sites are required, and the complex daily care is demanding for patients and/or their caregivers [3]. Still, many CF patients seem to cope surprisingly well with this severe illness and report psychosocial functioning that is comparable to healthy controls [4,5]. Some studies found

ratings of quality of life to be independent of patients' objective medical parameters like lung function [6] which has been interpreted as possible result of denial, anxiety and need for control [5]. However, experiencing acute decline in lung capacity and functioning is threatening to all and has been found to reduce satisfaction with life [7].

In sum, CF patients have increased need for emotion regulation and might be experts in avoidance of negative aspects of their situation. Otherwise, their daily need to cope might result in a strong sense of resilience [8], the “bouncing back from adversity” which has been called the “ordinary magic” of many a stressful childhood [9]. It is the aim of the current study to shed some light on the relative importance of these processes in coping with CF.

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1.1. Intolerance of uncertainty (IU) in cystic fibrosis

The progression of CF is highly variable and partly dependent on processes that are out of the persons' control (e.g. type of mutation). Therefore, tolerance of feelings of uncertainty might be vital in effectively coping with the progression of the disease and other related problems of life. Intolerance of uncertainty (IU) "can be viewed as a dispositional characteristic that results from a set of negative beliefs about uncertainty and its implications ... individuals who are intolerant of uncertainty find uncertainty stressful and upsetting, believe that uncertainty is negative and should be avoided, and experience difficulties functioning in uncertainty-inducing situations" ([10], p. 216). The construct has been developed within the domain of generalized anxiety disorder (i.e. excessive worrying over daily hassles), but has also been associated with other anxiety disorders and depression [11]. Difficulties in tolerating uncertainty foster cognitive avoidance and ruminations and hinder acceptance and effective problem solving [12].

Research into IU and coping with disease is scant and limited to cancer populations [13]. To our knowledge, IU has not been investigated in the psychological adjustment to cystic fibrosis, although uncertainty (e.g. about illness progression and treatment) might be an important factor in this group. For example, in a study on unmet needs of patients for CF-specific information [14], 28% of participants wanted to know "ways to deal with unpredictability of the future", after "ways to deal with decreased energy" (32%) and "new CF therapies" (31%). However, currently available empirical results are equivocal to what extent anxiety and depression are a problem in this group. For example, the TIDES-study with 6088 adolescents and adults across nine countries [15] found a prevalence of anxiety and depression that is 2–3 times that of community samples, whereas the UK subsample of this group (2065 patients, [4]) found rates comparable to the general population. These results are intriguing indicating that studies into resilience in CF are clearly needed.

1.2. Resilience in cystic fibrosis

With unexpectedly low self-reported anxiety and depression, many CF patients seem to show psychological resilience which has been defined as "the capacity of a dynamic system to adapt successfully to disturbances that threaten system function, viability, or development" ([9], p.7). Concepts range from recovery after trauma to even enhanced psychobiological regulation of stress-related brain circuitry and neurotransmitters, they range from a moderating *process* between stress and trauma (e.g. resilient personality variables like optimism) to a positive *outcome* in coping with stress (see [16] for recent contributions on each topic).

Examples of personality variables that have been shown to contribute to resilience across diverse domains (including chronic disease) are low negative emotionality and high positive emotionality [17], self-efficacy beliefs [18], optimism [19] or acceptance [20] among others. The concept has also been expanded to encompass family resilience and community

resilience which is embedded in even larger systems (culture) that exert influence on the (re)construction of meaning in trauma and disease [21].

Direct investigation of "resilience" in CF is scarce. However, some studies have examined individual factors that might contribute to resilience. Sawicki et al. [22] found that feelings of personal control are positively associated with scores in quality of life (QoL). Another study [5] included "sense of coherence" (perceived meaningfulness and manageability of life) with positive correlations to social adjustment and life satisfaction. Abbott et al. [23] found positive associations between optimism and several domains in CFQ and negative associations for distraction. In a study by Goldbeck et al. [24] QoL was negatively related to rumination and positively related to seeking social support. Also, acceptance has been marked as a major topic in a review of qualitative studies [8]. An empirical study on illness acceptance and well-being in CF [25] found positive associations with role, emotional and social functioning and predicted less depressive symptoms 6 months later.

The present study explores associations of intolerance of uncertainty and resilience variables ("personal control" and "acceptance") with QoL in CF patients. We expect both IU and resilience to be elevated in comparison with healthy reference groups and to have independent (respective negative and positive) predictive value on QoL. The second aim is the investigation of the relationship between IU and the resilience variables and their relative importance in predicting QoL, i.e. patterns that might shed some light on processes in emotion regulation and coping with cystic fibrosis.

2. Methods

2.1. Instruments

The Cystic Fibrosis Questionnaire-Revised (CFQ-R; [26], German version [27]) consists of 49 items (with differing scales scoring from "1" to "4") that assess 12 domains of QoL (physical functioning, energy, emotions, social limitations, role limitations, embarrassment, body image, eating disturbance, treatment burden, respiratory symptoms, digestive symptoms, weight symptoms and health perception). Higher values indicate higher QoL and scores are standardized into a scale from 0 to 100 ($CFQoL = 100 \times S/N$ where S is the domain score and N is the maximum score). Internal consistency of the German subscales are acceptable with Cronbach's alphas $> .70$.

The Intolerance of Uncertainty Scale (IUS; [28], German version [29]) consists of 27 items (scores ranging from "1 = not at all representative" to "5 = completely representative", higher values indicate higher IU) with a heterogeneous factor structure that has been difficult to replicate. The German validation of the IUS ([28]) resulted in a 3-factor solution ("restricted action due to IU", sample item: "When it's time to act, uncertainty paralyzes me"; "stress due to IU", sample item: "Uncertainty keeps me from sleeping soundly"; "vigilance with IU", sample item: "I always want to know what the future has in store for me") with 18 items and acceptable psychometric properties (alpha between .80 and .90 for subscales and scale) that could

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