

Gender differences in treatment adherence among youth with cystic fibrosis: Development of a new questionnaire

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Abstract

Background: Some prior studies have reported that girls with cystic fibrosis (CF) experience higher morbidity and mortality compared to boys. In this study, the authors compared boys' and girls' perceptions of disease-related strains and resources associated with living with CF, and the relationship of these factors to CF treatment feelings and behaviors.

Methods: All 10–21 year olds with CF at the Minnesota Cystic Fibrosis Center were invited by mail to complete a new self-report survey (Living with CF Questionnaire — LCFQ). Of these 177 youth, 58% (49 boys and 54 girls) returned surveys.

Results: Exploratory and confirmatory factor analyses revealed nine factors in the LCFQ. Partial support was found for hypothesized gender differences in these factors. Compared to boys, girls reported significantly more illness-related strains and worries, including emotional strains, greater treatment discouragement, lower self-esteem, and lower adherence to some aspects of the CF treatment regimen (coughing, eating high-fat foods, taking meds/pills).

Conclusions: Living with CF appears to have a greater emotional impact on adolescent girls compared to boys. These gender differences may contribute to the poorer pulmonary function observed among girls with cystic fibrosis during the adolescent years.

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Keywords: Cystic fibrosis; Gender differences; Treatment adherence; Emotional impact

1. Introduction

Cystic fibrosis (CF) is the most common inherited life-shortening, multisystemic disease among Caucasians. The majority of affected patients develop chronic lung disease characterized by airway obstruction and bronchial mucus plugging, which leads to recurrent infections and declining pulmonary function over time. Most patients also experience severe destruction of the exocrine pancreas, which produces malabsorption and malnutrition. Improvements in nutritional and pulmonary therapies and treatment at specialized treatment centers have resulted in increased life expectancy;

the predicted median age of survival in 2005 was 36.5 years in the U.S. compared to 14 years in 1969 [1,2]. However, these improved therapies require regular, lifelong adherence to a complex routine in order to be effective. A typical treatment regimen includes daily chest physiotherapy, a variety of inhaled medications, oral doses of antibiotics and pancreatic enzyme supplements, regular aerobic physical activity, as well as following a high-calorie/high-fat diet.

Most of the morbidity and mortality associated with CF is due to pulmonary complications. Persistent airway inflammation, chronic infection and inspissation of secretions leads to an irreversible and progressive obstructive process [3]. Both male and female patients develop this progressive decline in pulmonary function; however, the age of onset tends to occur at the ages of 12–14 years for girls and 19–20 years for

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boys [4,5]. The relative risk for survival is significantly lower for females compared to males for all ages from 2 to 20 years; and this gender gap does not narrow over time [2]. The reasons for these gender-based differences in outcomes have been perplexing issues that have yet to be fully explained. It is clear that nutritional status, airway microbiology, and pulmonary function are strong predictors of later mortality, although reports of gender differences in these factors have been inconsistent [4–6].

Behavioral explanations related to gender differences in treatment adherence, which in turn affects nutritional status and pulmonary function, and differences in desired and received support from family and friends may be factors associated with this gender gap. Based on our review of the literature and conversations with health care providers in a specialized CF treatment center, we postulate the following behaviors as possibly associated with increased morbidity among girls:

1.1. Inadequate fat and calorie intake

Studies of treatment adherence have shown that girls are less likely to adhere to a high fat, high calorie diet compared to boys [7,8]. Girls are more likely than boys to engage in dieting behaviors in response to the cultural unacceptability of female obesity [9], which may be related to the tendency of some girls with CF to embody the feminine cultural norm of thinness as an indicator of attractiveness [10]. Girls with CF are actually more likely to perceive their smaller stature as positive and have higher body satisfaction than girls without CF [9].

1.2. Suppression of coughs

Coughing aids in removing mucus, thereby being an important mechanism to facilitate the clearance of abnormal secretions. Youth with CF may be self-conscious about the impact of their coughing on others, and some may resort to suppressing it as a way to avoid negative attention. Cough suppression may be more characteristic of girls, who generally pay more attention to socially acceptable behaviors and fitting in with peers. Compared to boys, adolescent girls have greater public self-consciousness, which is largely attributable to the greater attention they pay to social relationships, including how others view them [11]. Coughing is less likely to fit girls' notions of "feminine;" whereas, boys generally are encouraged to cough and spit during intense sports participation and therefore, may not experience the same social discomfort [10].

1.3. Failure to take prescribed medications and enzymes regularly

Girls are more likely than boys to have periods of denial regarding their disease during which they discontinue important components of their treatment regimen, such as

skipping medications and enzymes [10]. Here again, because they are more aware of how others perceive them, girls may feel self-conscious about standing out as different during a developmental period when they want to fit in and be like their peers [11,12].

1.4. Reduction in physical activity

It is normative for healthy adolescent girls to decrease their levels of physical activity at puberty [13–15], and this gender difference is evident in girls with CF as well [16]. Although there has been increased athletic involvement among girls in the last two decades, the societal images of femininity still do not generally encourage physical activity or exertion for girls and may contribute to girls' decline in physical activity at puberty [10,17]. Boys with CF, on the other hand, are more likely to engage in sports and exercise as central to the cultural masculine identity and as an unconscious way to deny the presence of any limitation in their life due to CF [17]. The decline in physical activity for girls with CF may also be related to malnutrition [16]. Inadequate energy intake causes impaired muscular function, and impaired muscular function, including respiratory muscle, leads to a reduction in physical activity. Girls with CF have a poorer pattern of weight gain than males even before puberty [1].

1.5. Skipping chest physiotherapy

This has been reported as the most disliked component of treatment and associated with the poorest adherence [18]. Miller et al. [17] suggest that gender differences in treatment adherence may be related to girls' greater passivity and acceptance of life circumstances, which translates into a sense of powerlessness and lower expectations of self.

In contrast, the cultural masculine identity encourages boys to take control of their lives and to be more action-oriented.

1.6. Quality of social relationship patterns

It is also expected that parents and others may socialize and respond to boys and girls with CF differently. Given the small stature that is associated with CF, it is plausible that adults (and perhaps peers) may perceive girls with CF as weak and fragile, and not capable of vigorous physical activity. Girls may be subtly discouraged to participate, or at least not encouraged. In contrast, males with CF, even though small in stature and size relative to their peers, may strive to increase their body mass as a way to defy their illness and preserve their masculine identity [10,17]; and they may be encouraged by adults to participate in strenuous sports activities, as a way to compensate for their physical differences. Family support and functioning patterns, as well as a family's reaction to the illness, have been shown to affect CF treatment adherence [19–21]. It is possible that there are gender differences in how parents and others respond to the care and support needs of

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