

Non-adherence to treatment in cystic fibrosis

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Keywords: cystic fibrosis; adherence to treatment

Introduction

Non-adherence to treatment is one of the major problems in the management of cystic fibrosis. Although some authors have considered non-adherence not to be a serious problem^{1,2}, others have found a high incidence^{3,4}. There are a number of possible explanations for this variation in findings: the definition of non-adherence, the populations and variables studied, the methodology used and particularly how non-adherence is measured.

What is non-adherence and how is it measured?

The term non-adherence is often used as if it is a single entity, easily defined and readily accessible to measurement. Unfortunately there is as yet no universally accepted or acceptable definition. There are very few valid and reliable objective measures. Perceptions of adherence may and probably do often differ from reality. Measures of adherence that have been used include self-report, parent-report and physician report. Self-report is notoriously unreliable, parent-report can only be partially reliable, while it has been claimed that physicians are unable to predict adherence any more accurately than by chance⁵.

The most useful measures of adherence are objective, such as consistency of lung-function tests between those recorded at home and those in the laboratory. Other approaches are detection of antibiotics (eg flucloxacillin) in urine, and estimation of serum levels of drugs (eg cyclosporin) in patients who have received a transplant. A new assessment tool, the Medical Compliance Incomplete Stories Test (M-CIST) has been described and seems to discriminate between adherent and non-adherent patients⁶.

Dimensions of non-adherence

Rather than describing patients as adherent or non-adherent, it seems more sensible to consider the dimensions of non-adherence. For example consideration can be given to whether or not a patient is adherent to medication, to diet, and to physiotherapy. The degree of adherence to each is likely to vary. In one study adherence to medication was estimated at 90%, to diet at 30%, and to physiotherapy at 40%³.

Similarly patients can be considered to be fully or almost fully adherent, partially adherent, or predominantly non-adherent. Thus those patients who claim adherence, who are as well as might be anticipated, who systematically keep their diaries, and who show no discrepancy between lung function measures at home and in the laboratory, may reasonably be considered to be adherent to treatment. In contrast, those patients who are far less well than anticipated, who admit to at least some non-adherence, who do not systematically keep their

diaries, and who show a marked discrepancy between lung function measures at home and in the laboratory are clearly best considered as non-adherent. Those patients who fall between these two extremes may be considered as partially adherent. Clearly there can be many possible combinations of, and variations between, the above factors.

When trying to assess the degree of adherence by questioning, it is worth bearing in mind that few patients would readily admit to regular non-adherence, and even fewer parents are likely to do so. It may help, when broaching the topic, to emphasize the frequency of partial non-adherence. The issue can be raised by saying something along the lines that 'most people forget or can't be bothered to do their physio, *and* stick to their diet *and* take their tablets, and I wonder how often that happens to you'. This process of normalization gives permission to acknowledge occasional non-adherence, after which it is easier to explore the extent.

There are many ways in which non-adherence can be categorized, other than quantitatively. Koocher and his colleagues have outlined a typology of non-adherence, in which they describe three types: (i) inadequate knowledge, (ii) psychosocial resistance, and (iii) educated non-adherence⁷. In the first type non-adherence seems to be related chiefly to lack of information or inadequate understanding. The second type refers to those situations in which there is a predominance of psychosocial factors such as struggles for control and autonomy, peer group concerns, denial and avoidance, chaotic home circumstances, depression or despair. The final type involves conflicts and difficult choices based on a full understanding of both the reasons for the prescribed regimen and the result of not following it.

Another means of categorization is behavioural rather than cognitive. Patients may be classified as: (i) refusers, (ii) procrastinators, or (iii) deniers. Refusers make no effort to conceal their non-adherence, saying either that they don't need their treatment, that they are not going to be controlled by others, that there is no point, or that they consider the treatment worse than the symptoms. Procrastinators are less likely to be so blunt about their non-adherence, and will admit only to occasional omissions. They are more likely to say that they will adhere in future, although without additional help this is unlikely. Deniers, in contrast, will not admit to non-adherence, and are more likely to say: 'who, me?'

This is an appropriate point to draw attention to the techniques employed to avoid adherence. I am grateful to one of my young patients, J, who wishes to remain anonymous, for advising me of the many different methods available. Apart from the obvious such as denial or refusal, medication can be avoided by sleight of hand or tongue, using the former like

a magician and the latter to conceal tablets or cover the rotahaler. A deeply coloured drink such as ribena works wonders for concealing tablets that should have been swallowed. Full capsules and nebulas can be emptied or swapped with empty ones, and even filled later with water. The correct diet is easily avoided as this cannot always be supervised. Physiotherapy is the treatment that creates most resistance, and children will put more effort into avoidance than participation.

Predictors of non-adherence

Until the methodological problems associated with measuring adherence are overcome, there is bound to be uncertainty regarding not only the extent of the problem, but also those factors which predict or correlate with poor adherence. However a number of studies have attempted to identify such factors. Good adherence has been found to correlate with (i) family expressiveness⁸, (ii) the younger age group, high levels of optimism, good knowledge of CF, and high socio-economic status⁴, and (iii) an unsatisfactory marriage and infrequent maternal social contact⁹. This somewhat surprising latter finding may be explained on the basis of a mother's highly conscientious attention to the child's treatment leading to marital dissatisfaction and a lack of time for social contact. Alternatively a poor marital relationship and infrequent social contact may encourage a much higher level of maternal attention to the child's treatment.

Poor adherence has been found to correlate significantly with adulthood^{2,6,9}. The incidence of poor-adherence has also been reported to be 35% higher in females than males⁶.

Management

A perennial cry from CF carers is 'how can I get them to comply'. This question illustrates a key problem: carers see it as their task to coerce into compliance - a certain recipe for failure. A far more effective approach is to view the situation as requiring teamwork and cooperation - a therapeutic alliance.

Whichever schema are used for categorizing and describing non-adherence, there are clear implications for management, since before an appropriate strategy can be formulated, the cognitive and behavioural components need to be recognized and understood.

There are five main principles of treatment: (i) empathy, (ii) enthusiasm, (iii) exploration, (iv) education, and (v) expression of emotion.

An empathic, warm, and non-judgemental approach is essential if any sense of being criticized or disapproved of is to be avoided. It helps if poor adherence is normalized; ie, it is made clear that no-one adheres 100% to their treatment. This can be stated openly in a matter of fact manner, and the patients then asked how often they miss out on their physio, diet or medication.

Enthusiasm is a vital ingredient in the management of poor adherence, as it is readily communicated, and instills confidence and hope. A lack of enthusiasm or a critical or judgemental approach has the opposite effect.

Exploration of the underlying issues leads to a clearer understanding of the non-adherence. For example it is important to know whether information is available to the patient and family in a form that is appropriate for age and culture, and that the

rationale for the treatment regimen is clear⁷. Is there resistance to treatment due to social or cultural pressures, a chaotic home environment or family conflict, or denial, depression, or despair? Has the patient made an informed decision which can be articulated and reasoned?

Education plays an important, although not exclusive part in management of non-adherence. Where information is inadequate every effort must be made to provide it in a form that is age- and culture-appropriate. The rationale for treatment should not only be explained but discussed in a manner that allows for a complete understanding by the patient and key relatives. Written material with diagrams is at least as helpful as the spoken word, and probably more so.

Aiding the expression of emotions is possibly the most valuable aspect of the treatment of non-adherence. The sadness, anger, envy, fear, frustration, resentment and depression that are so common to CF sufferers and their families can at times become intolerable. Containing such a panoply of feelings is very likely to lead to denial, despair or some other form of emotional turmoil. It is not surprising that poor adherence commonly accompanies such states.

The opportunity to share, explore and offload such feelings is often beneficial, and may lead to improved adherence. The context for this treatment is determined by such factors as the patient's age and social circumstances. Children are best helped in the family context, with emphasis being placed on more open communication and particularly helping parents to acknowledge and accept their child's feelings, rather than denying, avoiding or playing them down. Teenagers and adults may prefer privacy for such discussions. However the feelings and reactions of key relatives should also be acknowledged, and help offered when necessary. Parents will need advice and support in managing the non-adherence. A more detailed description of psychological treatments in CF can be found elsewhere¹⁰.

Case illustration

Jenny, aged 11 years, was the third of four daughters of divorced parents, her mother having remarried 2 years prior to referral. Her paediatrician had noted deteriorating lung function and her mother was concerned by Jenny's resistance to physiotherapy and medication. She would make a wide range of excuses for the avoidance, such as having homework to do or feeling sick. Two maternal aunts had died from CF while awaiting transplantation.

At assessment by a child psychiatrist it was clear that Jenny was sad, angry and frightened. She blamed herself for her parents' separation, for the current arguments between mother and stepfather, and for the poor relationship she had with her stepfather. She blamed God for allowing her aunts to die, and was sure the same would happen to her. She saw no point in the treatment as her lungs were already getting worse and she considered an early death to be inevitable.

At a family meeting Jenny's mother fluctuated between sympathetic understanding and exasperation. The stepfather showed no affection toward Jenny, even when she actively sought it. He said that he was not an affectionate person anyhow, but Jenny did not help by being so difficult.

Treatment consisted of four individual counselling sessions for Jenny in which she was helped to explore

her feelings and differentiate between what was her responsibility and what was the responsibility of the adults. Her distress relating to her aunts and her fear for her own future was acknowledged, but she was helped to understand that the recent deterioration in lung function was due to poor adherence rather than an inevitable and irreversible process. In parallel Jenny's mother was helped to find ways of coping with her divided loyalties, and she and her husband were helped to resolve some of their own relationship problems.

Within a few weeks of the commencement of this treatment regimen, Jenny's mood brightened considerably, and she cooperated willingly with treatment. The marital relationship also improved, and the stepfather became more responsive and friendly to Jenny.

Conclusion

The recognition and management of non-adherence is a complex and important aspect of CF care. There are many different explanations for poor adherence, including psychosocial factors, inadequate information, and a deliberate and informed decision. Successful treatment is dependent upon a correct and complete understanding of the underlying issues. An empathic and non-judgemental approach, which acknowledges the normality of incomplete adherence is essential, while involvement of key relatives is also likely to improve the outcome.

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