

Compliance with treatment protocols: interventions for children with chronic illness

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The delivery of health care is, in part, dependent on the willingness and motivation of patients to follow the regimens prescribed. No matter how effective treatments are, if children and parents do not follow instructions adequately, then health care is compromised. During the past 20 years the medical literature has been concerned with the issue of compliance, however, the current debate on evidence-based practice has, so far, failed to address this important dimension. To date, little account has been taken of methods to improve compliance within medical protocols of treatment.

Many childhood chronic conditions such as asthma, diabetes, cystic fibrosis, and chronic renal disease require complex management regimens of medications to be taken daily as well as dietary or activity demands or restrictions. In addition, some children may have to undergo painful or demanding medical procedures. Treatment regimens may also bring with them major life disruptions such as attendance at clinics, frequent hospitalisations or treatment sessions, which cause absences from school. Some parents may have to give up work to deal with treatment demands. Families are responsible for following treatment protocols while dealing with the stresses and demands of the disease process.¹

The literature has consistently documented a link between regimen complexity and compliance. The rates of non-adherence cited for some conditions show that compliance problems are so frequent that they could be considered to be a normal response to the demands of illness and treatment. For example, when adherence rates to antibiotic regimens among bone marrow transplant patients were examined it was found that 52% of patients had problems.² Similar rates of non-adherence were found for multivitamin use in cystic fibrosis patients.³ The high rates of non-adherence among asthma patients have been described as a “cost problem” because of the increased rates of hospitalisation that are needed to maintain lung function.⁴

What should be done? Over the past 20 years, behavioural research has made some headway in determining the many factors affecting treatment adherence. In addition, there have been some developments in procedures to encourage and improve compliance and health outcomes. This brief article reviews

some of these findings and suggests ways that they may be implemented in clinical practice. However, as the literature about compliance is beset with a number of methodological problems I begin with a discussion of some of these issues.

Compliance: definition and measurement

Traditionally, compliance has been defined as “the extent to which a person’s behaviour coincides with medical advice”.⁵ However, in complex regimens where treatment may be individualised and standards flexible this definition seems inappropriate. For example, many different actions may need to be carried out on a daily basis and each action or procedure may need to be coordinated with others. In insulin dependent diabetes (IDDM) insulin injections must be given once or twice a day and must be appropriately timed in relation to meals. Regular exercise must be carefully coordinated with food intake to avoid hypoglycaemia. Regular testing of glucose also needs to be carried out to enable changes in insulin concentration, diet, or other aspects of the regimen that will maintain blood glucose as close to normal as possible. Under such conditions the measurement of compliance is much more difficult. Some have suggested that terms such as “levels of self care behaviour” should be used where there is no clear prescription available, while the terms adherence or compliance are reserved for situations when instructions are specific and do not fluctuate.⁶

HEALTH STATUS, TREATMENT OUTCOMES, AND COMPLIANCE

Within the medical literature a range of methods has been used to measure compliance—for example, biological measures such as assays or markers of drugs in body fluids, patient reports, medication counts, use of instrumentation (such as computerised medication dispensers) or measures of treatment outcomes. Each method has its own shortcomings.⁷ Health status or health outcomes are among the most frequently used measures but they can be the most problematic. Although adherence and health status are linked there have been few empirical tests of this association. Studies of compliance frequently confound these concepts—for example, using measures of health status and compliance interchangeably.

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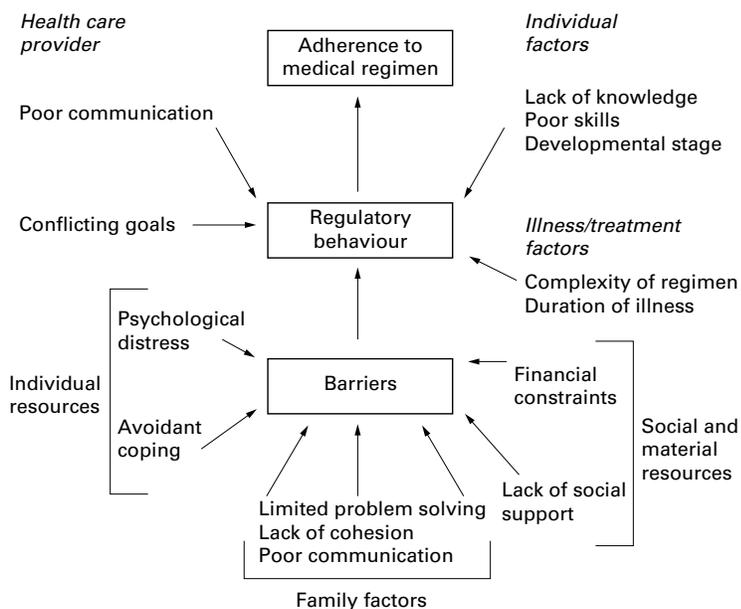


Figure 1 Factors affecting treatment adherence.

While measures of health status may reflect poor compliance they are clearly not the same as a range of other factors, such as misdiagnosis or adequacy of the treatment regimen, may also affect outcomes. For this reason it has been suggested that adherence and health status must be separately defined and measured. Some interesting measures such as the 24 hour behavioural recall interview have been developed to measure compliance in complex regimens independently of health status.⁸

COMPLIANCE: A UNITARY CONCEPT?

Compliance is often treated as if it were a unitary concept—for example, families or children may be designated as “compliant” or “non-compliant”. In addition, in a number of research studies compliance with complex regimens has been measured using a single composite score as if a child were equally adherent to all aspects of the regimen. It is now clear that adherence behaviours are not strongly correlated with one another and that children may be very compliant with one aspect of a regimen but not another. Accordingly, multifactorial models may be appropriate when measuring adherence.⁸

Factors affecting compliance

There is now a substantial amount of literature describing the range of factors that affect compliance (fig 1). Several studies have shown that age is significantly correlated with compliance. In studies of diabetic patients, adolescents exhibited poorer compliance than younger children to injections, exercise, dietary, and glucose test prescriptions.⁹⁻¹⁰ Similar findings have been noted for children with renal disease where adherence to dietary fluid restrictions has been found to decrease with age.¹¹ In contrast, younger children often have more problems participating in medical procedures. They show more procedural distress and are less cooperative during venepuncture, lumbar puncture, and bone marrow aspiration.¹²

Not surprisingly, socioeconomic factors also appear to be important. Families from low socioeconomic groups have more difficulties with appointment keeping, reporting children’s reactions to treatment, and adhering to dietary and medication regimens.¹¹⁻¹³

Illness factors are also related to compliance difficulties. For example, non-adherence has been found to increase with the length of time since diagnosis in a number of chronic conditions.¹¹⁻¹⁴⁻¹⁵ In addition, adherence problems may be greater where there is more functional impairment or additional physical handicap.¹¹⁻¹²

Adjustment and coping have been associated with problems in adherence. Difficulties adjusting to diagnosis and treatment, high levels of avoidant coping, and high levels of psychological distress have all been reported as more frequent among children who have difficulties with their treatment regimen.¹¹⁻¹⁶

Family factors have also been examined. Children whose parents are more supportive, more flexible, less critical, and good at problem solving have been found to have fewer problems in adherence.¹²⁻¹⁷⁻²⁰ Marital conflict and lone parent status can also impede adherence, presumably because to cope with the rigours and demands of treatment good supportive family networks are needed.¹¹⁻¹⁸

Finally, the behaviour of health care professionals is also important. In one survey of 473 outpatient visits over 15 months, 2578 treatment recommendations were made. However, the authors reported that few “adherence facilitating behaviours” were observed or recorded from the health professionals in the clinics.²¹ The organisation of clinics and training of health care staff have been noted as an important area for future research and intervention.⁴⁻²²

Interventions

Interventions to improve compliance fall into three main types:

- educational
- cognitive/behavioural
- self regulatory skill training.

There have been a number of useful reviews of these methods.²²⁻²³

EDUCATIONAL

Not surprisingly, numerous studies have shown that significant procedural errors are often made by parents²⁴ or children with chronic illness²⁵ when carrying out complex treatment regimens. For families with knowledge or skill deficits educational regimens are very important.

In some cases, patients or parents may see themselves as knowledgeable and compliant but problems exist because they have different goals from clinicians. Marteau and colleagues²⁶ found that the treatment goals of parents of diabetic children were governed by the avoidance of short term threats of hypoglycaemia whereas doctors’ goals were governed by avoidance of the long term threat of diabetic complications. The outcome of treatment was more closely related to parents’ than doctors’

Table 1 Cognitive behaviour therapy techniques for managing pain

Strategy	Rationale
Challenging negative thoughts	Reappraise the interpretation of pain
Relaxation	Lessen the experience of pain
Distraction	Cognitively distract from pain
Guided imagery/directed "daydreams"	Cognitive distraction and promotion of mastery

goals. In such cases it is obviously important for educational programmes to realign clinical and parental goals.

Psychoeducational approaches have attempted to improve adherence by promoting knowledge about the condition and its medical treatment, as well as providing training in recognition of factors that prevent adherence such as emotional reactions to diagnosis or treatment.^{11 27} It has been suggested that problems of adherence should be discussed from the outset and treated as a normal occurrence, which needs to be addressed jointly by the family and clinical team throughout treatment.

When successful, patient education takes into account:

- a child's developmental stage
- who will be carrying out the requisite actions (parent or child)
- why such actions are necessary
- what side effects might be expected
- what the likely outcome will be.

In addition, the understanding of parents and children about what is expected of them needs to be carefully checked as there are often surprisingly large discrepancies between what health care staff feel they have told patients and what patients actually recall.²⁸

Educational interventions can now use the considerable body of research evidence on the construction of written leaflets for patients that are easily understood. Advice is also available about how material might be organised and categorised to aid retention.^{29 30}

In a review of work with asthmatic children Lehrer *et al* suggest that psychoeducation can improve compliance with medication and self competence in controlling symptoms, as well as decrease the use of medical services.³¹ Delamater *et al* found that patients aged 3–16 years with diabetes who participated in self management training had significantly better metabolic control one and two years after diagnosis than those who received standard outpatient treatment.³²

However, research also suggests that although providing information to children and parents increases their knowledge about both their illness and treatment, it is often not sufficient to increase the likelihood of adherence to *all* aspects of the treatment regimen.³³ In such cases additional interventions may be required.

BEHAVIOURAL INTERVENTIONS

Behavioural approaches have been the most widely used interventions for addressing problems of non-adherence. These approaches generally incorporate techniques based on social learning theory and, more recently, work on attitudes, beliefs, and cognitions. The assumption underlying such approaches is that some behaviours (for example, dietary habits)

are difficult to change having been established over long periods of time and that lasting change is only possible by breaking down habitual patterns and building up new patterns of behaviour.

Programmes for chronically ill children have included:

- self monitoring—such as detailed chart keeping of medication intake
- establishing control over stimuli that evoke habitual patterns of behaviour—such as teeth brushing and temptations for increased drinking for children on dialysis
- goal setting—such as level of frequency of glucose monitoring in diabetic children
- behavioural contracting—such as written agreements between physician and family members about what specific behaviours are required
- corrective feedback and reinforcement—avoidance of blame and criticism and systematic encouragement or rewards for approximations to the desired goals.

Creer⁷ has reviewed the behavioural techniques successful with asthmatic children and Delamater³⁴ has reviewed the outcomes of a series of individual, group, and family interventions for children with diabetes. Results were promising. Of 12 group interventions for diabetic children over half of the studies showed improvements in metabolic control while a further four showed other indications of improved adherence.

In some cases adherence problems may be linked to other behavioural difficulties. Several behavioural interventions have been demonstrated to improve adherence to dietary protocols by direct treatment of feeding behaviour problems.³⁵

Systematic desensitisation has become the treatment of choice for helping children cope with venepuncture.³⁶ The process typically involves a combination of graded exposure and deep muscle relaxation. It has been shown to be effective within a short time scale, perhaps even after only one session.³⁷

Cognitive behavioural approaches have also been reported as effective in helping children manage pain and painful procedures. However, these tend to be used with older children and adolescents because an ability to verbalise thoughts is a prerequisite for this form of intervention (table 1).

There are several studies that have evaluated cognitive behaviour therapy (CBT) as an alternative to pharmacological treatment to reduce pain. Kazak *et al*, in an excellent study, report on the efficacy of drugs and CBT in the treatment of leukaemia.³⁸ Ellis and Spanos³⁹ review useful CBT interventions for children undergoing bone marrow aspirations and lumbar punctures but these techniques would also be useful for children undergoing other painful medical procedures.

There are now many studies that demonstrate that behavioural approaches are successful in the short term in improving compliance with medical regimens. However, there are few investigations that have demonstrated long term effects where fundamental lifestyle

changes are necessary in the context of chronic disease. A major research effort is needed to address methods to prevent relapse in adherence and to promote long term behaviour change for children with chronic disease.

Self regulatory skills training

Arguably the most interesting approach to adherence lies in the self regulatory framework of Leventhal⁴⁰ and the stages of change model of Prochaska and DiClemente.⁴¹ These models take account of the multifactorial nature of adherence problems (fig 1) and the need to address the problem of maintaining difficult lifestyle changes over long periods of time and preventing relapse. While much of this work has been in adults there is clear applicability for families of children with chronic illness.

Self regulatory skills training aims to foster patients' views of being effective managers of their own illness, and to achieve this a variety of procedures are included. Particularly important is the establishment of a collaborative relationship among health professionals, patients, and family members. Unlike some of the other approaches described above, the health professional responsible for the patient's treatment is closely involved in the intervention. An essential requirement is that the multidisciplinary team caring for the child and family adopts a single approach to their medical management, which incorporates the self regulatory skills perspective. The approach includes: self control training such as self regulation of medication, planning, and problem solving skills; training in intra-personal and interpersonal skills; relapse prevention; and attribution retraining.^{22 23}

Several studies have documented the practical problems for the families of chronically ill children and have established a relation between these and treatment adherence. An important aspect of a self regulatory approach is to encourage and support patients and families in identifying and solving some of the practical problems around treatment—for example, peer pressure.⁴²

It is also suggested that patients are inoculated for "failure" and "relapse" so that when this inevitably occurs they do not panic or engage in self denigration. Instead, each relapse is taken as a learning experience. Relapse training helps individuals and family members anticipate and plan for high risk situations where adherence relapse is likely.²²

Conclusions

A substantial body of research now exists that identifies the multifactorial nature of adherence problems in complex treatment regimens for chronic illness in children. There is also a growing body of evidence of systems of care that encourage patients and families in self regulatory treatment skills. Until recently the evaluation of psychological interventions in chronic childhood illness had been plagued with methodological flaws, and randomised controlled trials have been conspicuous by their absence. Poor sampling and poor data collection were common. While only a few studies have been reported in this article, there is little doubt that

certain evidence-based psychological interventions are effective in addressing some of the challenges faced by children with chronic illness, as well as their families. The task is now to incorporate these procedures into medical treatment protocols and systematically test their effectiveness in routine use.

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