

Psychological factors implied in adherence to aerosol therapy in CF

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Abstract. *Introduction:* Adherence to therapies in chronic diseases averages only 50%. Low adherence reduces the clinical outcomes of prescribed therapies. *Discussion:* In CF (Cystic Fibrosis) there is poor adherence for airway clearance and nutritional supplements due to lack of perceived efficacy and to the significant burden of daily routines and social/work activities. *Conclusion:* It is paramount to find new strategies to manage illness distress and to tailor, with together with caregivers and the patient, a better therapeutic approach. (www.actabiomedica.it)

Key words: adherence, psychological factors, cystic fibrosis, intervention strategies

Introduction

The WHO (World Health Organization) estimates that in developed countries, adherence among patients suffering chronic diseases averages only about 50% (1, 2). Poor adherence is the primary reason for worse clinical outcomes. It causes medical and psychosocial complications of disease, reduces the patient's quality of life, and misspends health care resources. Health care costs increase due to the greater need of medical or nursing care, and to the increase in the number and duration of episodes of hospitalization (3). Improving adherence might in fact, be the best investment for chronic disease therapies. According to the WHO, adherence is a complex behavioural process determined by several interacting factors. The main factors which may influence adherence are: 1) *social and economic factors*, 2) *health system organization*, 3) *therapy related factors* (duration, complexity, efficacy, iatrogenic effects), 4) *disease related factors* (severity of symptoms, level of disability, progression and severity of the disease), *patient-related factors* (knowledge, attitudes, beliefs, perceptions and expectations).

Cystic Fibrosis (CF) is a recessive autosomal chronic disease, which imposes a complex burden due to the therapeutic program, which consists of inhaled antibiotic therapy, inhaled mucolytic therapy, airway clearance, pancreatic enzymes, nutritional support, periodic medical consultations and hospitalizations. All these medical recommendations require a high level of patient adherence; however, scientific literature estimates an overall poor adherence that worsens, especially for airway clearance during adolescence where it ranges between 41 and 54%. Poor adherence is linked to worse health outcomes and therefore, it is very important to understand which barriers and facilitators may lead to better adherence.

Discussion of Adherence in CF

Several studies have identified many factors that may influence adherence to the CF treatment regimen, including parent and child knowledge and understanding of prescribed treatments (4).

CF patients generally show good treatment adherence when digestive (88.2%) and respiratory

medications (61%) are prescribed, whereas low adherence is seen following physiotherapy (41.2%) and administration of nutritional supplements as they may influence little or nothing the patient's quality of life. The improvement of adherence is associated to the *perception of efficacy* of therapies, (5) the *severity of disease* (a rapid progression of disease increases adherence), *feeling positive and immediate effects*, *regular contact with the care team*, *better understanding of treatment rationale* and *continuous encouragement and support from carers* (6).

Maureen (7) identified in CF patients six main barriers with frequency of response ranging between 36 and 64%: *Treatment burden* 64% (for length, frequency, and complexity), *Social demands* 60% (balance between treatment and social life), *Work demands* 60% (balance between treatment and work life), *Forgetting* 60%, *Absence of perceived health benefit* 56%, *Fatigue* 56%, and *Stigma/embarrassment* 36%. Seven facilitators were identified ranging between 76 and 44%: *CF clinic Attending* 76% (closeness of team care and appointments), *Support and reminders* 68%, *Presence of perceived health benefits* 68%, *Ease of completion* 48% (A low degree of effort required to do treatment enhanced adherence), *Habit/routine* 48%, *Distractions and rewards* 44%, and *Guilt* 44% (Feelings of guilt about non-adherence promoted adherence).

Usually, among CF patients, there is a worsening of adherence during adolescence linked to greater independence, less control by their parents, and their desire for freedom and normality. Older adolescents are generally more aware of their illness with fewer negative emotions and are less likely to think that physiotherapy is necessary (8). Despite awareness in older adolescence, adherence is low. This is probably due to their illness control beliefs that could lead to underestimate their own clinical situation and to psychologically protect themselves from the distressing impact of disease progression. Defence mechanisms, such as denial, are unconscious strategies that are put into practice to limit anxiety linked to disease and that allow the patients to plan their future. Defence mechanisms are required for psychological balance but unfortunately, could cause a worsening of adherence (9, 10). Specific coping strategies, which determine repressive adaptive style, are widely present in children with chronic illness to produce a control on anger and anxiety (11), but in

the long-run management of disease, high levels of Active Coping and lower levels of disengagement were associated with better psychological QOL and a lower level of anxiety and depression (12).

Scientific literature has underlined several technological and behavioural strategies to reduce treatment burden and improve adherence: *formulation strategies* (to concentrate the drug formulation and to reduce time of administration), *new aerosol devices* (to improve time and dose efficacy) and *behavioural strategies* (a collaborative approach to care, motivational interview, psychotherapy, problem-focused therapy) to foster better collaborative and personalized medicine (13).

The reduction of aerosol time may have a positive impact in terms of adherence thanks to the lowering of the overall therapy burden (14). Patients require supportive emotional interventions to self-manage their disease and feel the need to reduce the complexity of medicine regimens. They want control over their health and for this reason, regular follow-up and a feedback relationship with the care team to accept their needs is of paramount importance (15). The therapy burden involves overall families and their daily routine, deeply influencing their quality of life.

The management of CF involves caregivers and every family member, often causing anxiety, depression, and sleep disorders. A relationship, based on the collaboration between the patient, the family and the referring physician, can significantly improve adherence to therapies (16).

The medical treatments should consider the complexity and family system's needs and be proposed according to the resources and limitations of caregivers (17), and be aimed at offering psychological support to sustain hope and positive parent coping (18). The care team needs to tailor treatment and treatment-times when possible, reflect lifestyles, academic pressure and recreational pursuits, to integrate CF care into daily routines. An *open discussion* with patients and their families and good flexibility about breaks from treatment may prove useful in achieving optimal adherence in these patients (19).

A good theoretical framework of intervention to improve adherence is summarized in the Atreja's *SIM-PLE* model (20) 1. Simplifying regimen characteristics;

2. Imparting knowledge; 3. Modifying patient beliefs; 4. Participation in the decisions 5. Leaving the bias; and 6. Evaluating adherence.

Conclusions

Adherence is of paramount importance in CF care and for therapy outcome. Adherence involves several aspects and therefore, a multifactorial model is needed for a comprehensive understanding of this complex phenomenon.

Multi-professional intervention could allow an early assessment of risk for non-adherence and could plan specific cognitive, motivational and behavioural interventions to improve the patient's coping strategies in order to manage his own illness. Each and every member of the care team must be aware of the importance of adherence to therapy and of how to interact with patients and their families to develop common strategies to manage their disease and their needs (21). A continuous comparison between different professionals and a multidisciplinary approach are needed in order to make progress in this area.

WHO have identified five areas in which adherence in chronic diseases can be improved: 1) *social and economic factors*, 2) *health system organization*, 3) *therapy-related factors*, 4) *disease-related factors* 5), *patient-related factors*. Psychologists may contribute through a better understanding of the psychological mechanisms implied in low adherence and promote better adherence and quality of life.

Possible interventions aimed at improving positive affect/self-affirmation and at learning how to use positive affect to facilitate behaviour change (22). Psychological interventions on motivational aspects related to adherence (beliefs and behaviour), group and individual motivational interviews, improvement of information about illness, learning of new skills, reinforcement of the cognitive emotional aspects and inhaled technique training allowed an increase of adherence (23). Furthermore, there is substantial scientific evidence suggesting that the Motivational Interview, which adopts a communication style, is well-received by patients and encourages collaborative approaches to treatment (24, 25).

There are several technological and behavioural strategies to improve adherence but each intervention must be tailored to personal needs, limitations and resources (26).

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