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# Improving adherence to treatment in child health

Q5  Max Davie

## Abstract

Adherence is a common, important and under-recognised problem in paediatric practice, especially around chronic disease management. Poor adherence, usually either for some of the time or for some elements of treatment, is a complex phenomenon with sociological, psychological and medical roots, which requires a patient and skillful approach.

This paper presents the scope and degree of the problem, before explaining some of the ways in which patients arrive at a position of poor adherence, before presenting a practical approach to tackling poor adherence in paediatric clinics, incorporating ideas from motivational interviewing.

**Keywords** adherence; chronic illness; communication; motivational interviewing; psychology

## Q1 Introduction

Paediatricians are, as a rule, engaging sorts. Their clinics are full of bonhomie and smiles, and at the end of clinic visits there is, usually, a warm agreement that a certain management plan is carried out. But research suggests that these plans are not followed in up to 50% of cases. This article aims to explore why this is, why it matters, and what you as clinicians might be able to do about it. I will concentrate on the management of long-term conditions, as this is where difficulties tend to be most pronounced.

## What is adherence?

Adherence is the degree to which a patient (and in paediatrics often the patient's family) adhere to an agreed management plan. The term has been adopted in preference to compliance, which suggests obedience to medical advice handed down from on high. Adherence, by contrast, is seen ideally as the process of following a jointly generated management plan to which patient, family and clinician have contributed. The term concordance is also sometimes used, with similar meaning.

It is important to note at this point that adherence is not an all-or-nothing phenomenon: patients may adhere only some of the time, for a variety of reasons. Alternatively, they may adhere to certain aspects of management better than others: for instance it has been found that the adherence of young people with diabetes is much better for diet than for exercise. Equally, many patients adhere to treatment sporadically. For these reasons the

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term non-adherence has been largely replaced by incomplete adherence.


## How common is incomplete adherence?

This is a surprisingly hard question to answer, for a variety of reasons:

- It is hard to measure: physician or patient rating scales are affected by bias, serum or urine markers are affected by physiological factors unrelated to adherence, and even automated counting systems (for instance physio vests used in cystic fibrosis that record number of uses) can quite easily be cheated in most cases.
- It can be hard to tell what counts as incomplete adherence. Many children with ADHD don't take their medication at the weekend, and generally this does no harm. A parent may decide to reduce laxatives before advised in chronic constipation and turn out to have been right to do so. Do these cases count as incomplete adherence?
- Adherence rates vary widely between studies and conditions.

The one thing we can say with confidence is that incomplete adherence is very common, and happens in all branches of child health. Your patients do it, and so do mine. It may even be that you, like me, have been less than perfectly adherent in the past.

## Why does incomplete adherence matter?

It seems obvious that better adherence would lead to better health outcomes, and certainly at a population level this is demonstrably true. At an individual level, however, the story is more nuanced. Poor adherence would certainly make poor outcomes more likely, but it can sometimes be hard to convince a resistant patient that this ome data applies to them.

## What are the factors that lead to poor adherence?

There are few over-arching factors that determine adherence in all settings: it is more important to understand what lies behind each individual case. For this reason the following should be treated as a list of possible factors underlying a given case, rather than risk factors for a population.

### Demographic factors

Age is perhaps the most straightforward 'risk factor' — incomplete adherence increases markedly during the teenage years, as the young person plays out normal adolescent conflicts in the context of chronic illness.

Many studies have shown incomplete adherence to be more common in socially deprived families, but recent data has suggested that in some communities the richest are more likely to have difficulties adhering.

Social isolation is fairly consistently related to adherence problems at a population level; this is thought to be mediated by a lack of 'social capital' sapping the patient's motivation to stay healthy and participate in society. However at an individual level the relationship is often more complex: competing family demands can interfere with the delivery of treatment, while 'isolated' families can find strength in a shared purpose (but see below).

### Cultural factors

There is not it's evidence that specific cultural groups are more prone to incomplete adherence. However, it is very worthwhile talking to patients and families about who they discuss their illness with, and what people say about it; in fact this can be a very good way of drawing out health beliefs that would otherwise stay hidden. If the patient or carer are members of a support group, this can be a powerful source of support, but also a source of apparently authoritative advice which can be harmful, as in the case of some ME groups.

The media, and more specifically the internet, is frequently cursed by doctors for breeding poor adherence by presenting alternative narratives and misinformation, but it is important to remember that only information that supports a pre-existing intuition is likely to be printed out and brought to clinic. While challenging the factual assertions of such material, clinicians need to be aware that they are challenging the person who brought the material, and defensiveness can frequently result.

### Family structural factors

There seems to be some evidence that two parents are better able to deliver adherence, but only if their relationship is harmonious. Family conflict is corrosive to adherence in a number of ways:

- there may be a direct effect on the young person's mental health, affecting motivation
- the young person may unconsciously or consciously use his illness to alter or protect family relationships and status, most commonly in an attempt to keep parents together
- the illness may become the 'glue' that holds the family together, giving them a shared purpose and allowing other problems to go unaddressed. This can lead to an unconscious pressure on the young person to stay ill, a very dangerous position indeed.

Meanwhile, lone parents face extra challenges in coping with an ill child. This can overwhelm their capacity to organize all aspects of management. Equally, some data suggests an increased tendency for lone parents to become 'over-invested' in the child's illness. This leads to an anxious need to ensure perfect adherence, which can lead, naturally, to resistance and behavioural problems in the child. Feeding is an especially common battleground in younger children.

### Personal (and familial) factors

There is no evidence that race or gender have an effect on adherence rates, although the latter may have an effect on how adolescents, in particular, approach disease. Attempts to identify a 'non-adherent' personality have failed; instead we need to look at the beliefs, attitudes and skills of individual patients and their families.

### Patient beliefs

Imagine you are told tomorrow that there is something harmfully different about you. You may have felt some symptoms that indicate something is going on, but you don't feel any worse than other, 'normal' people. You cannot see this thing that is there in your body, but you are expected to believe that it is there. You are also told that a particular, uniformed group are the only people with the authority to advise you on this unknown 'thing'.

Now, if the thing you were being told about were a demon in possession of your body, most people would understand a sceptical attitude, and yet doctors often express incredulity that their patients might have difficulty accepting the truth of their diagnoses. We need to understand that patients are often doing a lot of emotional work in coming to acceptance of chronic disease.

The most 'helpful' attitude that a patient can take in most cases of chronic disease is a settled acceptance of the diagnosis, a fear of complications, and a tempered optimism about the possibility of a good quality of life. Naturally most patients fall in some way short of this ideal. Some deny the diagnosis, some the seriousness of its consequences, and some the efficacy of treatment. Merely factually correcting these beliefs is insufficient, as we will see below: we need also to address the attitudes that hold these health beliefs in place.

### Patient attitudes

Few children and adolescents reject western biomedicine entirely, but a proportion of families do, preferring natural remedies or traditional medicine from other cultures. Interestingly, it is rare to find a family from these other cultures that reject the western approach, and more common to find it in families that take a counter-cultural outlook within the western culture. Counter-culturalism has paid wonderful dividends for equality and personal liberty, but sometimes the hostility to any perceived authority it engenders can be unhelpful.

In fact, this suspicion of authority can be a factor in adherence problems for a variety of reasons; in families who have had negative experience of public authorities (medical, social or custodial), and in adolescents who have either experienced rigid unthinking and angry discipline, or no discipline at all. Perhaps the most difficult combination is a young person who experiences rigid indifference at school and no boundaries at home, and subsequently has no way of responding to the empathic, rational authority of the well-trained medic.

The delivery of a chronic illness diagnosis is often compared to a bereavement, and though the comparison can seem overdramatic there is a similar process of processing and accepting the loss of 'healthy' life. Contemporary accounts of bereavement discuss a 'shuttling' between processing the grief and shutting it out in favour of seeking normality – a similar process in chronic disease might explain why a young person is simultaneously fearful of the consequences of untreated disease (processing) and avoiding treatment contacts (shutting out in favour of normality). Drawing out such cognitive dissonance is a key step in managing tricky adherence cases, as we will see. Condemning or mocking such dissonance leads inevitably to the patient feeling threatened and belittled, with resistance and anger a common response.

Even having convinced the child and family of the existence of this (usually invisible) disease process, impressing the importance of correct therapy and the consequences of non-adherence can be extremely difficult. This is often related to the fact that the patient has to trade off tangible, present unpleasantness and inconvenience against possible, intangible future benefit, in a form of cost/benefit analysis. In any decision analysis, it is rational to apply some 'discount' to future benefits – choosing between £1000 today or £1000 in a year is after all, not too

difficult (even if one adjusts for inflation, for those pedants reading). But the degree to which future benefits are ‘discounted’ varies from person to person, and tends to peak in adolescence, meaning that this group value their future welfare less highly than the older, and indeed younger patient. The factors underlying this include neurobiological (underdeveloped frontal cortex) family dynamic (emerging from the parental ‘prudent’ outlook) and cultural ones (a position in society that places restrictions without encouraging responsibility). Connecting the young person to their future selves often required skill and patience. However in some there is an over-connection with future problems, causing a paralyzing anxiety which required expert help.

The other factor involved in the patient’s response to these dilemmas is their active or passive coping styles, and whether they focus on their own emotion or the problem itself.

Finally, having impressed upon the patient and family the seriousness of the situation, it is necessary to instill some optimism. For some conditions there is the helpful possibility of cure, which acts as a great spur to adherence, but for the majority of chronic paediatric diseases we are offering a tolerable but still impaired quality of life. Achieving motivation requires not only that the patient values their future life, but also believes themselves capable of attaining it. The former is to an extent the reverse of the ‘harm discounting’ mentioned above – how much do future benefits matter to me, now? But there is also the often misunderstood concept of self-esteem, thinking of oneself as a continuous through time and as being valuable – obviously not something that can be addressed in a short clinic visit, but which can over time be fostered by encouragement and positivity, especially in the context of secure family relationships. There is a connection between a breakdown of this self-esteem and depression, but it is important to remember that not all young people with poor self-esteem are depressed, nor are all depressed young people non-adherent.

The belief in one’s own ability to achieve improvement is also undermined in depression, but also in learned helplessness, a more subtle psychological phenomenon in which the patient believes the situation to be out of their control – it is easy to see how a young person emerging from a childhood of being looked after and protected by powerful others might have difficulty in feeling in control of their own destiny. As they attempt to re-take this control, they will inevitably make mistakes, and only by encouragement and acceptance will they be able to gain the confidence to manage their own condition.

### Patient skills

Some families and some children take more naturally to the routines of chronic illness than others. Families who have a settled routine can incorporate illness management into this more easily; for others the treatment regime may need to be adapted to fit around them.

Most treatments for children and young people given at home are designed to be delivered without special training or dexterity, but some, for instance insulin injection, require care in preparation and application (e.g. injection site management). Some families, though they may understand the procedure in theory, struggle to put it into practice, and regimes and instructions may need to be simplified and made more explicit. It is often easier to

impose regimes on younger children as they have the expectation that order will be imposed by adults – not so the adolescent!

### Disease-specific factors

Some paediatric diseases may be picked up at a pre-symptomatic phase, or alternatively have phases during which symptoms caused by the condition are either not noticeable or are outweighed by treatment side-effects. At these points the kinds of thought processes described above tend to lean towards non-adherence.

Another issue is whether the doctor, patient and family are all pursuing the same benefit. To take the example of diabetes: the doctor may be pursuing a low HbA1c, both as a marker for positive physical outcomes and a demonstrable quality marker for her service; the family may be pursuing settled adherence and a son who is less ‘mouthy’, while the patient wants only normality. Difficulties occur when these interests diverge, and it is useful for doctors to remind themselves that their own priorities are not the only ones at play, and that it is not necessarily irrational to think differently.

(Also some disease factors may be more salient to life and death in terms of both short and longer term consequences of adherence ‘breaks’ (e.g. PKU – short term) and organ rejection (long term)).

### Treatment-specific factors

Some treatment regimes are easier to follow than others. Some of the factors underlying this are obvious: a pleasant tasting liquid taken once daily will naturally be more easily adhered-to than an unpleasant-tasting medicine that has to be given frequently, as anyone who has tried to steer a young child through a course of penicillin will attest. Patches where available bypass this problem, while of course needles worsen it, at least initially. The interesting thing, however, is that advances in the convenience and palatability of medicines have not resulted in an overall improvement in adherence rates – but we have seen already why this might be.

The other important factor is what we mean by ‘treatment’ – all involved are sometimes guilty of equating treatment and medication, and the non-pharmacological aspects of treatment (diet, exercise, lifestyle) are neglected, despite their impact on outcomes. For the young person with cystic fibrosis, for example, while medication, nebulisers and physio are unpleasant and inconvenient, they are at least confined to particular parts of the day, whereas dietary advice and restrictions on lifestyle are always present, and can feel more oppressive for this reason. Again the patient and family make their own cost/benefit analysis, often with radically different weighting to the professionals.

### Can we do anything to minimise poor adherence?

As adherence has emerged as such a complex phenomenon, the reader might be forgiven for despairing of ever making a difference, especially in a brief paediatric appointment. Well, it is certainly true that patients with adherence problems can require considerable investment in time, and also that no one intervention will work for every patient (or every patient with a particular condition). However that investment will be rewarded with a deepening of the doctor–patient relationship, mutual



understanding and learning on both sides, and hopefully more reliable adherence!

In this section I aim to describe an approach to tackling adherence problems. This approach is made up of pre-existing ideas, but arranged in a way that is hopefully useful to the busy paediatrician.

Before we begin there are a few principles to establish:

- You need to work as a team, both with your clinical colleagues (medical, nursing, therapies, psychology), but also with primary care, education, social care and of course the family. (see later comment about sharing roles strategically).
- You need a comprehensive approach- leaping to conclusions about the 'single cause' of adherence problems can cause great trouble.
- The aim should be to form a therapeutic alliance with parents, working towards shared goals that have been chosen in collaboration.
- You may need to accept that 'good enough is good enough'.

These may sound a bit theoretical and worthy- in fact improvements can be achieved with time, the right attitude and a structured approach.

It might be useful to structure your approach as follows:

- Listen
- Explain
- Adjust
- Discuss

#### Part 1: Listen!

This is by far the most important step: many problems can be quickly drawn out and addressed by skilled active listening and common sense.

This can be further broken down into.

**a) Setting the right context:** first of all, make time for your patients who struggle with adherence- this is time you will most likely save back once they have improved.

You may need several conversations in order to make progress, so make yourself available between clinic visits by phone or email.

See the family in a comfortable, friendly setting.

Consider seeing the child separately (again, a sound time investment).

During the rest of the consultation, remain alert for clues to the adherence problem, for instance children saying what they think and being shushed.

**b) Adopting the right frame of mind:** your own attitude as a clinician is crucial. You must accept that incomplete adherence is normal, and seek to influence the patient's own decision rather than control that decision. I hope that the section above on patient attitudes makes clear how futile a finger-wagging, paternalistic approach is likely to be. By viewing the patient as a responsible agent, you are encouraging them to take that responsibility, and make sense of the contradictions in their own position. In order to do this you need to shed the medical role to an extent, in a way vacating an 'expertise position' in the consultation and allowing the family and patient to take up this

space. It feels uncomfortable and exposing, but such a shift is necessary to draw out what is going on. If you personally feel unable to make the shift, you may be lucky enough to have a colleague who will, and your job is to support them.

**c) Asking the right questions and reflecting thoughtfully:** it is helpful to assume incomplete adherence when asking about it, so rather than asking 'do you ever miss your dose' ask 'how often do you miss your dose?' or 'When are the times that it's hardest to remember about your dose/how often does this happen?' Factual, matter-of-fact questioning which quantifies adherence is not so loaded with negative connotations.

The young person, particularly, should have their feelings validated (without agreeing with their factual statements). It may seem a cliché to say "I can see how you might feel that way" but from a previously distant figure of authority like a doctor it can mean a lot! It can also normalise feelings to say 'other young people I talk to tell me they find  $\times$  hard'.

You need to sensitively explore what the young person and family are scared or worried about, while looking out for any indication that the family or patient feel trapped with few or any choices- showing that you understand this is also powerful.

When you hear something of the patient's feelings, reflect this back to them, partly so they know you understand, and partly so that they can have a chance to examine their own thinking. We will return to reflecting below.

#### Part 2: Explain

Adequate relevant knowledge about the condition and treatment is a necessary but not sufficient condition of adherence. When giving information that has not been requested it is helpful to introduce this slightly gently to avoid lecturing: something like 'I'd like to explain a bit about this if that's OK'. Break information into chunks, and check regularly that the patient is a) listening b) understands and c) finds it relevant. You can help with the latter by bringing in connections between the general information you're giving and their particular situation. Even here open questions can be useful; "so what do you make of that?". It is helpful to support verbal information with leaflets etc. but even more helpful to give the family a way of answering the questions that occur to them once they have left clinic. Again, it's important to bear in mind that trust in information is crucial and such trust is based mainly on personal relationships, so even if you are not the most knowledgeable and experienced member of your department, you may well be the best explainer for this family. Finally, remember that when someone asks for information, they may also be asking for support, or simply to talk.

#### Part 3: Adjust

At its simplest, this is a process of fitting treatment, as far as possible, around the family's life. Drug doses should be as infrequent as possible, and appointments co-ordinated to minimise visits to hospital.

However a more interesting process is a two-way one where the family's routines and habits are moulded to incorporate treatment. At its most mundane this can be as simple as giving medicine after teeth-brushing, but it can also evolve to quite comprehensive planning and contracts made between healthcare teams, families and patients.

Younger children in particular can need encouragement to form the habit of treatment and may benefit from reward charts and systems aimed at encouraging adherence, although care must be exercised to make the rewards attainable and frequent enough that the child does not get discouraged. It is also important that should the child refuse treatment, this results in no reward, but the child is not forced to comply – it is worth missing the occasional treatment to avoid undermining the child's emerging ownership of their treatment. (nice point) With adolescents, parents have often grown used to not expecting the patient to adhere so act first (e.g. phoning to check they've taken medication, prompting about eating which is interpreted as 'nagging' and sets up vicious cycles. Encourage them to leave space for the YP to act first e.g. YP takes responsibility for testing – parent ONLY phones if haven't heard by agreed time, prompt once and leave for an agreed time period etc. Also might explore fitting treatment in with YP friendly aids such as IT, phone Apps etc (not that I know too much about this!)

#### Part 4: Discuss

Once you have listened, empathized, explained and adjusted, there will still be some patient whose adherence falls short of 'good enough'. For these I have borrowed concepts chiefly from the motivational interviewing literature, but other approaches such as solution-focused therapy and problem-solving therapy have their contribution to make. I would suggest that anyone interested in these methods explore the further reading below and talk to their local clinical psychologist. However, a few principles and techniques can be covered here:

It's important to state that there is consensus that the best management of problems is multidisciplinary, and that it can help to have different team members taking different roles, so that one person may act with medical expertise and advice, while another gets alongside the young person, and follows their thoughts and emotions without seeking to influence.

In motivational interviewing, the clinician avoids arguing for change, instead inviting change by reinforcing and encouraging small changes generated by the patient. The patient's perspective is centre-stage, and change comes from a process in which their perspective is reflected back at them so that they are encouraged to examine it. 'Cracks' in any resistance can then be identified and developed, and suggestions for change, coming from the patient, are encouraged and validated. This may sound complex in theory, but in fact these techniques can be used by non-specialists in mainstream clinical practice.

When approaching an adherence discussion, the following steps can be useful:

- Agree the topics to be covered with the patient and family – don't try to cover all issues at once
- Get the conversation going as explained above under **Listen**. Monitor the conversation for clues to a desire to change
- The aim is then to help develop a discrepancy between current behaviour and the patients' own goals. Several techniques can be useful here:
  - You may ask the young person what they would change about their current situation, or for three wishes.
  - You can provide information about what other people in this situation have found, and check their response to this.

Many young people will produce aims that can be matched to desired behaviours, and this is explored below. However, resistance is common.

- It's important to avoid argument and direct confrontation and adjust to resistance rather than opposing it directly. Rather than responding with persuasion, you will lower resistance if you sidestep an argument and encourage conversation, by reflecting the patients perspective back to them and subtly suggesting new ways to look at the situation (reframing). As a general rule of thumb, it's good to keep a pace behind the patient so that the young person leads the way towards change, and try not to convey that you want change MORE than the patient does (as everyone else does this, especially parents). Take for example the following exchange in an ADHD clinic.

"I just don't know why mum worries about me. I'm fine"

"You don't think she should worry"

"Well, not about the stuff she goes on about"

"Do you think that we could talk about what she should and should not worry about, so that we can help her worry in a more useful way"

The conversation is thus set on a new path without the young person being confronted. Somewhat paradoxically it may also be helpful to be cautious about too much change, too quickly.

See further reading (especially Duff and Latchford) for more examples.

- Once you have a disparity between current behaviour and intended behaviour, you can help the young person to consider the desirability of change and the barriers to it.

Some useful tools at this stage are:

- Scaling questions – decide out of 10 how desired a given change is, and then out of 10 how likely the change is to be achieved. This opens up discussion of barriers in a way that can allow for problem-solving
- Decision matrix – a 2 by 2 table which examines quite simply the advantages and disadvantages (on one axis) or change and non-change (on the other axis)

During this part of the process, the patient needs to be encouraged to find their own answers and solutions, and validated when they make steps towards this- never has the old cliché of 'no such thing as a bad idea' been more true!

- Planning for the next appointment: at this point, review the patient's plans, and encourage and praise any progress made when any contact occurs.

The aim is that the young person's self-efficacy is fostered to the extent that they start to take 'ownership' of their treatment, leading ultimately to better, more consistent management and outcomes.

#### Conclusion

Problems with adherence are an everyday phenomenon in the paediatric clinic – minimising their impact requires an understanding of how adherence becomes problematic. This understanding in turn requires an open, non-judgemental and holistic view of the various factors at play and a willingness to be flexible in modifying them. Hopefully adopting the approach outlined in

this paper can LEAD to better understanding between clinicians, families and young people, and better outcomes for all! ◆

#### FURTHER READING

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#### Practice points

- When approaching a case of poor adherence, consider the context of patient, family, treatment and professional factors carefully
- LISTEN in a neutral and non-judgemental way
- EXPLAIN the condition and treatment clearly
- ADJUST regimes as appropriate
- DISCUSS change in a non-directive way
- Read about different techniques, including motivational interviewing