Factors affecting adherence in adults with cystic fibrosis

This is the second article by Amanda Plummer and colleagues on their research into adherence in adults with cystic fibrosis. Here they describe factors that they found to affect adherence in this population.

Abstract

Objectives: In this study our aim was to explore the factors affecting adherence in adults with cystic fibrosis (CF).

Design: The study consisted of semi-structured interviews.

Participants: Twenty-five patient participants.

Main outcome measures: Patient participants' views, barriers, and the facilitators and motivators that influence medicine use by adults with CF.

Results: Twenty (80%) participants thought their medicines were beneficial or very beneficial, 18 (72%) thought that medicines were important or very important at relieving symptoms and 20 participants (80%) thought they were important or very important in preventing longer-term problems. Barriers to adherence were grouped into the following themes; time, personal characteristics, relationships, accessibility, state of health, medicine routine and medicine properties. Although 12 participants (just under half of all patients) stated they were aware of adverse effects, almost two thirds (16) described adverse effects of their medicines suggesting that they were accepted as the norm. Ten described some physical difficulties with medicines and nine reported no problems. Facilitators to adherence included general facilitators, medicine routine and individual medicines, whereas the effect of medicines, health-related fears and relationships were described as motivational factors. Just over two thirds (17) thought they had enough knowledge about their medicines. A lack of knowledge was identified for particular drugs.

Conclusions: Recommendations for changes in practice are proposed.

Introduction

Many factors have been shown to affect adherence in the general population. Meichenbaum and Turk identified more than 200 variables,[1] which included drug appearance, colour, taste, and tablet size.[2] Adherence may vary according to the medication used, and prophylactic treatments[2] and complex regimens[3–6] are associated with reduced rates of adherence. For example, the number of medicines taken,[7,8] the number of times each day the medicine needs to be taken[8–13] or the length of regimen[13–15] all impact upon adherence rates. Patient knowledge may have a positive effect upon adherence although this is not automatically the case.[16] If a patient has made a deliberate decision not to take treatment then information will only influence this if it changes beliefs or contradicts earlier knowledge. Cox and colleagues published a useful and comprehensive systematic review of communication between patients and health care professionals about medicine-taking and prescribing.[17]

The treatment regimen for cystic fibrosis (CF) is often complex and intrusive. Treatment may take a large portion of the day, leading to adherence problems in a predominantly young, mobile population. Studies specific to CF have identified that adherence with individual treatments varies according to their perceived unpleasantness and effect on daily activities. For example, some of the general reasons influencing adherence include 'not being bothered' or 'too time consuming'[19] and 'emotional reasons', such as resentment.[20] Not surprisingly, forgetfulness was the most common reason for omitting therapy.[18] Adherence was also decreased with a perception that treatment did not make any difference,[18,19] and with the more time-consuming treatments.[20,21] Although many of these factors influencing adherence apply to all treatments in some cases the reasons were found to be unique to the specific treatment.[22] Belief in the efficacy of a treatment was found to be predictive of increased adherence.[23] Interestingly, the incidence or fear of adverse drug events is not well studied in the CF population; the two main studies that have attempted to find out about patients' difficulties with their regimens have not highlighted adverse drug reactions.[18,24]

A positive relationship has been shown to exist between knowledge and adherence.[25–27] Kelly[28] and Conway and co-workers[18] found a positive relationship with both increased knowledge of the treatment regimen and its purpose. Specific gaps in patients' medicines-related knowledge have been widely documented.[29–31] Previous studies in CF have tended to concentrate on the barriers to adherence or patient knowledge. This study explored patients' views about their use of medicines, and the barriers, facilitators and motivators relating to medicine use that are regularly experienced by adults with CF. Suggestions are made for potential interventions to address these.

Methods

This qualitative study consisted of semi-structured interviews with 25 patients attending the Adult Cystic Fibrosis Unit at Sheffield Teaching Hospitals NHS Trust.

Results

1. Views regarding medicines use

Patients were asked to describe their medicines in terms of benefit, disruption, symptom relief and prevention of longer-term health problems on a Likert scale ranging from strongly disagree to strongly agree. The findings are shown in Figure 1.

Twenty (80%) patients thought their medicines were beneficial or very beneficial. Only one person described them as causing a disruption to their life, which appeared to contradict the general way that patients described disruption to their daily routine, for example rearranging work or social activities to accommodate intravenous antibiotics. Almost three quarters (17) felt medicines were important or very important at relieving symptoms and 20 (80%) thought they were important or very important in preventing longer-term problems. As expected those patients with more severe disease thought their medicines were less beneficial at preventing damage, and after transplant all patients reported maximum benefits for preventive well-being.

All 25 patients expressed views about taking their medicines. Thirteen patients (just more than half) categorised their use of medicines as a 'necessity'; seven (just more than one quarter) categorised them as 'a desire not to take but accepted their necessity'; three patients expressed 'a desire not to take' their medicines and two patients reported a 'neutral attitude' towards their medicines. Approximately one-third of participants (eight) offered additional comments that provided some insight into the reasons for cautionary behaviour when adhering to medicine regimens. For example, four participants raised concerns about medicine side-effects; two stated they thought medicines were 'unnatural'; two thought medicines were important but that other factors were equally important, such as exercise; and three asserted that medicines 'should be individualised' but two thought from experience that this was not so.

2. Barriers to adherence

All participants identified barriers to adherence, which when analysed could be grouped into seven themes; time, personal characteristics, relationships, accessibility, health status, medicine routine and medicine properties. Specific details within each theme are outlined in Table 1.

Although only 12 patients stated they were aware of adverse effects from taking their medicines, 16 described adverse effects during the interview. This suggests that some patients may accept adverse effects from medicines as being normal. Eight participants described experiencing no adverse effects from their medicines. There appeared to be a majority with some understanding that it was sometimes necessary to 'balance the adverse events against the therapeutic benefit'.

> Studies specific to CF have identified that adherence with individual treatments varies according to their perceived unpleasantness and effect on daily activities.

Nineteen patients responded to questioning about their experience of any physical difficulties with taking their medicines. Of these, nine described no problems, but 10 described some physical difficulties, including the size or shape (11), taste (5), nausea with oral medicines (5), smell (3), not being able to take any capsules (2), feeling sick with all tablets in the morning — although the participant who reported this also linked it to morning sickness from her pregnancy (1).

3. Facilitators and motivators

When exploring the general barriers to adherence a number of themes emerged. All 25 participants identified:

(a) generic factors, such as access to medicines, or habit
(b) the medicine routine appeared to influence adherence and
(c) increased adherence appeared to be connected to individual medicines. For example, absence of side-effects made the participant feel better.

Motivational factors appeared to be influenced by the effect of the medicine, the presence or absence of health-related fears, and the quality of personal relationships in the social environment. Table 2 provides further examples of facilitators and motivators.

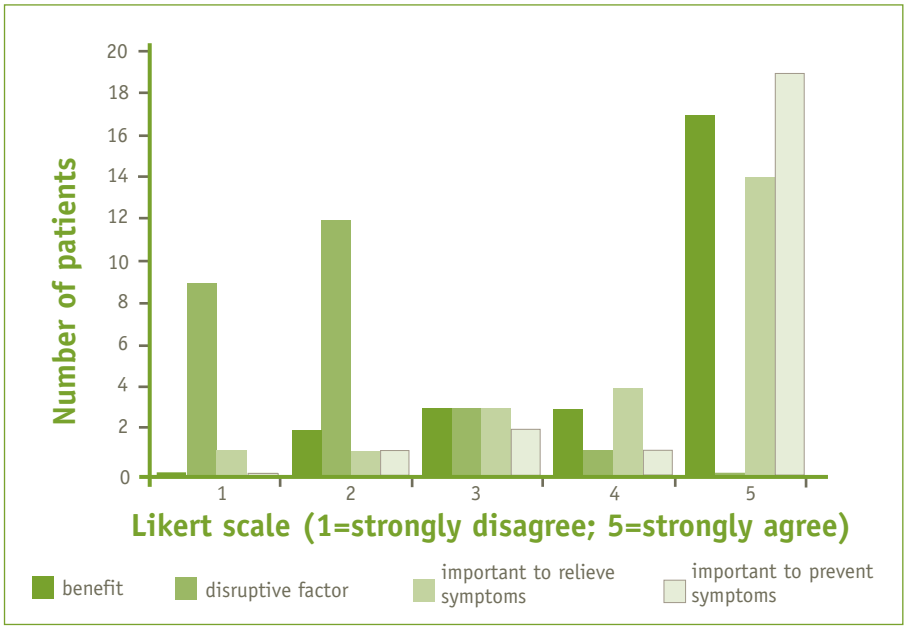


Figure 1. Patient views on their medicines

Table 1. General barriers to adherence

a) Time

Lack of time was identified by 14 respondents. Specific reasons given were:

- a general lack of time or that they were too busy (6)
- a lack of time at work (3)
- the time for the nebuliser-physiotherapy routine (1)
- the impact of dependant children created a lack of time (4).

b) Personal characteristics

Identified by 14 respondents, this included laziness or not being bothered to take their medicines (7), forgetfulness (5) and inability to maintain the habit of taking medicines (2).

c) Relationships

The childhood-parental role was thought to have created the barrier for two participants.

d) Accessibility

Two people identified the need to keep medicines out of reach of children as causing a barrier.

e) State of health

Two people described barriers to adherence from their perceived state of health. One said that feeling too well reduced adherence, while the other said her lungs were already damaged.

f) Medicine routine

Ten people described aspects of the medicine routine that provided barriers to adherence:

- problems with morning doses and the lack of time (4)
- the quantity of medicines taken in the morning (2)
- multiple doses in the day (2)
- separated medicine times (1)
- middle of the day doses (1).

g) Properties of the medicine themselves caused barriers for 12 people in the following categories:

- problems taking medicines before food (6), for example, flucloxacillin
- need to be taken out of house (5), for example, pancreatic enzyme supplementation
- lack of immediate effect (3)
- preventive action or no perceived benefit (2)
- lack of side-effects reinforcing non-adherence (1)
- combinations that can't be taken together (1)
- tablets perceived too small to be effective (1)
- the need to take two hours away from milk (1)
- the need to dissolve in water (1).

h) Route of administration

The most common barrier to adherence from the administration route was nebulisation (9) including the time to set up and clean (5), lack of portability/ immobility (3), not being bothered (3), perceived lack of effect (3), the effort taken to prepare when unwell (1), the medical feel (1), the noise (1), dislike of a son breathing in fumes (1) and that the lungs are already damaged (1).

i) Social reasons

Eight people identified social reasons that reduced their adherence. The most common was an unwillingness to take medication in front of others (3), two people described struggling to fit it into their lifestyle, and two had difficulty with their child's school hours, two described holidays as a problem and one person any change in routine, for example a change in job.

4. Knowledge

When asked about their perceived knowledge of medicines only 17 participants thought that they had enough knowledge about their medicines. An apparent lack of knowledge was identified for particular drugs; three people gave incorrect information about antibiotics and vitamins; two people said they had been given the information but could not remember it. A general lack of knowledge of side-effects was raised despite this being the type of information most often requested. Two people said they had little knowledge about their medicines but thought that this was by their own choice and therefore acceptable.

Eight participants used the medicine packaging or patient information leaflet (PIL) as a source of information. A lower number than might have been expected stated they obtained information from health care professionals, with more receiving information from the CF unit than from professionals in primary care. Most patients preferred to get their information from the prescriber, pharmacist or anyone with knowledge about the medicines. Only two patients would prefer leaflets as a source of information compared with eight who said they use this as a source of information. One person stated as the preferred source 'anyone who knows the medicine and also knows them as a person'.

Discussion

Not surprisingly, because of the nature of CF and the emphasis placed on medicines, a high percentage of patients and members of the CF team thought medicines were important in relieving symptoms and preventing long-term problems. Surprisingly, only four patients spontaneously expressed concern about side-effects of their medicines and only three expressed a desire not to take any medicines — much lower than figures from other studies in epilepsy[7] and rheumatology.[34]

When asked to score the disruption effect of medicines lower scores were seen compared with the descriptions of how medicines affected their lives. One reason could be that this study did not address physiotherapy, which is often described by patients as the most difficult to adhere to and is associated with lower adherence rates than other treatments.[18,24]

When describing their memories of medicines a large number stated they could not remember when they were first prescribed medicines because these had always been part of their lives. This process of normalisation may contribute to the perceived low level of actual disruption caused to their everyday lives; there is no disruption because this is their life.

Beliefs about the importance of treatments have been shown to be strong predictors of adherence to treatments in CF.[35]

Table 2. Facilitators and motivators

1. Facilitators

The general factors stated were:

- accessibility (8)
- habit (7)
- understanding the need for medicine or duration of action (6)
- portability (5)
- normality of medicines within this patient population (2)
- part of identity (2)
- having control (2)
- being given a choice of treatment (1)
- nothing makes it easy (1).

The medicine routine helped if:

- the medicines could be taken together (5)
- the patient used a compliance aid (5)
- were not time-consuming (3)
- for intravenous and nebulised antibiotics it helped if the next dose could be prepared while taking the last dose (3)
- had no time restrictions within the day (2)
- were prescribed once daily (2)
- individualised routine (2)
- taken with meals (2)
- the medicines fit into lifestyle (1)
- twice daily or less (1).

The individual medicines helped adherence if:

- they made the patient feel better (4)
- had no side-effects (2)
- had side-effects from non-adherence (2)
- avoided injections (1)
- were available in larger strengths (1)
- oral antibiotics were described as easier than IV (3)
- IVs ready prepared (3)
- a belief that IV antibiotics were important (4)
- nebulisers being ready made (6)
- nebulisers not being released into the atmosphere (2)
- newer nebulisation technologies (5).

2. Motivators

- the production of symptoms or side-effects from not taking (15)
- the effect of maintaining health or preventing illness (9)
- fears regarding their health (10)
- knowledge of the necessity of medicines (4)
- and awareness of the consequences of not taking (2)
- relationships with dependant children (4), parents (3) or partner (3)
- contact with the CF team (1)
- work or future career ambitions (2).

However, the two patients who described the benefit of medicines as poor had perceived adherence levels of 95% and 100% of their medicines, suggesting that the belief that their medicines were not beneficial did not necessarily affect their adherence.

The strongest concerns expressed about medicines appeared to be about antibiotics and included general use, oral, nebulised and intravenous forms. The worries related to the fear of resistance and a desire to avoid treatment until necessary. These findings agree with other published research.[13,36]

Positive views of pancreatic enzyme supplementation and the necessity of treatment was described, and again this supports other published findings.[19] This would suggest that it is the barriers to treatment that prevent adherence to pancreatic enzyme supplementation rather than the patients' views about the medicine.

The variance in views and specificity to each individual makes it difficult to recommend generic interventions to improve adherence other than to discuss with each individual their fears, anxieties and preconceptions. A full medicine review should include views about all the medicines prescribed.

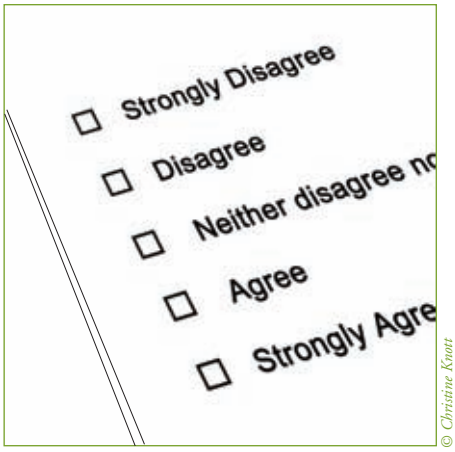
The differing adherence rates to individual therapies described in our first research article on this subject (see p47 this issue) was influenced by a many factors. The number and complexity of these interrelating factors will not come as a surprise to anyone working with adults with CF and is supported by literature evidence in both CF and non-CF populations.[2,13,18–20,37,38]

The most common barriers to medicine-taking were the time involved, the medicine routine, properties of the medicines, route of administration, physical or social reasons and forgetfulness. To improve adherence it is necessary to take into account all factors relevant to a particular individual and their willingness at that moment in time to change behaviour. The appropriate course of action will vary and should begin with a review of the need for the medicine and an assessment of the individual's ability to adhere to treatment.

> Most patients preferred to get their information from the prescriber, pharmacist or anyone with knowledge about the medicines.

The advent of new delivery systems for inhalation therapy have the potential to reduce the time to nebulise therapy and developments in inhaler technology may reduce this further. A discussion of the medicine routine will help identify patient-specific barriers. For example, accessibility of medicines and ways to overcome this, or problems with the properties of the medicines, such as size or taste. For medicines that should be taken frequently it is difficult to reduce the problems arising from the social environment and the appropriate course of action will depend on the scale of the problem for the individual, such as psychology and support.

Most patients thought they had enough knowledge about their medicines but some specific gaps were seen. This was less than found in other studies[29,39] but did highlight inaccuracies in perceptions of the need — particularly for vitamin supplementation. A general lack of knowledge of side-effects was found despite this being the type of information most often requested by patients. The policy to encourage patients to take an active role in their treatment



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decisions requires a higher and more consistent level of knowledge than observed here. However, the level of knowledge and desire for this varied between patients. A range of appropriate sources of medicine information should be available to patients and information provided of unsuitable sources, for example, the PIL for unlicensed medicine use and unregulated internet sites. An acknowledgement that 'increased knowledge may lead to an informed decision not to adhere to treatment' is necessary.

Factors that facilitated adherence were found to be individual and need to be discussed with each patient. The medicine routine can be adjusted for most medicines, but some will always present difficulties, for example those that need to be taken before food or pancreatic enzyme supplementation to be taken throughout the day.

Conclusions

Many factors were shown to affect adherence to medicines in this study. It is important that treatment for such a complex condition is individualised and patients are involved in their treatment decisions. Recommendations for change in practice are outlined below. Future research is needed to explore the effect of adherence in an individual over time, the efficacy of the prescription of all medicines with food, the information needs of adults on transfer to adult clinics and before referral for transplant assessment, and the adverse effects experienced and information given.

Recommendations

1. Education

- Information should be presented in more than one format, such as verbal and written, and in a manner that is accessible to the recipient (patient, partner, parent) and relevant to the age of diagnosis, current age and stage of disease.
- Information should be targeted to the individual's needs.
- The patient should be involved in the assessment of information needs.

2. Patient involvement

- Patients should be empowered to input to treatment decisions where possible and where they wish to do so.
- The multidisciplinary team should agree objectives to patient care with the patient.
- Adults should be provided with autonomy and control, where possible.

3. Medication review

- CF specialist pharmacists should complete a full medication review when a patient is newly transferred to the regional centre and at each annual review.

4. Prescribing recommendations

- Each patient's treatment regimen will be individualised.
- Do not prescribe medicines before food if the patient is unable or unlikely to adhere. If this is necessary, however, consider advising patient to take with other medicines and explain the disadvantages to this.

Declaration of competing interests

The author(s) declare that they have no competing interests.

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