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Original Article

Stigma and optimism in adolescents and young adults with cystic fibrosis☆

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Abstract

Background: Despite increased life expectancy among patients with cystic fibrosis (CF), few studies have examined coping among adolescents and young adults with CF. Previous research suggests that stigma associated with chronic disease is related to worse physical and psychological health, but optimism may be protective. This study examined stigma and optimism among patients with CF.
Methods: Seventy-two patients with CF (ages 14 to 25) completed a self-report questionnaire assessing stigma, distress, CF-specific quality of life (QoL), and optimism. Objective health data were recorded from patient medical records.
Results: Greater stigma was associated with lower pulmonary function, QoL, and optimism. Stigma was positively correlated with distress. Optimism moderated the relationship between stigma and anxiety ($p < 0.001$), and between stigma and emotional functioning ($p < 0.01$).
Conclusions: Stigma is related to worse lung function and psychological health in patients with CF, but higher levels of optimism may act as a protective factor.

Keywords: Cystic fibrosis; Stigma; Optimism; Quality of life; Coping

Cystic fibrosis (CF) is characterized by both visible and concealable physical symptoms, a burdensome and time-intensive treatment regimen, and a shortened life expectancy. However, medical advances over the past six decades have led to improved quality of life (QoL) and increased life expectancy, with estimates approaching 50 years or more for those born with CF in 2000 or later [1]. As a result, CF has evolved from being viewed as a terminal childhood disease to a childhood-onset, chronic condition. However, relatively little is known about how individuals cope with the disease during adolescence or early adulthood. Thus, it is important to clarify psychological factors that may influence adaptation to CF during adolescence and early adulthood. Of particular interest in the context of adolescent development is the degree to which stigma associated with CF may have a negative influence on patient outcomes and whether a dispositional trait such as optimism may act as a buffer in the process of coping with CF.

Health-related stigma is a social process in which the experience or anticipation of negative social judgment based on a health condition results in social rejection, blame, or devaluation [2]. Conditions leading to stigma include physical deformities, showing any physical signs of illness, and belonging to a social group that results in a "spoiled identity" or undesirable reputation

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[3]. Additionally, factors such as the course of the condition over time and the extent to which the characteristic disrupts social interactions may influence stigma [4]. Previous research in other medical conditions has consistently found that stigma is related to increased psychological distress, worse health-related QoL, and lower self-esteem [5–7]. Although the relationship between stigma and physical health in medical populations has received little attention, psychosocial stress has been associated with poor physical health outcomes in a number of studies [8–10]. Stigma may be a particularly relevant form of psychosocial stress during adolescence and early adulthood when sense of identity is developed, greater independence from parental figures is negotiated, and social comparisons increasingly influence the establishment and maintenance of social relationships.

According to classic definitions of stigmatizing illness [3,4], CF may be stigmatizing due to visible symptoms (e.g., coughing, stunted or delayed growth, and taking medications with meals), a shortened life expectancy, risk for increased comorbidities and illness severity with increased age, having a genetic abnormality, and the potential for treatments and symptoms to disrupt normal functioning or activity. Qualitative data suggest that patients with CF may feel different from their peers as a result of the daily time requirements for treatments, which often occur throughout the day [11]. Consequently, patients may experience increased social anxiety in social settings [11] or choose to be noncompliant with their treatments in order to feel similar to their peers [12,13]. Some patients with CF may choose to conceal their diagnosis from others by attempting to minimize symptoms or hide medication usage [14]. Despite the relevance of stigma in the context of CF, no quantitative studies of stigma have been conducted to date among patients with CF.

Prior studies of adult medical patients have found that the dispositional trait of optimism may buffer illness-associated stress [15] because optimism is a personality trait characterized by a general expectation of favorable outcomes [16]. Past studies suggest that greater optimism may be associated with better QoL and less distress among patients with CF. Optimism appears to be negatively correlated with psychopathology and positively correlated with QoL, but unrelated to disease severity [17]. In addition, a coping style characterized by optimistic acceptance has been associated with better QoL, especially psychosocial aspects of QoL [18]. Among children and adolescents with CF, optimism has been negatively related to internalizing symptoms (e.g., depression), independent of pulmonary function [19]. No prior study has evaluated the relationship of optimism and stigma among patients with CF.

The primary aim of this study was to evaluate the relationship of stigma to psychological and physical health in adolescents and young adults with CF (ages 14 to 25). Specifically, it was hypothesized that stigma would be related to increased symptoms of depression and anxiety, poorer CF-specific QoL, lower optimism, and worse physical health as measured by indicators of illness severity (e.g., pulmonary function, body mass index (BMI), hospitalizations during the prior six months, number of medications, and comorbid conditions). A second aim of this study was to evaluate optimism as a moderator of the relationship of stigma to psychological distress (e.g., depression, anxiety), CF-specific QoL, and illness severity (i.e., pulmonary function). It was hypothesized that stigma would be associated with lower psychological distress, better QoL, and better pulmonary function in the context of higher optimism. In the context of lower optimism, stigma was expected to be related to more psychological distress, worse QoL, and poorer pulmonary function.

1. Methods

1.1. Participants

Participants were recruited between July 2010 and March 2011 from a large pediatric and adult CF center in the Midwest. Male and female outpatients were eligible for participation if they were between the ages of 14 and 25, had a physician's diagnosis of CF, and had the capacity to give informed consent, or assent if under 18 years of age. Informed consent was obtained from a parent or legal guardian if the patient was under the age of 18.

Recruitment occurred by directly soliciting patients with CF during their regularly scheduled clinic visits. If interested, the patient (and parent or legal guardian if under 18) reviewed and signed the consent form, which granted access to their clinic medical records. Participants then completed a questionnaire packet during the clinic visit or online at a later time. The questionnaire packet required approximately 30 min to complete. The online format was provided as a convenience to encourage study participation and prevent the participants from feeling obligated to complete the questionnaires during the clinic visit. Follow-up calls were made, as needed, to remind participants about completing the online questionnaires. Participants received a $5 gift card for completing the assessment. This study was approved by the hospital Institutional Review Board.

1.2. Measures

Medical/health data were collected from patient medical records including BMI, hospitalizations during the prior six months, number of current medications, number of co-morbid medical diagnoses, and pulmonary function testing (PFT) results. Due to the relatively low number of hospitalizations, these data were coded as a dichotomous variable (yes or no for hospitalization in the prior six months). Comorbid diagnoses were identified by chart review and a summary score was calculated reflecting all additional medical diagnoses (excluding psychiatric diagnoses). Pulmonary function was measured with the percent predicted of forced expiratory volume in the first second (FEV_1), measured during PFT at the clinic visit.

Self-report questionnaires assessed demographic and background information, as well as the following measures of stigma, psychological well-being (depression, anxiety, and optimism), and CF-specific QoL:

1.2.1. Stigma

Perceived and enacted stigma were measured with Fife and Wright's [5] Social Impact Scale (SIS). This 24-item self-report scale was developed to assess the impact of stigma among