

Editorial

Education makes people take their medication: myth or maxim?

It is a source of frustration to many clinicians: you know what the patient's problem is, you know that effective and safe treatment is available, you've explained the disease and its causative mechanisms, the treatment and its principles, and the importance of taking the controller medication daily, you've prescribed this highly effective therapy and you've approached the patient with respect and patience, yet somehow the patient does not take the medication. When this patient has another exacerbation, you know it could have been prevented by following your advice and taking the medication.

When we, as clinicians, are faced with such a nonadherence scenario, our default mode is to repeat the message that we delivered when we first saw the patient and provided self-management education: we stress, once again, that it is really important that the patient takes their daily controller medication. Apparently, many healthcare professionals believe that such repeated education makes people take their medication. In this editorial, we argue that this is a myth. There is extensive high-quality evidence that education, on its own, does not promote adherence to daily controller medication in patients with a chronic disease [1, 2]. There is also evidence to support an effective alternative approach: healthcare professionals can do a lot to promote adherence in their patients through shared decision making

[1, 3, 4]. The key to promoting adherence through education is not in what message we convey, not in the content of information we provide, but in how we provide it. In this sense, the statement in the title is also a maxim: education can certainly promote adherence, if performed effectively. Therefore, we also review the evidence on the principles of effective patient education which healthcare professionals can use to promote adherence.

In this review, most of the evidence and recommendations that we provide on adherence and adherence-promoting communication strategies comes from paediatric studies and our experience in paediatric care. In this setting, parents are primarily responsible for making the decisions on the treatment of their child's medical condition, and most communication about the patient's adherence to daily controller therapy is conducted between adults, *i.e.* the healthcare professionals and the child's parents or caregivers. This may help to understand why the principles of adherence and nonadherence, and the communication strategies healthcare providers can employ to promote adherence in their patients, are the same in paediatric and adult care. To improve readability of the remaining text, we use the word "patient" to include the people responsible for the patient's medication taking behaviour, irrespective of the patient's age.

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Education on its own doesn't make people take their treatment as intended. However, when it follows shared decision making, in which patient and doctor together agree on the best course of therapeutic action, education helps patients take their treatment. <http://bit.ly/2G2XswD>



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Nonadherence: the most common cause of uncontrolled chronic disease

Although the guideline-based daily controller medication prescribed for chronic diseases such as asthma shows clinically relevant beneficial effects in clinical trials and meta-analyses, we regularly encounter patients in whom this treatment does not seem to work as well [5]. In patients with such uncontrolled disease, the guidelines prompt us to step up treatment, increase the dose, add more drugs, or screen for relevant comorbidity affecting disease control. Despite their strong evidence base in cases of true therapy-resistant disease, such interventions are not likely to be effective as long as the major underlying cause of poor disease control remains unaddressed: nonadherence to follow treatment recommendations [6–8].

In 2003, the World Health Organization (WHO) summarised the evidence, available at that time, on the scope and the impact of nonadherence [4]. The WHO described it as a “worldwide problem of striking magnitude”, with mean adherence rates in chronic disease of 50%, meaning that the average patient with a chronic disease only takes half of the medication doses prescribed to them. It described the consequences of this poor adherence as “poor health outcomes and increased healthcare costs”, and it cited a systematic review concluding that “increasing the effectiveness of adherence interventions may have a far greater impact on the

health of the population than any improvement in specific medical treatments” [9].

Sadly, this situation has not improved much since. Nonadherence in chronic respiratory disease remains common, even in patients with very severe disease. For example, when asthma nurses visited the homes of children referred to a national UK centre because of problematic severe asthma, medication was either absent or out of date in 23% of cases [10]. The average adherence rate of daily inhaled corticosteroids (ICS) therapy in children with asthma is still around 50% [3, 11], reducing the likelihood of achieving asthma control.

Normal medication adherence behaviour

The most widely used theoretical model to describe adherence and self-management behaviour in chronic conditions is the so-called common-sense model (figure 1) [12–14]. According to this model, patients develop their own cognitive representations of their illness, including beliefs about causes of the illness, the impact the illness will have on their lives, how long the illness will last, and whether or not it is controllable or curable. Together with the emotional responses to the threat of the illness, these representations are known as “illness perceptions”. Illness perceptions are shaped by early experiences with being sick, the response from caregivers and family on sickness, and by accounts of illness in the lay press and on the Internet. Thus, illness perceptions are much more influenced by cultural, social and psychological factors than by “objective” medical severity or demographic characteristics. The patient’s illness perceptions strongly determine the patient’s perceived need of medication, which is one of the main drivers of adherence [15].

On the other side of the model, driving the perceived concerns about medication, medication beliefs comprise doubts about the necessity of medication to maintain or promote health and concerns about the potential adverse effects of treatment. Both quantitative and qualitative studies show strong associations between these medication beliefs and medication adherence [13, 14]. Patients consciously or unconsciously balance the perceived need and perceived concerns of medication, and the tip of this balance determines the degree of adherence [13]. The word *perceived* is of key importance – it is the patient’s perceived need and concerns of medication that drives their adherence behaviour, not the objective medical need or adverse effects of medication based on evidence and guidelines. This is one of the reasons why simply repeating the objective medical need of taking medication daily is so ineffective: [1, 2] it does not address the most important factors driving adherence behaviour.

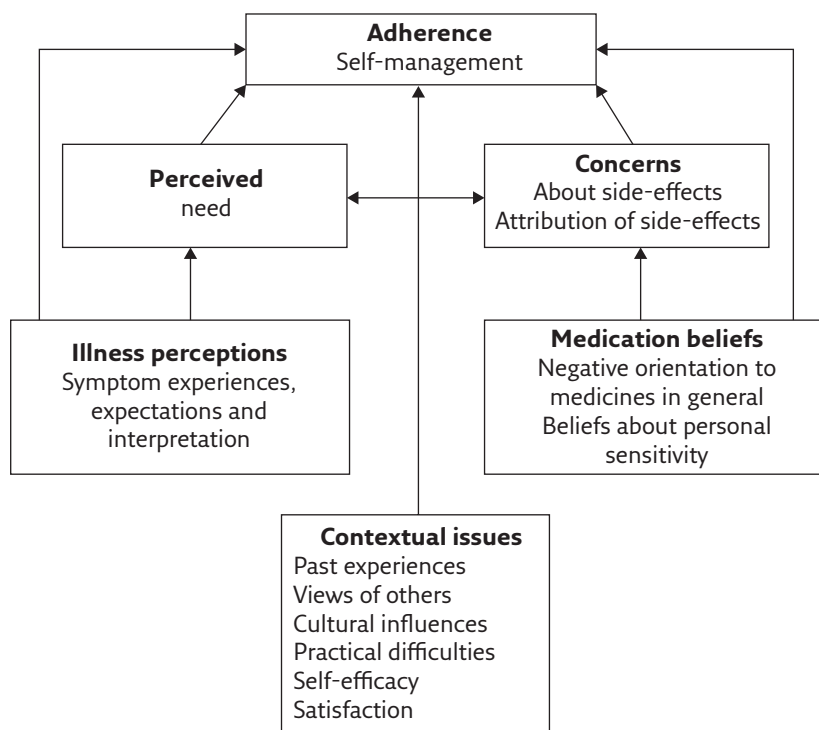


Figure 1 The common-sense model of medication adherence behaviour. Data from [12, 13].

Main forms of nonadherence

The many factors that affect adherence relate to healthcare systems and healthcare providers (*e.g.* short consultation time, lack of healthcare providers' knowledge on adherence), social and economic issues (*e.g.* illiteracy, poverty and lack of support systems), therapy itself (*e.g.* complexity of treatment and side-effects), patient issues (*e.g.* self-efficacy and psychosocial stress) and condition-related issues (*e.g.* severity of symptoms and comorbidity) [4]. Within this complex interplay of factors associated with adherence, three different types of nonadherence can be distinguished (table 1).

Unwitting nonadherence relates to patients who do not understand the rationale or logic of the treatment (*e.g.* do not know the difference between brown and blue inhalers), mix up different treatments (*e.g.* use the blue inhaler daily and the brown as needed), or misunderstand dosing regimens (*e.g.* take medication once every 4 days instead of four times a day). This may be affected by patients' cognitive abilities, language barriers and individual's health literacy.

Unwitting adherence can be addressed by education on the rationale of treatment, *e.g.* the difference between daily controller therapy and reliever therapy. However, the documented ineffectiveness of such education [1, 2] suggests that unwitting nonadherence, although it does occur occasionally, is not the main cause of nonadherence.

Erratic (or chaotic) nonadherence relates either to the complexity of the treatment itself or to the chaos of the patient's life. Failing to understand a complex treatment schedule could also be classified as a form of unwitting nonadherence, and this should be amenable for targeted education. The chaos of a patient's life, however, is less easily adjustable. In families dealing with serious issues like poverty and debt, psychiatric disease, addiction, violence, unemployment or relationship problems, these issues can take priority over taking medication every day [16, 17]. Repeating or providing education on disease mechanisms and rationale of treatment, or on the importance of taking medication daily, will have little effect on these patients. Helping these patients to successfully self-manage their disease requires tailored support after careful elucidation of factors contributing to nonadherence [16, 17].

Research suggests that deliberate (or intelligent) nonadherence is the most common type of nonadherence, with a strong association of illness perceptions and medication beliefs to adherence rates [12, 13, 15]. Many patients choose to ignore the healthcare professional's advice to take medication daily. Some of them believe that they know more about the best treatment for them than the healthcare provider does [18], others respect the professional's knowledge and skills but are convinced that there are other, personal or social, considerations which take priority over medical knowledge in

Table 1 *The differential diagnosis of nonadherence*

Type of nonadherence	Characteristics
Unwitting	Misunderstand dosing regimen, fail to understand rationale for treatment
Erratic (or chaotic)	Difficulty following treatment because of its complexity or because of chaos of patients' lives
Deliberate (or intelligent)	Deliberately decide that perceived concerns of medication outweigh its perceived need

Adapted from [4] and [16].

deciding whether daily controller therapy is good for them (or their child). For example, all parents we interviewed about their view on ICS therapy for their child with asthma disliked or even hated the idea of having to give daily medication to their child, and they used strong words like "poison" and "chemical rubbish" to describe these medication [19].

Assessing adherence and its determinants

Being able to assess adherence reliably is important because it allows the clinician to understand to what degree poor adherence may play a role in a patient with uncontrolled disease. In addition, knowledge of the type of nonadherence in an individual patient is a prerequisite to be able to provide targeted support to improve adherence and, consequently, improve disease control.

The accuracy of different methods to assess adherence varies considerably (table 2). Patient or parent self-report consistently overestimates true adherence, partly because of social desirability bias [3, 20]. The use of anonymous adherence questionnaires may partly overcome this problem, but adherence assessed by validated questionnaires such as the medication adherence report scale still considerably overestimates adherence assessed objectively by electronic methods [22]. Physicians and asthma nurses also overestimate their patients' adherence [3]. Pharmacy refill rates only assess whether the patients have picked up the medication, not whether they have used it [3, 21]. Weighing or using the dose counters on returned inhalers is more accurate, but still open to "dumping" and falsification [3, 21]. Pharmacological techniques (assessing drug levels in blood or urine) can be technically challenging (given the low systemic availability of drugs like ICS), are costly and require repeated blood or urine samples. Because ICS therapy reduces exhaled nitric oxide fraction (F_{eNO}) levels, F_{eNO} has been proposed as a potential ICS adherence marker. However, we found a poor association between F_{eNO} levels and adherence in children with asthma followed up for 1 year [24].

Table 2 *Different methods of assessing adherence*

Method	Accuracy	[Ref.]
Self-report	Highly inaccurate	[11, 20, 21]
Validated anonymous questionnaire	Highly inaccurate	[11, 22]
Physician or asthma nurse assessment	Highly inaccurate	[3]
Pharmacy refill rate	Inaccurate	[3, 21]
Returned inhalers: canister weighing, dose counters	Fairly accurate	[21]
Pharmacological methods: blood/urine drug levels	Fairly accurate	[23]
Exhaled nitric oxide measurement	Inaccurate	[24]
Electronic monitoring	Highly accurate	[3, 21, 25]

Because of their high accuracy, electronic monitoring devices are considered to be the gold standard of adherence assessment [3, 26]. These devices record the exact date and time of each actuation of the inhaler device (in asthma and other diseases using inhaled medication), allowing accurate calculation of adherence as a percentage of the prescribed dosages of medication [26]. Adherence rates >80% are needed to achieve optimal asthma control [27, 28].

Although electronic adherence monitoring is recommended in research studies and in cohorts of children with problematic severe asthma [3, 11], it is too cumbersome and costly to serve as a standard adherence screening tool in the large majority of patients with mild-to-moderate chronic asthma or other respiratory conditions.

None of the adherence assessment methods (table 2) provides the healthcare professional with a reliable tool to distinguish between the three most common types of adherence (table 1). Taking a history remains the most important tool to obtain information about unwitting or erratic nonadherence [16]. Illness and medication beliefs, the main drivers of deliberate nonadherence, can be assessed by validated questionnaires [29, 30]. In the following sections, we will discuss how these can also be explored by talking to patients, and how this conversation can be used to support the patient in achieving optimal adherence.

Shared decision making

As discussed above, almost all patients have strong illness and medication beliefs which play a major role in determining adherence to daily controller therapy. Most patients will not express such concerns spontaneously, either out of embarrassment or because they do not want to disappoint the healthcare professional who evidently does their best to help them. Whether

or not patients are willing to disclose these adherence-hindering perceptions depends on the patient's trust in their physician [31, 32]. Such trust develops gradually, and is determined more strongly by relational and communicational issues than by the physician's medical competence [33].

Taking a medical history through talking to patients and their families has always been a doctor-centred approach, focusing on obtaining the medical information needed to support clinical reasoning and make a diagnosis [34]. This reflects the long domination of the paternalistic decision-making model in medicine [35]. In the past decades, the increasing recognition of the importance of the patient's perspective on their medical problems and the treatment for these problems, with their impact on adherence and other health-related behaviours, has paved the way for another, more collaborative approach to talking to patients and making decisions in medical consultations. This approach has become known as shared decision making [36, 37]. The evidence supporting shared decision making is considerable (box 1). The justification for the shared decision model primarily comes from the ethical perspective of respecting patients' autonomy [37]. Almost all patients expect and prefer to be involved in the decision making process in consultations with a healthcare professional, and prefer to collaborate with their physician [39]. More generally, shared decision making also appeals to the basic human need of being seen, respected and taken seriously [37]. In studies comparing shared decision making with more traditional doctor-centred approaches in medical consultations, shared decision making is associated with patients being more satisfied with the decision making process, the consultation as a whole and the healthcare professional [37, 38]. In addition, they are more satisfied with the decision taken, which increases their likelihood of following through with the actions related to the decision and, hence, with their adherence to the agreed-upon treatment [3, 38]. In shared decisions, patients also tend to go for less invasive and exhaustive treatment options than with paternalistic decision making, which may have an impact on healthcare costs as well [37].

Despite its strong justification and accumulating evidence for its beneficial effects on relevant patient outcomes, shared decision making is applied in clinical practice to a limited extent only [37]. We recently showed that although most physicians preferred shared decision making, they commonly reverted to paternalistic decision making, primarily because they felt the patient was incapable of being meaningfully involved in the decision at hand [40]. Although many physicians thought they already performed shared decision making, they had a limited view of the steps involved in this process, and they hardly ever made clear that a decision had to be made or invited the patient to express their views on what mattered to them in making

BOX 1 Evidence supporting the use of shared decision making in consultations [33, 37, 38]**Justification**

- Patients prefer humane, personalised care
- The importance of patients' autonomy allowing them to be actively involved in decisions impacting their health
- Patients prefer to collaborate with their physician
- Basic human need to be taken seriously and listened to respectfully

Effects

- Increased patient satisfaction with decision-making process and with consultation
- Increased satisfaction with decision being taken, less decisional regret
- Patients choose less exhaustive and invasive treatment options
- Increased adherence

the decision [40]. This is in agreement with earlier findings that healthcare providers ask for caregivers' input on the asthma management plan for their children in only 9% of cases [41].

How can we move from doctor-centred to patient-centred consultations supporting adherence?

The considerable body of evidence supporting a patient-centred approach, in particular shared decision making, as a means to improve patients' adherence to the proposed therapy is reviewed in detail elsewhere [3, 42-44]. The communicative

strategies involved in patient-centred consultations are summarised in box 2.

The opening of a consultation sets the scene for the atmosphere in the consultation, and the patient's trust in the clinician [45, 46]. Rapport building and trust are essential in improving adherence [32, 48]. Setting a collaborative agenda can be promoted by asking patients and their families what they wish to discuss during the consultation, instead of starting with the ubiquitous question "how are you?" (which hardly ever generates meaningful information) or asking doctor-centred questions related to diagnosis or management, *e.g.* questions used to assess asthma control [49].

The first step towards successful shared decision making is to inform the patient that a decision has

BOX 2 Communicative strategies healthcare professionals can employ to promote adherence [3, 33, 45, 46, 47]**Start of the consultation**

- Rapport building
- Collaborative agenda setting
- Aligning expectations

Eliciting the patient's perspective

- Explore illness and medication beliefs respectfully
- Invite patient to share their views and preferences on treatment and outcomes
- Ask for potential barriers in following through with the treatment plan

Show empathy

- Foster the relationship with patients and their families throughout the consultation
- Remain mindful of own thoughts, feelings and distractions
- Do not prescribe one therapy, but present options with pros and cons
- Acknowledge patient cues with empathic responses
- Provide information only at request or with the patient's permission

End of the consultation

- Co-create a plan, respecting and supporting patient's preferences as much as possible
- Invite patient and family to ask questions
- Seek explicit agreement on the treatment plan
- Remain flexible to adjust plan according to patient's preferences

BOX 3 *Practical tips to improve adherence in everyday consultations*

- Ask patients what they want to discuss in the consultation
- Emphasise that you feel it is important to hear the patient's views and preferences
- Ask patients specifically about their illness and medication beliefs and their barriers to follow treatment recommendations
- Listen attentively to what they have to say, respond respectfully and empathically
- Provide information and education only at request or after obtaining permission
- Propose treatment rather than prescribing it
- Seek explicit agreement with the shared treatment decision

to be made, and that the healthcare professional values the patient's views and preferences as important input in this process [36, 37]. As discussed above, most patients will not volunteer their illness and medication beliefs, but are willing to discuss them if the physician respectfully asks them to express their views and feelings regarding the medication, and explores these with "curious pursuit" [45]. This will generate important information on the potential role of deliberate nonadherence. Similarly, although patients tend to be reluctant in volunteering information about barriers to adherence like poverty, chaotic family routines, or psychiatric illness (factors related to chaotic nonadherence), most are willing to disclose them to an interested and empathic listener [16, 50]. Empathic and attentive listening will foster the relationship and build trust in consultations [33]. Conversely, reprimanding patients for not achieving the desired level of disease control or not taking the medication as prescribed increases patients' anxiety to come to the consultation, decreases trust in the healthcare professional, and reduces the effects of the education being provided [50].

Even if guidelines for the patient's medical problem show a strong preference for a certain therapy (*e.g.* ICS for persistent asthma), there is always the option of not applying this therapy. In view of the strong resistance patients express against medication in general [19], we have stopped using the word "prescribing" when discussing treatment, preferring to present the treatment as a proposed option that can be chosen or not. In weighing the pros and cons of such proposed treatment, both medical arguments and the patient's personal views and preferences should be taken into account [3, 37]. Providing information in manageable chunks, only at the patient's request, or after obtaining the patient's consent to provide it, helps in enhancing the patient's motivation to listen to and process the education provided [51–53].

Shared creation of an agreed course of action can help to ensure that the treatment proposed aligns with the patient's views and preferences [45, 46], and increases the likelihood of the patient following through with the treatment plan. This can be further supported by asking the patient for their explicit agreement with the

treatment plan, and with their confidence in being able to follow it [53].

Practical tips to perform shared decision making and improve adherence in consultations

Although specific training helps in implementing shared decision making in clinical practice [54, 55], the tips presented in box 3 may help to get started in everyday consultations to move towards more patient-centred care through shared decision making consultations and promote adherence.

Studies in paediatric and adult patients with asthma have shown high adherence to daily controller therapy when the approaches presented in boxes 2 and 3 are taken [27, 56, 57]. For example, in our cohort of children with persistent asthma followed up for 1 year, the median adherence rate was 84% [27], the highest adherence rate ever reported in a study in patients with a chronic disease. We and others also showed that such high adherence was associated with excellent asthma control [8, 28, 58], confirming the impact of interventions promoting adherence, as predicted by the WHO in 2003 [4].

Conclusions

"Education makes people take their treatment" is both a myth and a maxim. Although education is needed to allow patients to understand the rationale and logic of treatment, education on its own does not make patients take their treatment as intended. However, there are methods to use education in such a way that it does promote adherence. Patients will be more likely to understand and accept health education when healthcare professionals take a patient-centred approach, encourage the patient to share their views and preferences on the treatment, and use these to come to a shared treatment decision. Studies have shown that shared decision making improves adherence and, consequently, disease control.

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