

The compliance conundrum in cystic fibrosis

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INTRODUCTION

The RSM conferences on cystic fibrosis (CF) have all focused on recent advances in our understanding of the disease and its treatment. These include sophisticated approaches such as gene therapy and heart-lung transplantation. Yet the single biggest challenge facing clinicians is that of finding a way of helping patients to adhere to treatment regimens with physiotherapy, antibiotics, enzymes and exercise, all of which are designed to maintain health. The issue that lies at the heart of the effectiveness of CF treatment is compliance—the process by which patients decide whether or not to follow the treatment recommendations.

Non-compliance is a problem in the treatment of all conditions, and there is both good news and bad. Dick Podell put it rather well in the context of compliance with hypertensive medication. His findings from 1975¹ have stood for over 20 years and seem to relate well to other areas of care. He argued that around one-third of medical advice finds its target and is acted on, and two-thirds does not for reasons both deliberate and accidental.

Koocher *et al.*² studied 1200 critical incidents from 223 patients with CF and members of their immediate families. They identified three basic types of non-compliance in CF and confirmed that there is both deliberate and accidental non-compliance. They identified:

- . Non-compliance caused by the patient's inadequate knowledge
- . Non-compliance caused by the patient's resistance
- . Non-compliance caused by the patient's 'educated' choices.

Non-compliance is not a peripheral issue: it is a practical matter that lies at the heart of clinical practice. It is also a matter of moral importance as well as a matter of life and death. Non-compliance is a problem in the care of all chronic conditions. Reviews by Giuffrida and Torgerson³ and by the Royal Pharmaceutical Society of Great Britain⁴ show that no condition is immune from its effects. It affects whether or not patients pick up their prescriptions, or even

whether they live or die. Horwitz⁵ studied 2175 post myocardial infarction (MI) patients and found that poor compliers were more likely than were good compliers to die within a year, whether they were on the active ingredient (propranolol) or placebo, and irrespective of other controlled factors such as seriousness of MI, demographic factors or psychological factors such as stress. This raises the possibility that compliers may be forming an effective partnership with their medical practitioners to look after themselves generally.

Not surprisingly, the issue of compliance has formed the basis of a great deal of research, much of which was conducted in the 1970s and 1980s. Most of the original research was of poor quality but more recent studies have been excellent, showing both how and why non-compliance happens, and how compliance can be improved. In this paper, we will explain the topic in some depth before offering potential solutions. We will then suggest a style of consulting with patients which maximizes the chances that the patients will follow through on the treatment and other plans made.

THE CAUSES OF NON-COMPLIANCE

Some of the earliest studies investigated the hypothesis that non-compliance was caused by a lack of knowledge on the patient's part. This very rational view is appealing and suggests that explanations are all that is needed. Yet if we ask ourselves how often we floss our teeth or take regular exercise, or finish all courses of antibiotics, courses of action we 'know' are advisable, we discover that knowledge is insufficient to influence behaviour. On balance, the research shows that lack of knowledge does not account for poor compliance, though the evidence of studies in CF is more equivocal. By the late 1970s, the studies were 2:1 against the association of knowledge with compliance⁶. Neither was compliance associated with social class. The studies were 3:1 against, although social class differences between the doctor and the patient (particularly differences in education) may account for many communication difficulties⁷.

It is true, however, that patients frequently misunderstand something the doctor is saying in their consultations. Philip Ley⁸, after studying the extent of patient understanding of various forms of medical information concluded that doctors are very likely to overestimate patients'

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understanding. This may account for some non-compliance (accidental) but does not explain deliberate rejection of advice. Ley also provided evidence from many studies to show that patients only remember on average around 50% of the information provided in consultations, and that compliance was enhanced by helping patients remember. One of us (DP) has been unable to replicate this finding, however, discovering that much more than 50% was typically remembered in general practice consultations and that instruction about medication was remembered best of all⁹.

Non-compliance is caused by a variety of factors including:

- . Patients' beliefs
- . Their feeling that they can control what happens to their health
- . Their intellectual and emotional appraisal of their condition
- . The way their medical consultation is conducted.

Patients' beliefs

Research on patients' beliefs has spawned the Health Belief Model¹⁰ in which five factors are described as predictive:

- . How likely they are to get sick
- . How serious the problem will be
- . The costs and benefits of treatment
- . How likely the doctor will be able to help
- . What it is they are experiencing.

Crucially, each of these factors is a matter of subjective, patient perception, rather than of objective, measurable fact. There is considerable evidence that these factors are predictive of both health behaviour and health outcome, yet the model seldom receives complete empirical validation. Abbott *et al.*¹¹, for example, found that reported compliance in CF was not predicted by either perceived seriousness of the condition or perceived susceptibility to recurrent infection. On the other hand Goodas and co-workers¹² found that perceived seriousness did predict reported compliance in their CF study.

Despite the current equivocal status of the Health Belief Model, all clinicians know that patients' beliefs do have a powerful effect on their behaviour. Therefore, they need to be identified and taken into account. Of particular importance is the patient's view of the costs and benefits of treatment recommendations. No sensible patient will follow advice that he or she believes will be worse than the condition at which it is aimed, or which the patient believes will be insufficiently effective to make a material difference.

Patients' perceptions of control

When patients believe that they cannot directly control their health, they tend not to look after themselves well. They also tend not to comply well with medical advice. Patients' beliefs about control come down to a simple distinction between external controllers (so called because they believe that external factors control their health) and internal controllers (who believe that they control their health themselves). Jaspars *et al.*¹³ describe this under the heading of Health Locus of Control and summarize some of the literature conducted in that tradition.

In CF, Abbott *et al.*¹¹ found that perceived lack of personal control facilitated compliance with physiotherapy, pancreatic enzyme and vitamin therapies. In these forms of therapy the perceived power of the physiotherapist or of the medication are high. Perceived personal (internal) control facilitated compliance with exercise therapy in which the patient has to take a more active role.

The implication for effective consulting is that doctors need to reinforce patients' beliefs in their own capacity to influence their health and to look after themselves. They need to show that there is some point in a particular patient following the treatment recommended.

Intellectual and emotional reactions

Leventhal and Cameron¹⁴ proposed a model that synthesized many of the dominant ideas about predicting patient compliance. The model proposed that patients have two reactions to any stimulus such as a change in their health—an intellectual reaction and emotional reaction. Intellectually, patients create a representation of the problem which may have several distinct elements. It may include several different ideas about the problem such as what 'it' is, how it was caused, how serious it is, and so on. This provokes a need to consider how to cope with the problem, and an appraisal of how well this intellectual package fits together. If the fit is poor, modifications may be required either to the actions considered appropriate, or to the ideas entertained about the condition itself.

There is a parallel emotional reaction. The emotional experience provoked by the problem also requires an action plan for coping with the emotions. If the emotions are strong, a powerful plan may be required. This plan and its intellectual equivalent interact, influencing each other. Strong fears can thus lead to denial or to the unconscious minimization of the significance of a problem.

The implications here are relatively clear. The consultation has to deal with this self-regulating mechanism. The doctor has to understand what the patient understands and feels about his or her problem before attempting to change those views. Clearly, it is important to influence the

patient's thoughts and feelings before attempting to influence behaviour.

THE CONSULTATION

The way a consultation is conducted influences patient compliance. The style of consulting that works most effectively is one in which patients are fully involved in all aspects—diagnosis as well as decisions about the management of the problem. It is a wonderful irony that, in order to increase patient compliance, doctors have to create a partnership of power with the patient in which the patient is the senior partner. However pushed for time the doctor may be, authoritarian consulting styles do not work in the long term. If the diagnosis and treatment are seen as the doctor's alone, then compliance is likely to be poor. If the diagnosis and treatment have been arrived at together, compliance is likely to increase (although then the very term compliance seems out of place).

Sherrie Kaplan and colleagues¹⁵ studied the effect of consultations not only on compliance but also on control of hypertension and diabetes. They found that

‘...poorer control of diabetes and hypertension at follow-up was associated with less patient control, less effective information seeking by, and less involvement of, the patient and less emotion/exchange of opinions by physician and patient during the baseline office visit.’

Thus, consultations can make a significant difference both to compliance and to health. The consultations that make a difference involve patients in every aspect, encouraging questions and sharing decisions with the patients.

Involvement is not the only factor that makes a difference. The other powerful factor is tailoring. By tailoring, we mean adapting the recommendations in the consultation to the unique circumstances of the patient. Standardizing recommendations and explanations may be tempting to a hard-pressed clinician, but it is counter-productive. Patients tend to disregard or minimize the significance of general explanations and advice. They pay more attention to, and follow through with, advice that is believed to be for them personally.

In CF, Conway *et al.*¹⁶ found that poor patient compliance was associated with perceived unpleasantness and degree of infringement with daily activities. Yet these authors also argued that:

‘Non compliance is universal and should be recognised as normal behaviour. There are no reliable criteria for predicting any patient's level of compliance. Treatment protocols should be planned around individual patient's requirements, modifying treatment ideals where

necessary according to the exigency and pattern of that patient's lifestyle.’

Tailoring and involvement go hand in hand. It is easier to tailor recommendations to the patient's lifestyle and personal goals when the patient is fully involved in the diagnostic and treatment decisions. It is also easier to involve the patient with the explicit aim of tailoring the recommendations.

A MORAL DILEMMA?

In order to be considered effective, consultations have to achieve tasks that lead to desirable outcomes. The long-term outcome required is a positive change in the patient's health or quality of life. This depends on sound diagnosis and appropriate actions taken to address the presenting problem. Non-compliance is an intermediate outcome that can render the consultation ineffective.

Yet compliance is not necessarily a good thing. Medical fallibility leads to errors and non-compliance may be entirely justifiable on these grounds. There is also the matter of individual freedom and responsibility. Patients have to suffer the consequences of their decisions and so, arguably, they should be encouraged to take the decisions themselves when they are able to do so.

These arguments potentially pose a dilemma. Consultations could be conducted so as to maximize compliance or maximize patient choice. Fortunately, the evidence suggests that the same consulting style maximizes both simultaneously. Consultations that maximize choice (and involvement in the consultation) also increase the probability that patients will follow through with the plan created in the consultation. These consultations put the patient in greater control and contribute to their understanding of their health. They are then more able to make well-informed decisions about it in the future.

SO HOW SHOULD CONSULTATIONS BE CONDUCTED?

Based on the empirical evidence available at the time, Pendleton *et al.*¹⁷ proposed seven tasks for each consultation, the achievement of which made the consultation effective. These tasks were proposed in the context of primary care, but were not restricted to that setting. The tasks have subsequently formed the basis of many curricula in medical schools, membership examinations of medical professional bodies and vocational training schemes for postgraduate training.

The first two tasks establish the agenda for the consultation. Tasks 3–5 suggest how the consultations agenda might be handled. The final tasks (6–7) relate to the consultation as a whole.

Task 1: Discover the reasons for the patient's attendance

- . The nature and history of the problem
- . What might be causing the problem
- . The patient's ideas and concerns about the problem, and his/her expectations of what the doctor might do about it
- . The effects of the problem on the patient.

Task 2: Consider other problems

- . Continuing (additional) problems
- . At risk factors.

In the case of the first task, 'taking a history' and 'making a diagnosis' roughly correspond with the first two bullet points but they are by no means sufficient. These steps are important, but are incomplete for reasons we have set out above. Understanding the patient's point of view is a critical preliminary to (later) involving the patient in the management of the problem and also to helping the patient understand the doctor's view of the problem. In the case of the second task, issues other than the presenting problem may be introduced by the doctor.

Practical suggestions for implementing tasks 1 and 2

- . Try asking 'What did you think was happening to you?' or 'what did you think had caused it?' to get at the patient's ideas
- . Ask 'What worries you most about this?' to get at his or her concerns
- . Make a note of the patient's ideas and concerns so you can refer to them again in a subsequent consultation
- . Ask 'What are you most hoping from me today?' to find out the patient's expectations
- . Also ask 'How has this problem affected you from day to day?' to ascertain the effect of the problem on the patient.

Task 3: Achieve shared understanding of problem with patient

The choice of how the problem should be managed needs to be made with the patient. It needs to be tailored to the patient's unique circumstances and, obviously, patient involvement is the best way to achieve this. At this stage of the consultation, the doctor and patient need to be building a shared understanding of the problem—75% of consultations tend to display significant agreement anyway¹⁸. Tests, clinical findings, disease processes and the like, all need to be explained and related to the patient's expressed views.

Task 4: Choose with the patient an appropriate action for each problem

Involvement in decision making builds commitment to the decisions taken and demonstrates implicitly the physician's acknowledgement of the balance of power in the treatment of most conditions.

Task 5: Involve the patient in the management

Effective consultations involve the patient in the management of the problem. They also help him or her to understand the balance of responsibility—where the medical role ends—and the importance of their own actions. This reinforces the patient's efficacy as a self-carer.

Practical suggestions for achieving these tasks

- . If you have a clear view of what the patient thinks about the problem, relate your explanation to it. 'You were telling me that you thought you had an infection. I think you have an inflamed bowel—in fact I could see inflammation when I examined your back passage a moment ago. Let me explain the difference'
- . Encourage your patient to ask questions and to have an opinion on how things should be handled. This may occasionally seem inconvenient, but patients who are more involved tend to follow the advice better, as we have seen
- . Set out the treatment options and invite a comment. 'There are three ways to handle this problem with your bowels—diet, medication and surgery. We tend not to recommend surgery unless the other options fail as there is always an element of risk with an operation. Now, your problem is troubling you a lot, and diet is unlikely to get the problem under control fast enough, although we may be able to work on your diet once the problem is controlled, so I'm thinking that medication would be best in your particular case. What do you think?' A similar approach can be taken with medication options; tablets, foam or suppositories, and so on

Task 6: Use time and resources appropriately in the consultation and in the longer term

The efficient use of time and resources includes considering how the effective achievement of the tasks might be accomplished in the least costly manner.

Task 7: Maintain a helpful relationship with the patient

The definition of a good relationship with the patient in this context is a straightforward matter: a good relationship helps both doctor and patient achieve the tasks that make the consultation effective.

These matters do not occur at any particular time during the consultation, they are addressed on many occasions as the consultation progresses. The patient may also need time to take on and discuss new ideas with his or her support group after the consultation, and the doctor might want to acknowledge this. Achievement of these tasks is best judged at the end of the consultation.

Practical suggestions for achieving these tasks

- . Building or maintaining a relationship takes time but can get off to a better or worse start. Do not sit across a desk—it puts a barrier between you and the patient. Sit across the corner of the desk or even along the same side of the desk—that way your patient will feel more at ease and speak more readily
- . If you can, get up and go out into the waiting room to bring your patient in. At the very least, stand up to greet your patient and even shake his or her hand as he or she enters your consulting room¹⁹
- . Be open with your notes or computer entries. This will reinforce the openness of the relationship.

CONCLUSION

At its heart, the compliance issue has a paradox; that in order to be influential, the medical practitioner has to share his or her power with the patient. Patients remain authoritative about their experience of their condition. Patients alone can set goals for themselves, and make the choices about the costs and benefits of treatment. Healthcare professionals know how patients' goals can best be accomplished by working with their condition and its treatment.

There are a number of clear implications for medical practice. When doctors, nurses, physiotherapists, or any other healthcare professionals deal with patients, they need to:

- . Show the patients how to make a difference to their health
- . Teach them how to formulate and ask questions in their consultations
- . Help them discuss their thoughts and concerns with the doctor or nurse
- . Involve them at all times in diagnostic and treatment decisions
- . Reinforce their efforts to look after themselves well . . . and never undermine them.

The manner in which consultations are conducted makes a difference to compliance and to the patient's subsequent experience¹⁷.

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