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Psycho-Social Aspects in Children with Cystic Fibrosis

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Abstract

Cystic fibrosis (CF) is a multisystemic genetic disorder affecting 1:2500 newborns. Its prognosis has changed in the last two decades with increasing life expectancy. Nevertheless, this disease can impact the psychosocial development. Children with CF and their caregivers may experience different significant stressors that can lead to poor adaptation, increase depressive and anxious symptoms and decreased quality of life. Psycho-social interventions are concerned with adherence to treatment, emotional and social adaptation and health-related quality of life. Although the life expectancy increased, it is important to assure a better quality of life. The authors present the psychiatric and the psychosocial aspects of CF found at children with cystic fibrosis and their caregivers. They conclude that precocious identification and effective treatment of depressive and anxious symptoms could improve the patient's daily functioning and the disease management.

Keywords: children; cystic fibrosis, psycho-social aspects, resilience, genetic disease, social interventions, stigma.

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Introduction

Cystic fibrosis (CF) – an autosomal recessive disorder, is the most common life-shortening genetic disease of Caucasian population. The disease affects mostly the lungs, but also the pancreas, liver, kidneys and intestine. The feature of the disorder and their severity varies among affected individuals. The management of CF requires a daily, time-consuming treatment regimen that includes antibiotics, nebulizers, chest physiotherapy, pancreatic enzyme replacement therapy, nutritional therapy and the therapy of complications. Therefore, cystic fibrosis can interfere or impair daily life activities and social interactions. Advances in medical treatment have prolonged the life of patients with CF. Dealing with chronic illness and societal pressure can lead to stress, anxiety and depression that have direct and indirect consequences for health outcomes. Barbero remembers that "people with CF are people first and not a disease" (Barbero, 1994). The disease affects personal relationships, health status, body image, self-esteem and vocational certainty.

Although actual treatment has considerably improved the survival of patients with CF, the relevant psycho-social aspects have still been insufficiently considered. Due to the importance of identifying and treating the psychological and psychiatric symptoms and of the consequences for long-term health outcomes, we propose to present the impact of these psychological symptoms on health outcomes, such as pulmonary exacerbations, nutritional status and on the quality of life.

Impact of CF on the patient

Chronic illness, in particular CF, influences the children in all stages of development. In the first 2 years of life the parent-child relationship is very important for the developing of the infant and the quality of attachment predicts child psychosocial factors like behavioral and emotional regulations, social skills and the ability to cope with stress management. Children between 3-5 years of age continue their psychosocial development, the understanding of the disease is improved, but don't understand the idea of death. Children between 5-9 years of age recognize death, but regard it as a person (Teicher, 1969). They don't understand why they must take tablets and nebulized drugs and make physiotherapy and their siblings or friends not. For patients between 9-12 years of age peer acceptance is an important problem, the flatulence, tiredness and complex treatment being obstacles to conformance to the peer group (De Wet & Cywes, 1984). Young peoples can experience difficulties with learning due to school absenteeism and extended periods of hospitalization.

Adolescence is a critical and tumultuous period enough without having a serious disease. Adolescents experience many physical, cognitive, mental, emotional and psychosocial changes. The health issues experienced by adolescents with chronic diseases are linked to the illness they suffer from, to adolescence in general and to psycho-social problems generated by the interaction between the disease, the adolescent and his immediate environment (Sawyer S., 2012; Cojocaru & Popa, 2013). Adolescents with CF not only have to deal with the normal changes expected, but also have to deal with the transition of assuming responsibility for their care from the parents and transitioning their care from a pediatric to an adult care team. Moreover, many of these young adults have to deal with the impact of the progressive deterioration of their disease. During consultations, adolescents frequently ask "why do I have CF and not my sister or my brother?" The presence of a complex chronic disease can complicate adolescence by affecting pubertal status and stature. In adolescence, majority of patients with CF report a dissatisfaction with their body due to the excessive thinness, slightly protruding abdomen, mild clubbing of the fingertips and to the delayed secondary sexual characteristics (De Wet & Cywes, 1984; Teicher, 1969, Whiters, 2012) and the interface between bio-psychological development and disease make this period challenging for the adolescent with CF. Visible signs of illness and of treatment such as scars, physical "bumps" from indwelling intravenous access and take of the medication in front of peers can create significant physical differences for children with CF. During adolescence, relationships between both same and opposite sex peers come closer. Adolescents with CF report that they have fewer friends and develop fewer relationships with persons of the opposite sex. Related to this, most patients feel isolation and non-acceptance by the peer group that could determine depression, anxiety and additional distress. Different symptoms like flatulence, steatorrhoea and coughing are very distressing and isolate adolescents (Whiters, 2012).

Presence of pulmonary exacerbations and of diabetes can adversely affect quality of life of patients with CF. Respiratory infections are a danger, making school a hazard. Pulmonary disease remains the most common cause of morbidity and mortality in CF. The thick and viscous secretions provide an opportunistic environment for the colonization of bacterial infections. Patients with CF are susceptible to lower respiratory infections with very aggressive germs like *P.aeruginosa, H. Influenzae, S.aureus, Str. pyogenes*. Once infection is established, eradication is in many cases impossible and progressive lung disease often aggravates morbidity and mortality risk (West, 2002). Pathogens the most frequently involved in community acquired pneumonia are resistant to many antibiotics (almost 20 % of cases), and by consequence, the treatment need to be done with at least two antibiotics (in up to 80% of cases) or it could be initially inadequate (Torres *et al.*, 2014).

In recent studies, CF is considered as a risk factor for multidrug resistant strains. Frequent cures of antibiotics for pulmonary infections are followed by adverse effects such as digestive troubles which impact the quality of life. Chronic infection with transmissible *P. aeruginosa* strains confers a worse quality of life in CF patients. Compared to patients with chronic infection, acquisition of sporadic *P. aeruginosa* may not significantly impact on the psychological wellbeing of the patient (Ashish *et al.*, 2012). Prevention of cross-infection with transmissible strains is essential to ensure better physical and psychological outcomes for patients with CF. For this reason and due to the bacterial resistance of the organisms it is not recommended that patients with CF to come into contact with other individuals with CF. Both patients and caregivers report a negative emotional impact of not socializing with other patients and feelings of alienation created by segregation. The isolation leads to a lack of peer support and potential social isolation (Goldbeck, Fidika, Herle, & Quittner, 2014). Britto *et al.* (2002) observed that the increasing number of pulmonary exacerbations in the previous 6 months and the decreasing time since the last exacerbations have a detrimental effect on QOL. Infections increase health care costs which include laboratory exams for the detection of microbial pathogens, broad spectrum antibiotics and frequent hospitalizations. An effective way to prevent pulmonary infections is the vaccination of children with CF. A recent study demonstrated the sustained declines in hospitalizations for childhood pneumonia during the decade after the introduction of pneumococcal vaccine. Furthermore, substantial reductions in hospitalizations for pneumonia among adults were observed. Vaccination of children has a great impact on unvaccinated persons regarding the frequency of hospitalizations, the decline in the length of stay, the stability of in-hospital rates of death from pneumonia and antibiotic consumption (Griffin, Zhu, Moore, Whitney & Grijalva, 2014).

Cystic fibrosis related diabetes (CFRD) is distinct from type 1 and type 2 diabetes, but has features of both. CFRD occurs in approximately 20% of adolescents with CF and the additional diagnosis of CFRD has a negative impact on pulmonary function and survival in CF. CFRD can also have psychological impact on children and their caregivers. The need for more demanding treatment and different restrictions may have a heavy blow and an additional burden to the patient with CF (Tolbert, 2003). Many patients with CFRD feel over-burdened by the extra-health responsibilities. Successful management requires support from a multi-disciplinary team with the necessary specialist knowledge and skills. Close liaison between the CF team and the diabetes team is essential. Good communication between diabetes and CF care providers is essential because poor team communication and inadequate information from health care providers have been identified as significant sources of stress for patients with CFRD. The treatment team should address psychosocial issues and recognize the risk of depression (Moran *et al.*, 2010). The CF treatment is complex and includes use of antibiotics

and nebulizers, enzyme replacement therapy, physiotherapy and nutritional therapy. Many children with CF, especially adolescents refuse to take enzymes while eating with friends. Frequently, the conflict between child and parent regarding adherence to treatment can have negative impact on the emotional health of both (Kamper, 2012). The adolescents and their parents considere that the three most common barriers to treatment adherence are lack of time, forgetfulness and unwillingness to take medication in public (Cohen-Cymberknoh, Shoseyov, & Kerem, 2011). Poor adherence is also associated with higher heathcare costs and wasted resources.

Adolescence is in the same time a period of experimentation and this may include: new hair colors, body piercing, styles of dress, drug use, alcohol use (13% drink more than recommended amounts), smoking (46% had tried smoking, 3% smoke regularly) and sexual activity (40% engaged in unprotected sex) (Bryon, Havermans, & Noordhoek, 2012). Many teens with CF have said they use alcohol or drugs to self medicate due to depression and anxiety and to seek a temporary relief from the challenges of the disease (Sandu *et al.*, 2013). Depression also contributes to self-harm, namely "cutting," as well as eating disorders. In teenage girls the desire to be thin can lead to non-adherence with pancreatic enzyme therapy and ignoring of dietary advice. The physical and emotional impact of this experimentation can sometimes be much harder for teens with CF. Adolescents present an increased awareness of the future and of death. The morbidity and mortality factors pose cognitive, emotional, and behavioral challenges for many children with CF and their families (Ernst, Johnson, & Stark, 2011). Barbero (1994) has identified different obstacles that make difficult for the individual with CF to adapt and accept the illness. One of them is vocational planning. Though some chronic illness is associated with an increased risk of suicide, the studies of teenagers with CF reported that the prevalence of suicide is not common (Whiters, 2012). In the opinion of Pakhale S. *et al.* (2014) stigma has been demonstrated to have a significant impact on health outcomes and quality of life and could be associated with lower adherence to the treatment (Hutuleac, 2013). Transition of the patients from a pediatric CF centre to an adult CF centre is accompanied by physical, mental and social changes temporarily disrupting the normal life and requiring a period of adjustment (De Vries, 2012). The transition of the CF patients from adolescence to adulthood is more difficult because they have to gain medical independence and to face the reality that there is no radical medical treatment. The transfer of the patients can also generate anxiety and many of them refuse to move from the pediatric centre (Pfeffer, Pfeffer, & Hodson, 2003, Whiters, 2012). With advancing life the patients' self-esteem declines, the frustration and emotional disturbance increased and the compliance decreased.

Drust *et al.* (2001) studied the psychosocial impact of lung transplantation and they observed that the common emotional responses included manageable fear/anxiety of lung rejection and uncertainty of the future, impatience with disruptions

of daily routines caused by post-transplant medical management and its effect on the attainment of set goals, and frustration with parental over-protectiveness. In patients with chronic diseases, inclusively in CF, anxiety and depression have been shown to have direct and indirect consequences for health outcomes: less compliance with medical and dietary regimens, frequent cancel or miss clinic appointments, increased health care utilization, higher health care costs, worse quality of life (QOL) (DiMatteo, Lepper, & Croghan, 2000; Katon & Chiekanowski, 2002; Whiters, 2012). Patients who are depressed are three times more likely to be nonadherent than those who are not depressed. They are less likely to follow dietary regimens and are also more likely to engage in risky behaviors (smoking, drinking). Furthermore, children whose mothers exhibited depressive symptoms are more likely to use the emergency department. (Cruz, Marciel, Quittner, & Schechter, 2009). The barriers to treatment adherence include inadequate knowledge, forgetting, rebellion, less parental supervision or forcing to comply with treatment by the parents, a wish to conform to peers, difficulties with time management and disagreeing with the physician (Pfeffer, *et al.*, 2003; Whiters, 2012).

Several mechanisms have been suggested for the link between depression and poor adherence: (1) depressive symptoms may have an effect on self-care behaviors, such as diet, exercise, and disease management, because it is associated with decreased energy and motivation to perform complex tasks; (2) depression is associated with cognitive distortions including worse perceptions of self-efficacy, which reflect one's ability to initiate and accomplish complex tasks (Quittner *et al.*, 2008). Although actual treatment has considerably improved the survival of patients with CF, the relevant psychological aspects have still been insufficiently considered. This paucity of high quality research has led to an under-appreciation of the prevalence of depression and anxiety in clinical practice in pediatric CF population. Of the few studies of school-age children and adolescents with CF, some reported a rate of depression ranging from 11% to 14.5% in contrast to a rate of 2-6% in the general pediatric population (www.tides-cf.org). Published rates of anxiety have ranged from 5% to 9% (Demyttenaere *et al.*, 2004). Analyses of comorbid symptoms indicated that adolescents reporting depression were 14.97 times more likely to report anxiety (Driscoll, *et al*, 2009). Burke cited by Cruz *et al.* (2009) observed a high lifetime prevalence rate of specific anxiety disorders (4% panic disorder, 11.5% phobias, 11.5% separation anxiety and 10% over-anxious disorder. Quality of life (QOL) is a measure of the impact of the disease on psychological, psychosocial and physical functioning. CF has a negative impact especially on physical functioning aspects of QOL. Change of disease severity may well be more likely to correlate to level of psychological and psychosocial functioning (Pfeffer *et al*., 2003).

Impact of CF on the caregivers of children with CF

The newborn screening for CF has many benefits, but also presents some hazards: false-positive values that may cause parental anxiety, false-negative values that may lead to a delay in diagnosis and reporting of carriers may be unwanted information and may cause discrimination. The diagnosis of CF causes a number of emotions and for many the first reaction is "I can' believe this". The communication of diagnosis of CF is followed by sorrow, depression, loss and disempowerment for the parents. After communicating the diagnosis of CF, the first consultation with parents should focus on the relationship between parents and the team that monitors the child. Then, caregivers of children with CF may experience a variety of significant stressors such as guilt for having passed a genetic disease to one's child, quarterly appointments with CF healthcare team, hospitalizations due to pulmonary infections, time-consuming and complex treatment regimens (minimum 45 minutes for nebulized antibiotics and chest physiotherapy), decreased amount of time spent with other family members and shortened life expectancy of the child (Driscoll, Montag-Leifling, Acton, & Modi, 2009). Parents of CF children are at risk of overprotecting their child. Fear of infection determines the parents to restrict the physical movements, toys and social contacts. All daily activities are affected indirectly by the diagnosis. For example, mealtime is the area of most reported difficulty. The parents are concerned to achieve a high daily caloric intake for their child, but they encounter problems as food refusals, non-compliance to eat and leaving the table (Bryon, 2006).

In some cases, we can found negative psycho-social aspects related to the evolution of the disease: (1) some parents think that if their child will go to school, he will be overloaded and the disease will worsen; (2) other parents think that frequenting the community, the chances of child to contact serious infections are higher; (3) there are parents who worry about the incorrect administration of treatment when the child will no longer be under their constant supervision (Pop & Popa, 2006). For parents of children with CF the transition from child care to adult care is an emotional step. If before the transfer the parents are responsible for the child's care, after the transfer they must gradually transfer it to the child and adult healthcare professionals. The responsibility they feel towards compliance of care of their child and the fear of decline are discouraging factors in their role in the transition process (De Vries, 2012).

Little is known about depressive and anxious symptoms and QOL in caregivers of children with CF. There are few studies that consider that the rate of depression in parent caregivers is also high compared to parents of healthy children. In a trial of 88 parents of young children with CF, ages 1 to 11 years, 29% of parents scored in the clinical range on a depression screening tool. This is similar to a study of role strain in parents of young children with CF, in which 36.4% of the mothers'

depressive symptoms fell within the clinical range (Quittner & Slater, 2005). Furthermore, even higher rates of depression were reported in a study of parents soon after the diagnosis, with 64% of mothers and 43% of fathers scoring in the clinical range (Quittner, DiGirolamo, Michel & Eigen, 1992; Pfeffer *et al*., 2003). So, family problems can affect the patients themselves. Many factors are associated with psychological and psychiatric problems and poor Health Related Quality of life (HRQOL): (1) inadequate knowledge and incorrect beliefs about CF may be associated with the psychological distress; (2) the interaction between nutrition, pulmonary inflammation response and lung health remains complexe and incompletely understood, although there is a growing consensus that nutritional interventions lead to the delay of the progression of pulmonary disease (Milla, 2007). There is evidence that acute changes in health do have an effect on QOL: (3) hospitalizations for pulmonary exacerbations have a significant and negative impact on patient's QOL (Bodnar, *et al,* 2014); (3) *P. aeruginosa* is the most common pathogen in lung infections in patients with CF. The importance of its early detection is due to its correlation with a more pronounced reduction in pulmonary function, which results in impaired quality of life and poorer prognosis of patients chronically colonized with the bacterium (WHO Technical Report, 1998); (4) comparatively with other European countries where neonatal screening for CF is performed, in Romania the diagnosis of CF is usually delayed because neonatal screening is not available. Therefore, it is difficult to prevent the development of early lung disease. These negative differences compared to other countries may decrease the life expectancy and the HRQOL; (5) nutritional status is correlated with progression of lung disease, recovery from sickness and life expectancy; (6) non-compliance to treatment: the reasons of accidental or intentional non-compliance are inadequate knowledge, rejection or denying of diagnosis, psychosocial resistance, educated non-adherence, forget-fullness, underestimating of the severity of their disease, particular treatments; (7) from ages 12-18, adolescents experience many physical, cognitive, emotional and psychosocial changes. The interface between biopsychological development and disease make this period challenging for the adolescent with CF.

Impact of CF on relationships in families of children with this disease

Between mother of the child with CF and his child there is an intense reciprocally interpersonal relationship. Mother try to be with her child as much as possible and she want to try anything that might offer hope for cure. In the same time, for the child hospitalized his mother's absence is a cause of distress (Teicher, 1969). The long time spent and the increased cost for the caring of children with CF determine social and financial deprivation of the other members of the family.

The life of the parents is centered on the child with CF and they consider themselves as a major factor determining the child's behaviour. In the same time, the lack of communication between family members impairs family functioning, causing separation and divorce. Other reasons that could explain the divorce is the great genetic risk attached to further pregnancies in the families with a child with CF, limited time due to the implementation of lengthy treatment regimens and curbed holiday possibilities (De Wet & Cywes, 1984). The absence of divorce not always means marital stability, the parents remaining together for the sake of the child. Oppenheimer and Rucker (1980) observed that home treatment was more efficient when children lived at home with both their parents then when family was breakdown. On the other hand, Allan quoted by De Wet (1984) observed that in an Australian study 25% of the marriages became more closely especially when fathers are actively involved in the care of the child with CF and support the mother in the periods of stress.

The disease also has impact on siblings of patients with CF: (1) the younger siblings present somatic complaints, consider the treatment of their brother as favoritism and sometimes simulate CF; (2) the older siblings are concerned and have a protective attitude against the brothers with CF. The teenage girls expressed some concern about the risk of being CF carrier; (3) the siblings closest in age to the patient consider that they lacked the mother's attention (De Wet & Cywes, 1984). The strong emotional reactions of having a child with a chronic illness may promote more negative parenting relationships with well children. This differential treatment may have effects on the siblings, the quality of the sibling relationship being negatively affected with long-term social implications for both children (Ernst, Johnson & Stark (2011).

Conclusions

Inadequate knowledge about CF may be associated with psychological distress. Prevention of cross-infection with transmissible strains is important for a better physical and psychological outcome. Precocious identification and effective treatment of depressive and anxious symptoms could improve the patient's daily functioning and the disease management. For the early detection and effective management of depression and anxiety in patients with CF it is necessary: (1) to screen for these conditions annually together with primary care physicians; (2) to develop decision rules about when to treat these symptoms in clinic versus referral to outside specialists; (3) to establish a referral network of specialists in the community who have experience treating depression in patients with chronic illnesses; (4) to increase training for members of the CF multidisciplinary team regarding depression and anxiety. A better psychological support means a better

psychological functioning. Good friends are a necessary source of support for children with CF and could lead to minimizing the visible differences from others.

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