

# Can we improve treatment adherence in patients with chronic disease?

Gérard Reach<sup>a</sup>

<sup>a</sup> Avicenne Hospital, APHP and EA 3412, CRNH-IdF, Paris 13 University, Sorbonne Paris Cité, Bobigny, France

## Summary

The purpose of this article is to show that the legitimate desire to improve adherence in patients with chronic disease presents two challenges: firstly, understanding why certain patients do not follow the recommendations given to them; we show that this is in fact due to a perfectly understandable phenomenon, whose psychological mechanisms we will describe, with certain traits explaining behaviors which at first seem surprising. Then, from this observation, we will analyze the ethical challenge of any attempt to “improve adherence”: in an era where autonomy is advocated, how is it possible to decide what is good for people without falling into paternalism at best and manipulation at worst? We will show that it is possible to give priority to the principle of beneficence, which aims to help patients maintain their health, but on condition of never losing sight that medicine treats, beyond illnesses and patients, autonomous individuals, defined as beings endowed with a reflexive mind. In particular, we will show how a model of chronic care can and must incorporate two key words: trust and what is called patient education, which finds here an ethical definition.

**Key words:** Adherence, chronic disease, patient education, autonomy, ethical principles

It was in 1979 that the concept of patient adherence (the concordance between patient behaviors and medical prescriptions) entered into the medical literature under the name “compliance”, a term that has since been abandoned because of its passive connotation [1]. Since then, there was an accumulation of evidence demonstrating the major deleterious impact of patients’ non-adherence on the efficacy of care, the rate of hospitalization, the mortality of patients and healthcare expenditure. In 2003, in a document published under the auspices of the World Health Organization, it was suggested that improving the efficacy of interventions aiming to improve adherence would have a greater benefit on healthcare than any biomedical progress [2]. This explains the interest that healthcare professionals (HCPs), the pharmaceutical industry and public authorities have in this issue: for HCPs, it is about improving the efficacy of care they provide, for the industry, developing the concept of proper use of medication, which involves adherence – and obviously, increasing sales of medication – and for the public authorities, improving the efficiency of the healthcare

system by avoiding in particular a waste of resources which costs billions.

However, this desire to “improve adherence”, laudable and legitimate at a first glance, is not as obvious as it seems. Indeed, it is remarkable that the same year that the concept of adherence was introduced in the medical field, contemporary medical ethics was enriched with two new principles: while ethics had been based on beneficence and non-maleficence (doing no harm) since Hippocrates, in a seminal work Beauchamp and Childress proposed adding principles of justice (equitable access to care) and autonomy [3]. This last principle, which dictates taking into account the opinion of the patient, was widely adopted. In France, the so-called right of patients law of March 4th, 2002, specifically states in its article L. 1111.4:

*“Every person makes, with the healthcare professional and given the information and recommendations provided by the HCP, decisions about her health: The doctor must respect the choice of the person having informed her of the consequences of her choices. If the choice of the person to refuse or discontinue treatment puts her life in danger, the doctor must make every effort to convince her to accept the necessary care. No medical act or treatment can be carried out without the informed consent of the person and this consent may be withdrawn at any moment.”*

How, in these conditions, can we not see a possible contradiction between the desire to improve the adherence of patients and a legislative text, which can be read as an acknowledgement of the right of patients *to not adhere*? Such a question may seem provocative; it requires reflection that shows how it is possible to resolve what appears to be a conflict between the two ethical principles of beneficence (the desire of the HCPs) and autonomy (the right of the patients).

The purpose of this paper is to attempt to provide an ethical justification of the “desire to improve adherence”, in other words, to reconcile these two ethical principles. We will see how a thorough psychological analysis of patient non-adherence in chronic diseases, a phenomenon which we will show to be perfectly understandable, leads to exploring the very concept of autonomy, which points to the solution of the conflict: the development of a medicine of the person, rather

than a medicine of diseases, avoiding the pitfalls of paternalism and manipulation and in which there are two keywords, trust and patient education, for which we will give an ethical justification.

In general, we propose using certain philosophical concepts, to defend the principle of beneficence by showing that this defense is not inconsistent with the principle of autonomy. This defense, as in any trial, reflects only the views of the advocate who built it and an opposite view of the problem is possible, in the same way that the philosophers that we call in are those who support our argument: it would have been fair to present the views of other philosophers and ethicists with opposing views. We will give one example demonstrating the biased nature of our argument: we cite at the end of our text an article by Shinebourne and Bush defending paternalism in the doctor-patient relationship. It would have been fair to cite the following chapter of the bioethics textbook in which it was published, where Veatch and Mason Spicer argue against paternalism in the therapeutic relationship [4].

## 1. The non-adherence of patients, a paradoxical, yet “natural” phenomenon

### Serious cases and seemingly more harmless cases

Non-adherence is surprising: how can patients not carry out what is being offered *for their benefit*? Is health, the supreme benefit, not what everybody would like to maintain? However, there are facts that are obvious: there is a plethora of patients who do not treat themselves, whether for silent diseases such as diabetes, high cholesterol, hypertension or osteoporosis, for painful diseases such as gout (the disease where non-adherence is the most common [5]), for situations where non-adherence has a heavy toll such as HIV (the development of resistant strains of the virus) or is fatal (rejection of heart transplant if immunosuppressive therapy is stopped). These last cases are particularly surprising and suggest that non-adherence represents a paradoxical phenomenon.

Let's consider a less serious case of non-adherence that concerns physical activity in a disease such as type 2 diabetes. The philosopher David Hume wrote in 1760: “Ask a man *why he uses exercise*; he will answer, *because he desires to keep his health*. If you then enquire, *why he desires health*, he will readily reply, *because sickness is painful*.” [6] Physical activity is an essential part of diabetes therapy, yet one study showed that only 26% of patients engage in it, the two most cited reasons being a lack of time and bad weather [7]. But if we wonder at such an attitude, should we not ask ourselves about our own behaviors: does it not often happen that we do not do what we ought to do? Are there not doctors who smoke and who do not exercise? What we would like to suggest here is that the non-

adherence of patients can be seen as a much broader phenomenon: in general, we do not always do what reason tells us to do. Non-adherence is certainly paradoxical, but it could well be a perfectly understandable phenomenon, *natural* even, in other words caused by mechanisms that, as we will see, arise out of a kind of “physiology of mind”.

### The possible causes of non-adherence: from simple neglect to an “intentionalist” model of non-adherence

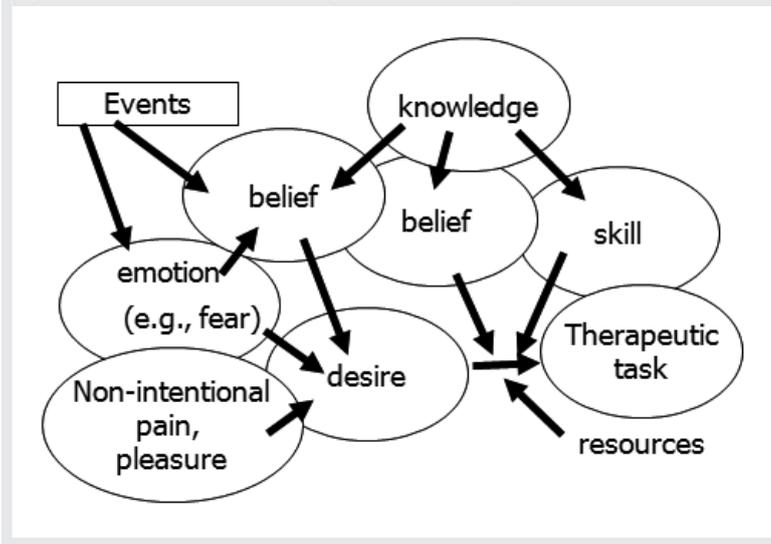
We do not always *do* what we know we should do: first of all, we can simply *forget to do it*: forgetting is certainly a gateway to non-adherence of medication and a way to fight against non-adherence is to screen it with a simple question – “do you sometimes forget to take your medication?” It is likely that these are the easiest cases of non-adherence to solve, for example by associating taking the medication with a ritualistic behavior (keeping the medication beside the toothbrush), or using electronic alarms, text messages etc.

However, forgetfulness is not the only reason people fail to adhere. Figure 1 represents the mental states that, generally speaking, lead us to *do something*, in the areas we are involved in, a “therapeutic action” (for example, take a tablet, refuse a cigarette, etc.) [8]. We can therefore use this figure to enhance our understanding of adherence and non-adherence.

In this model, the arrows have a causal significance, just as in physiology insulin causes a decrease in blood sugar, which is why we previously spoke about a “physiology of mind”. This differs from traditional models of psychology, such as the Health Belief Model, in which arrows linking a belief and a behavior essentially have statistical significance (if you believe that smoking is bad for your health, you are more likely to belong to the group of people who stop smoking). This is where Donald Davidson's causal theory of action represented a philosophical turning point: he defended the idea that the reason of an action is also its cause [9]. We can see here the emergence of possible causes of non-adherence. To treat oneself, the patient must know that she has to do something and how to do it (knowledge and skills), she must hold certain beliefs, for example that the treatment is effective or that she is capable of implementing it; she should not be afraid of the side effects of treatment or have more fear of the consequences of the disease (role of the emotions); she must not consider the treatment as painful; she must have the necessary resources. Above all, she must have the desire to do it.

In our book, *The Mental Mechanisms of Adherence to Long Term Therapies* [8], we put forward this “intentionalist” model of adherence: the term “intentionalist” suggests that people's choices, whether or not to carry out a therapeutic action, depends on the involvement of mental states termed “intentional” insofar as they have a content (for example, “exercise is good for my health”

Figure 1: The mental states leading to adherence (adapted from reference 8)



is the content of the belief (“I believe that exercise is good for my health”). We can see in Figure 1 that the action is not only caused by mental states that have a content (knowledge, skills, beliefs, desires, emotions), but also by non-intentional states, which do not, such as pain, pleasure, to which we could add boredom, anxiety, fatigue etc.

#### Why non-adherence could be a natural phenomenon

In fact, we do not always have control over the factors that determine carrying out what we have called therapeutic actions and which are represented in Figure 1. Firstly, we can lack the necessary resources and another easy way to detect this cause of non-adherence is to ask people: do you have the means to follow the treatment that I am offering you?

But the real problem lies in our mental states. For example, we cannot decide to believe something in the same way we decide to go away for the weekend [10]. It may even happen that we come to believe things knowing full well that they are false, what philosophers call self-deception, or what is known in medicine as denial (I know I am sick and yet I can believe I am not), which is often a cause of non-adherence. Emotions arise in response to events (see Figure 1) and, as the philosopher Pierre Livet [11] said, they cause a revision of our beliefs and our desires. We do not have control over the occurrence of events and the ensuing emotions: as Pascal said, the heart has its reasons, which reason does not know.

The same applies to our desires. Firstly, we do not have only one desire, and just as we can have conflicting beliefs, the desire to get better may be opposed by another desire that is not moving in the same direction. Secondly, this opposition between conflicting desires may also be the opposition between patients’ desires and the desires of those who offer them treatment:

therefore, when we say we should improve adherence, we must understand that it is nothing but a profession of faith that includes the desire, or rather the point of view – or the interest – of healthcare professionals, the healthcare industry, public authorities, but which may not match the desire, the point of view – or the interest – of the person concerned. It is to be expected that the healthcare professional focus her interest on the patient’s health: it is, after all, her job, but the patient’s interest could have a different focus, for example her family, her work, her culture, etc.

In fact, it is in the context of a multiplicity of beliefs and desires that patients should make therapeutic choices, to treat themselves or not. This is probably what the philosopher Donald Davidson was referring to in his causal theory of action [9] when he expressed the fact that we act “after all things have been considered”. But he also acknowledged that even after such deliberation, we sometimes do not do what we had decided, all things considered, would be good to do. To explain this “weakness of will” [12] that has intrigued philosophers since Aristotle [13], he put forward the concept of a divided mind, which he also used to explain self-deception [14]. There is the me who would like to be healed and the me who does not care, just as there is the me who knows he is sick and the one who believes he is not. But if the self is divided, who makes the decision? We can see that the existence of this weakness of will, an “apparent” phenomenon according to Aristotle, must allow consideration of the idea that patient non-adherence, many cases of which can be described as the medical manifestation of weakness of will [15], may well be a natural phenomenon.

#### The force of desire and the double trap of temporality in chronic diseases

Often, in chronic diseases, the choice of adherence or non-adherence can be seen as a choice between an abstract and distant reward, maintaining health, and a near and concrete reward, for example the pleasure of smoking, the entire cluster of grapes, napping in front of the television, avoidance of the boredom of going to get the tablets, etc. A whole new field, neuroeconomics [16], shows that many people are naturally impatient, preferring a small, near reward to a large, distant reward and specifies the mechanisms in the brain. This trait, patient or impatient, is linked to adherence. Thus, it can be shown using a fictitious monetary choice such as “Which would you prefer, 500 euro now or 1,000 euro in a year’s time?” that smokers more often choose the immediate gain [17]. We showed in a cohort of diabetic patients that those who choose the immediate small amount are usually patients who do not adhere to their medication and have poorly controlled diabetes [18].

We can also notice that the particularity of chronic disease is that it lasts: treating oneself means that we want to avoid complications when we get older. But we

have difficulty imagining this person, especially when we are young. Should we therefore do work for this person now? As the philosopher Derek Parfit put it, “My concern for my future may correspond to the degree of connectedness between me now and myself in the future. Since connectedness is nearly always weaker over longer periods, I can rationally care less about my further future.” [19] Similarly, for the philosopher Harry Frankfurt, caring about something implies projecting oneself into the future [20]. Such a concept can help bring an understanding of why non-adherence is more common in young people [21], especially adolescents, but also in cases of social deprivation [22].

This effect of time on adherence in chronic diseases may help to explain what is possibly the most serious aspect of non-compliance, *non-persistence*: after a certain period, patients simply stop taking medication. What we may be seeing is the effect of fatigue and the disappearance of emotions that arose when the diagnosis was given, and which initially motivated people to take care of themselves. We understand that there is a potential lever to improve adherence here: namely detect non-persistence periodically and regularly remind patients of the benefits of treatment. Unfortunately, it is also possible that non-persistence is even present at the level of medical follow-up: if they don't show up, how will we know that they don't take their medication? Systems to reach patients may therefore have a place here.

### How we really decide: thought systems 1 and 2

What is described above should not be interpreted to mean that the patient *chooses* between adhering and non-adhering behavior. A few years ago, a campaign for the prevention of diabetes complications showed a young man to whom it was said: you have not chosen to become diabetic, but you have the choice to prevent its complications. This is highly questionable. In fact, in many of our actions, our decisions are made quickly, without being reflected upon, using rapid modes of reasoning called heuristics, avoiding cognitive effort. This system of thought, called system 1, is the one most often implemented, and it has the advantage of allowing us to decide quickly. It is the opposite to system 2, which is a slow, rational system, weighing the pros and cons, and requiring the effort of reflection [23].

For example, when we ask ourselves what is the frequency of an event, we replace this question with the following: can I easily find in my memory the occurrence of such an event? The use of this “availability heuristic”, typically using system 1, may be misleading if this event is unpleasant, because we tend to remember unfortunate events more easily than happy events [24]. Moreover, Kahneman and Tversky showed in their Prospect Theory [25] that our aversion to loss is greater than our attraction to gain. Thus, a patient can usually remember cases of hypoglycemia occurring when there was an increase in her dose of insulin than

those where the change resulted in normal blood sugar; she will then be reluctant to do it again when it is necessary, preferring the avoidance of hypoglycemia, an immediate event, to the distant benefit of avoiding chronic consequences of hyperglycemia: we have suggested that these concepts that call upon the way we currently conceive human reasoning may also be relevant for understanding the mechanisms of non-adherence [26].

In summary, a patient's following a medical prescription or not, which we call adherence and non-adherence, should be analysed in the context of current conceptions of human decisions. The latter are not only rational. An irrational part exists, linked in particular to the use of rapid modes of reasoning and to the effect of emotions: in terms of the latter, philosophers have suggested that they were involved in the genesis of the weakness of will [27] and self-deception [28], which, as we have seen, can lead to non-adherence.

It may also happen that some patients are non-adherent, simply to defend an area of freedom they feel is threatened. Psychologists called this kind of disobedience reactance [29]. On the contrary, some patients may be adherent by pure passive obedience: we showed that declaring that one puts his seat belt on when sitting in the back of a car is an independent determinant of adherence to medication [30].

Thus, it may well be that adherence or non-adherence reflects certain character traits, people being more or less patient or impatient, more or less obedient or disobedient, etc. [31] In fact, patients are human beings with a mind whose complexity is reflected by a capacity for both rationality and irrationality. Here we come to the question we asked: How in these conditions is it possible to want to “improve people's adherence”? Is there not a risk of psychological intrusion that would be morally questionable?

## 2. How the desire to “improve adherence” is ethically justifiable

### Why the principle of beneficence may lead to paternalism

The word *care* in English, which means both treatment and worry, comes from the old English *caru*, *cearu*, *sorrow*, *anxiety*, *grief*, from the Proto-Germanic *\*karo*, itself derived from the Indo-European root *\*gar*, *cry out*, *call*, *scream*. Etymologically at least, care seems to be the response given to a sob or a cry. Therefore, maternal care may well be the innate response of the mother when she hears her baby cry for the first time. Innate response: the mother knows what is good for the baby. It is the care that defines welfare.

This is what the philosopher Stephen Darwall proposed in his book *Welfare and Rational Care* [32]. He takes the example of the depressed person, who thinks she is worthless. If I just empathize and imagine how

she feels, I might stop there. He contrasts empathy and sympathy. Empathy is imagining what is good *from the point of view* of this person, while sympathy is imagining what is good *for* this person. Darwall defines sympathy as follows:

*“It is a feeling or emotion that: 1) responds to some apparent obstacle to an individual’s welfare; 2) has that individual himself as object; 3) involves concern for him, and thus for his welfare, for his sake”.*

Sympathy, as defined here, is simply beneficence. But Darwall goes further: he suggested that someone’s well-being (welfare), which is good for her, cannot be defined by her (as shown in the example of the depressed person), but by an external person who cares for her. Darwall’s book is not about medicine; it is the book of a philosopher. But if we try to apply this conclusion to care, *care* in the medical sense, we understand that, evidently, the principle of beneficence runs the risk of what is called paternalism.

#### **The four models of doctor-patient relationship**

Ezekiel and Linda Emanuel described four possible models of the doctor-patient relationship [33]. In the paternalistic model, I decide for you (besides you’ll thank me one day). In the informative model, on the contrary, it is you who decides, based on the information I give you, this information being as complete as possible. In the interpretative model, not only do I give you this information, but in addition, I will help you to specify your preferences. Finally, in the deliberative model, not only do I give you the information and help you to specify your preferences, but in addition I tell you mine, and then you decide.

One can have the impression that the first and fourth models are similar in terms of their result, the patient can be led to do what the doctor wishes: is the deliberative model not paternalism in disguise? This is the paradox that we arrived at: does treatment, beneficence, involve paternalism? In other words, is there an antinomy between care and autonomy?

#### **Solution to the paradox: reconciling the principles of beneficence and autonomy**

It is clear that what distinguishes the interpretative model from the deliberative model is that in the first I only help you specify your preferences. In the second, I give you mine and I invite you to deliberate on our preferences. The key could therefore lie at the very definition of the concept of preference.

We can say that someone prefers A to B if she gives more value to A than to B. Let’s take the example of smoking again. Would you like to smoke? Yes. Now suppose I ask you: do you agree with your desire to smoke and you answer in the affirmative. *In this case* you give value to your smoking: your desire to smoke seems desirable. We can thus define with David Lewis

the concept of preference as a positive desire about a desire [34].

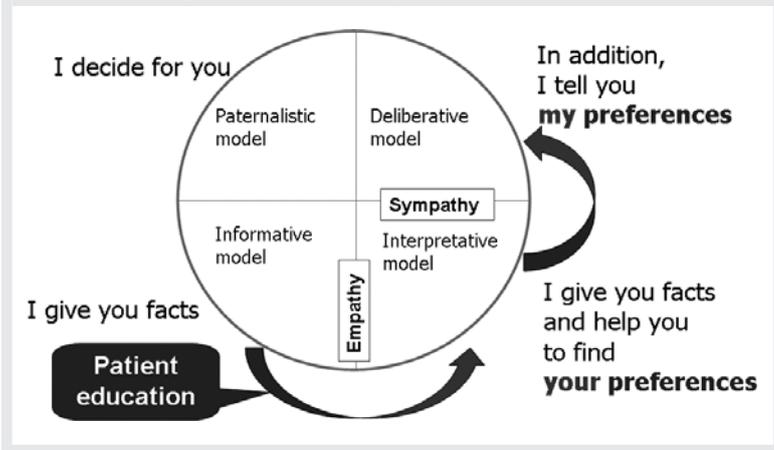
This notion of second-order desire, or reflexive activity of the mind, also defines the concept of person: according to the philosopher Harry Frankfurt, a person (and not just a wanton) is a being capable of having second order mental states: desires about desires. Not only do I want to smoke (or not smoke) that cigarette, but in addition, I am a person *if I want to have the desire* to smoke (or not smoke) [35]. Finally, the philosopher Gerald Dworkin put forward the following definition of autonomy: an autonomous person is a being who has preferences, who is able to reflect on her preferences, and, at the end of this process, *is able to change them* [36].

It is precisely here that we find the solution to the ethical question we posed: how is it possible to justify the desire to improve the adherence of patients with chronic disease? In fact, there is no opposition between the principles of beneficence and autonomy: beneficence is possible and loses its intrusive nature if we conceive that treatment is not about *diseases* or *patients*, but *people*, in other words, autonomous beings, defined as beings endowed with a reflexive activity of the mind. Figure 2 shows the four models of ethics in a circular form: while the deliberative model appears to be close to the paternalistic model, it differs in that it is only reached after an ethical path.

We can also propose that passing from the informative model to the interpretative model, in which the doctor helps the patient to elucidate her preferences, requires empathy, and passing to the deliberative model, in which she gives her own preferences, requires sympathy as we have defined it. Sympathy, which is to be concerned with the welfare of the patient becomes synonymous with the concept of beneficence. We can also see the definition of love within the meaning of the Greek word *philia*, if, as Aristotle reminds us, loving someone is wanting the best for him: there could therefore also be a place for love, in the sense of *philia*, in the therapeutic relationship, which we suggested in our book, *Une Théorie du soin, Souci et amour face à la maladie* [37].

We recently proposed that what is called patient education can be precisely defined as the process that builds this ethical path (Figure 2) [38]. This new area of medical practice introduced by diabetologists in the 1970s [39] (so exactly when the ethical and philosophical concepts described in this text were forged) aims to give the patient the opportunity to make the best use of the tools of her treatment, but also to understand its meaning. We understand why patient education is, as the WHO says, an integral part of treatment [40]: not only for technical reasons (teaching patients how to treat themselves), but also for a deeply ethical reason which is giving the patient the opportunity to exercise her autonomy, in other words the reflexive activity of her mind. Not carrying out patient education, on the

**Figure 2: How can beneficence be ethically justifiable?**  
(modified according to reference 33, and published in reference 38)



other hand, would mean disrespect, because this would mean that I think that you are not capable of changing your mind.

We can see that patient education leads the patient to deliberation, in other words, to using her mind's "System 2". As such, it differs profoundly from manipulation, which acts at the level of System 1, as does a "nudge" [41] (change people's behavior unbeknown to them, for their sake). It seems to us that if such a process can be morally acceptable at a population level, as recently proposed by Yashar Saghai [42], it would be ethically questionable to use it at the individual level in the patient-doctor relationship, which treats people, in other words beings endowed with a reflexive mind.

**Conclusion**

The desire to improve patient adherence may have several types of reasons, some of which are in the interest of the patient, others in the public interest, or simply in the interest of companies that manufacture drugs, such interests being in no way contradictory. However, we must be clear: these points of view and interests may not be those of the patient and one cannot advocate respect for people's autonomy and at the same time claim that we can decide what is good for them (principle of beneficence) without at least providing an ethical justification for this approach, which was the purpose of this text.

It appears that what we call non-adherence may have two types of causes: firstly, it can simply be forgetting to take medication and we can find solutions that are more or less simple to put into practice, ranging from simple "tips" to technology. Similarly, if it is simply a case of ignorance, one of the roles of patient education is to solve this; indeed, these cases do not then come under non-adherence, but rather are caused by a deficit in patient education. Non-adherence can also result

from a lack of necessary resources to put the prescribed treatment into practice: here also, it is up to the therapist to check when prescribing treatment that the patient will have the means to follow it.

But the real non-adherence, which poses an ethical problem when we want to fight against it, is that which comes under complex psychological causes, which involve phenomena such as people's weakness of will, propensity for denial, and character traits that cause them to not be able to carry out an action, that is in fact unnatural, which is to carry out a treatment that they may not see as necessary, especially in the context of silent diseases. It is difficult to fight against traits, and it is perhaps questionable to intervene at this level. In addition, the physician must accept the fact that some patients "having all things considered", as Davidson put it, may choose short-term non-adherence over desire, in the long term, to extend life. This perfectly rational conscious choice does not fall within the phenomenon of weakness of will, which implies that, irrationally, the patient finally chooses the present when he had decided, all things considered, on another choice, in this case that of the future [15]. It is obvious that such a conscious choice must be respected.

Outside of this case, we can reconcile the two ethical principles of beneficence and autonomy by taking the definition of the autonomous person, who according to Dworkin and Frankfurt operates at a reflexive activity of the mind. By addressing an autonomous person more than a "patient", in other words, a being capable of evaluating her preferences and potentially changing them, in a word deliberating, the desire for beneficence becomes legitimate. It seems to us that this is the true role of what is called patient education. It fully addresses the intelligence of people, respects their autonomy and also gives them the opportunity to exercise this autonomy through deliberation. It really puts an end to paternalism, which refuses any discussion, and distinguishes itself from simple manipulation, which is only effective because it is hidden.

**Patient education and trust**

But there is more. Patient education makes it possible to establish a relationship of trust, in which the interests of the patient and the healthcare system come together, under the concept of "encapsulated interest" developed by Russell Hardin: "I trust you because I think it is your interest to take my interests in the relevant matter seriously in the following sense. You value the continuation of our relationship and you therefore have your own interest in taking my interests into account. That is, you encapsulate my interests in your own interests" [43]. We can see that this definition of trust allows the therapeutic relationship to be a place of exchange. But "the doctor must in turn realize that trust (of doctor by patient) has to be earned, gained, must not be abused and should not be assumed – indeed why should it be" [44].

One study has shown results consistent with the concepts discussed above. It showed that trust was the variable most strongly associated with patient satisfaction vis-à-vis their doctor, and that the ability of doctors to have complete knowledge of their patients on the one hand, and the trust of patient in their doctor on the other hand were the variables most strongly associated with adherence: patients with high trust in their doctor engaged in eight health behaviors more often, including exercise, quitting smoking and protected sex [45]. Another study showed that trust in the doctor was an independent determinant of the ease with which patients accept their doctor prescribing them another tablet [46]. In fact, the whole practice of medicine is based on a relationship of trust: how else would the patient respond to their doctor's "questioning", to agree to undergo a clinical examination, and finally to take the prescribed medication?

Patient education could well be a way to establish such a relationship of trust. Among the factors that determine the trust the patient has in her doctor, there is not only, obviously, an evaluation of skills (the care taken in evaluating the situation and the quality of the treatment prescribed), but also the ability to understand the uniqueness of the patient's experience, the clarity of communication, the ability to build a true partnership and to show respect [47]. One study attempted to prioritize the importance of the determinants of trust. Within this, there is the importance of the quality of communication in both of its aspects, verbal and non-verbal [48].

Finally, it appears that the desirable improvement in patient adherence vis-à-vis their treatment, which was the subject of this text, firstly involves the ability of healthcare professionals to adopt such a relational attitude, the implementation of which, it must be emphasized, takes time, which may represent an obvious difficulty in the context of short consultations. Training for healthcare professionals is also necessary and will doubtless involve a profound reform of the spirit of teaching in medicine, still centered on the medicine of diseases and undoubtedly not enough on the medicine of the person.

*The topics covered in this text are expanded on in the author's three books: Pourquoi se soigne-t-on, Enquête sur la rationalité morale de l'observance, foreword by Pascal Engel, Le Bord de l'Eau, 2005, second edition, 2007; Clinique de l'observance, l'exemple des diabètes, John Libbey Eurotexte, 2006, and Une Théorie du soin, Souci et amour face à la maladie, foreword by Bernard Baertschi, Les Belles Lettres, 2010. An English translation of the first book should be published soon by Springer ("Philosophy and Medicine" series) under the title: The Mental Mechanisms of Patient Adherence to Long Term Therapies, Mind and Care.*

*The author has no conflict of interest to declare with regard to this text.*

## Zusammenfassung

Ziel dieses Artikels ist es zu zeigen, dass der legitime Wunsch, das Befolgen von Anweisungen bei Patienten mit chronischen Erkrankungen zu verbessern, zwei Herausforderungen aufweist: Zum einen gilt es zu verstehen, warum sich bestimmte Patienten nicht an die Anweisungen, die ihnen gegeben werden, halten; in diesem Zusammenhang zeigen wir, dass dieses Phänomen völlig verständlich ist und beschreiben seine psychologischen Mechanismen und Eigenschaften. Auf diese Weise erklären wir Verhaltensweisen, die auf den ersten Blick überraschend erscheinen.

Zum anderen muss man aus dieser Beobachtung die ethische Herausforderung ableiten und analysieren, wie man die Therapietreue bei Patienten verbessern kann. In einer Zeit, wo Autonomie befürwortet wird, gilt es, sich die Frage zu stellen, wie es möglich ist, die besten Entscheidungen für das Patientenwohl zu treffen, ohne in Paternalismus zu verfallen. Wir argumentieren, dass es möglich ist, den Vorrang dem Prinzip der Wohltätigkeit zu geben, das den Patienten hilft, ihre Gesundheit zu erhalten; dabei wird allerdings nicht aus den Augen verloren, dass die Medizin nicht Krankheiten und Patienten behandelt, sondern autonome Individuen. Diese werden als Wesen mit einem reflektierenden Geist definiert. Insbesondere zeigen wir, wie ein Modell der chronischen Versorgung zwei Schlüsselbegriffe übernehmen kann und auch muss, nämlich Vertrauen und Aufklärung der Patienten, die hier eine ethische Definition erhalten.

## Résumé

Le but de cet article est de montrer que le souhait légitime d'améliorer l'observance des patients atteints de maladie chronique présente deux défis: d'abord, comprendre pourquoi certains patients ne suivent pas les recommandations qui leur sont données; nous montrons qu'il s'agit en fait d'un phénomène naturel, dont nous décrivons les mécanismes psychologiques, certains traits de caractère pouvant expliquer des comportements qui paraissent à première vue surprenants. Ensuite, partant de cette constatation, nous analyserons le défi éthique que présente toute tentative «d'amélioration de l'observance»: comment, à une époque où l'on prône le respect de l'autonomie, est-il possible de décider ce qui est bon pour les gens sans tomber au mieux dans le paternalisme et au pire dans la manipulation? Nous montrons qu'il est possible de donner la priorité à un principe de bienfaisance, qui vise à aider les patients à conserver leur santé, mais à la condition de ne jamais perdre de vue que la médecine soigne, au-delà des maladies et des malades, des personnes autonomes, c'est-à-dire des êtres doués de réflexivité. En particulier, nous montrons comment un modèle du soin des maladies chroniques peut et doit intégrer deux mots-clés: la confiance et ce qu'il est convenu d'appeler l'Education Thérapeutique du Patient qui trouve ici une définition éthique.

**Correspondence**

Professeur Gérard Reach  
Service d'Endocrinologie  
Hôpital Avicenne  
125, route de Stalingrad  
F-93000 Bobigny, France  
Tél.: 0033 1 48 95 51 58  
Fax: 0033 1 48 95 55 60

E-mail: gerard.reach[at]avc.aphp.fr

Manuscript submitted: 17.11.2013

Revisions submitted: 8.1.2014

Accepted: 9.1.2014

**References**

- Sackett DL. Compliance with therapeutic regimens. Baltimore, The John Hopkins University Press, 1979, 1–6.
- WHO report. Adherence to long-term therapies, evidence for action, 2003, p. 11.
- Beauchamp T, Childress J. Principles of Biomedical Ethics. Oxford, New York, Toronto: Oxford University Press, 1st edition, 1979.
- Veatch RM, Mason Spicer C. Against paternalism in the patient-physician relationship. In: Principles of health care ethics, Gillon R, Lloyd A, eds., Wiley, 1994, p. 409–20.
- Reach G. Treatment adherence in patients with gout. *Joint Bone Spine* 2011;78:456–9.
- Hume D. An Enquiry into the Principles of Morals, Appendix I.
- Shultz JA, Sprague MA, Branen LJ, Lambeth S. A comparison of views of individuals with type 2 diabetes mellitus and diabetes educators about barriers to diet and exercise. *J Health Commun* 2001;6:99–115.
- Reach G. Pourquoi se soigne-t-on, Enquête sur la rationalité morale de l'observance, 2<sup>ème</sup> ed. Préface de Pascal Engel, Le Bord de l'Eau, 2007. English translation, forthcoming (The Mental Mechanisms of Adherence to Long Term Therapies, Springer, 2014).
- Davidson D. Actions, reasons and causes, *Journal of Philosophy*, 1963, In: Essays on Actions and Events, Oxford, Clarendon Press, 2001, 3–19.
- Engel P. Introduction: the varieties of belief and acceptance. In: Engel P, editor. Believing and Accepting, Philosophical Studies Series. Dordrecht: Kluwer Academic Publishers; 2000:1–30.
- Livet P. Emotions et rationalité morale. P.U.F., Collection Sociologies, 2002.
- Davidson D. How is weakness of the will possible? In: J. Feinberg, ed. Moral concepts, Oxford, Oxford University Press, 1970 and In: D. Davidson, Essays on Actions and Events, Oxford, Clarendon Press, 2001, 21–42.
- Aristotle. Nicomachean Ethics, Book VII, 2, 1–2.
- Davidson D. Paradoxes of irrationality, in Problems of Rationality, Clarendon Press, Oxford, 2004.
- Reach G. A novel conceptual framework for understanding adherence to long term therapies. *Patient Preference and Adherence*. 2008;2:7–20.
- Kalenscher T, Pennartz CM. Is a bird in the hand worth two in the future? The neuroeconomics of intertemporal decision-making. *Prog Neurobiol* 2008; 84:284–315.
- Bickel WK., Yi R., Kowal B.P., Gatchalian K.M. – Cigarette smokers discount past and future rewards symmetrically and more than controls: Is discounting a measure of impulsivity? *Drug and Alcohol dependence* 2008, 96, 256–62.
- Reach G, Michault A, Bihan H, Paulino C, Cohen R, Le Clésiau H. Patients' impatience is an independent determinant of poor diabetes control, *Diabetes Metab* 2011;37:497–504.
- Parfit D. Reasons and Persons, Clarendon Press, Oxford, 1984, p. 313–4.
- Frankfurt H. The Importance of What we Care About, Cambridge, 1988.
- Briesacher BA, Andrade SE, Fouaizi H, Chan KA. Comparison of drug adherence rates among patients with seven different medical conditions. *Pharmacotherapy* 2008;28:437–43.
- Wamala S, Merlo J, Boström G, Hogstedt C, Agren G. Socioeconomic disadvantage and primary non-adherence with medication in Sweden. *Int J Qual Health Care* 2007;19:134–40.
- Kahneman D. Thinking, Fast and Slow. Allen Lane, 2011.
- Baumeister RF, Bratslavsky E, Finkenauer C, Vohs KD. Bad is stronger than good. *Rev Gen Psychol* 2001;5:323–70.
- Kahneman D, Tversky A. A Prospect theory: an analysis of decision under risk. *Econometrica* 1979; 47, 263–292.
- Reach G. A psychophysical account of patient non-adherence to medical prescriptions. The case of insulin dose adjustment. *Diabetes Metab* 2013;39:50–5.
- Tappolet C. Emotions and the intelligibility of akratic actions, In: Weakness of will and practical irrationality, Stroud S, Tappolet C, eds., Clarendon Press, Oxford, 2003, p. 97–120.
- Correia V. La duperie de soi et le problème de l'irrationalité. Des illusions de l'esprit à la faiblesse de la volonté. Thèse, 2010.
- Brehm JW. A Theory of Psychological Reactance, New-York, USA: Academic Press, 1966.
- Reach G. Obedience and motivation as mechanisms for adherence to medication. A study in obese type 2 diabetic patients. *Patient Prefer Adherence* 2011;5:523–31.
- Reach G. Two character traits associated with adherence to long term therapies. *Diabetes Research and Clinical Practice* 2012;98: 19–25.
- Darwall S. Welfare and Rational Care, "Princeton Monographs in Philosophy", Princeton University Press, Princeton, 2002.
- Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. *JAMA* 1992;267:2221–6.
- Lewis D. Dispositional theories of values, Proceedings of the Aristotelian Society 1989;63:113–137.
- Frankfurt H. Freedom of the will and the concept of has person, *J of Philosophy* 1971;68:5–20.
- Dworkin G. The theory and practice of autonomy, Cambridge, Cambridge University Press, 1988.
- Reach G. Une Théorie du soin, Souci et amour face à la maladie, Préface de Bernard Baertschi, Les Belles Lettres, 2010.
- Reach G. Patient autonomy in chronic care: solving a paradox. *Patient Prefer Adherence*, 2013;8:15–24.
- Miller LV, Goldstein J. More efficient care of diabetic patients in a county-hospital setting. *N Engl J Med*. 1972;286:1388–91.
- World Health Organisation. Therapeutic Patient Education: Continuing education programmes for health care providers in the field of prevention of chronic diseases. Report of a WHO working group. 1998, WHO Copenhagen, 1998.
- Thaler RH, Sunstein CR. Nudge: Improving Decisions about Health, Wealth, and Happiness. New Haven: Yale University Press, 2008.
- Saghai Y. Salvaging the concept of nudge. *J Med Ethics*. 2013 doi: 10.1136/medethics-2012-100727.
- Hardin R. Trust and Trustworthiness, Russel Sage Foundation, 2004.
- Shinebourne EA, Bush A. For paternalism in the doctor-patient relationship, In: Principles of health care ethics, Gillon R, Lloyd A, eds., Wiley, 1994, p. 407.
- Safran DG, Taira DA, Rogers WH, Kosinski M, Ware JE, Tarlov AR. Linking primary care performance to outcomes of care. *J Fam Pract*. 1998;47:213–20.
- Zikmund-Fisher BJ, Hofer TP, Klamerus ML, Kerr EA. First things first: difficulty with current medications is associated with patient willingness to add new ones. *Patient* 2009;2:221–31.
- Thom DH, Campbell B. Patient-physician trust: an exploratory study. *J Fam Pract* 1997;44:169–76.
- Thom DH. Stanford Trust Study Physicians, Physician behaviors that predict patient trust. *J Fam Pract*, 50, 2001, p. 323–28.