

POINT OF VIEW

Challenging non-compliance

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J Med Ethics 2003;29:257–259

One of the hardest tasks for a physician is to treat and take care of patients suffering from such chronic disease as diabetes. The difficulties arise mainly because the medical treatment and the necessary follow up demand that the physician interfere with, or at least influence, the whole lifestyle of the patient. The diabetic must pursue a distinct way of daily living: he must change his eating habits, go on a diet, create a healthy lifestyle and keep to it. Patients may know about the necessity of being on a diet, but a great number of them don't have any understanding of such basic terms as "protein", "carbohydrate", "lipid", or even "calorie", which are essential to an understanding matters to do with diet.¹ While it is obvious that scientific and technical terms should be translated into everyday language, and acknowledging that providing patients with information is an essential part of care, it is not possible, and not even necessary to give every piece of information to every patient.

Just as with any other chronic disease, a good outcome can only be achieved through a strong commitment to serving the interest of the patient. In order to accomplish this, physicians must be aware of the ethical implications raised by non-compliance. The authors are very much in agreement with the American sociologist, Peter Conrad, who stated that:

From a medical perspective, patients who do not comply with the doctor's orders are usually seen as deviant, and deviance requires correction. But many chronically ill people view their behavior differently, as a matter of self regulation.

He is also right when he states that "compliance" looks very different when seen from the patient's perspective. As an example, patients might adjust their medication to meet their everyday social needs rather than complying exactly with their doctor's recommendation.²

Thus, perhaps the best way to deal with "non-compliance" may be from a position based in understanding and tolerating the patient's "deviant" behaviour. Most physicians seem to take it as the part of the professional mission, that they dreamt so much about in their youth before entering medical school. Hence, their attempts to persuade patients to comply with their instructions is not necessarily based on a paternalistic attitude, but rather on a genuine commitment to help, whatever the nature of the challenges or obstacles to helping might be. Neither patients nor the law accept paternalism any longer. And neither "the doctor knows the best" nor the doctor's silence is viewed as good medical practice anymore. Not very long ago, before the fall of Communism, silence and deception were the rule, the norm. A decade later, and with the development of democracy, informed consent has become the most important patient right in Hungary.

A good working atmosphere and a healthy moral climate make therapeutic efforts much easier in all institutions.

And if the clinic or institute has a good name in the community, this may also be conducive to good outcomes, because then patients can come to the institute with less fear and with some degree of trust. Even where many of the

favourable conditions are present, some cases of non-compliance cannot be successfully dealt with.

Following are some actual cases in which our therapeutic approach has been successful.

GENUINE CONCERN

SG, male, aged 24, forest ranger who has been diagnosed with diabetes for five years. It was treated with insulin. At the time of diagnosis, he was still a student, attending lectures and learning such medical practices as how to take blood pressure at his college. There were no unusual problems, mainly because he was not an outgoing type of person, and he soon mastered the techniques of giving himself the insulin shots. He regularly measured his sugar level. His diabetes was under control. After finding employment, however, his daily life changed, and his daily schedule changed significantly: one day he worked a day shift, the next a night shift. Also his mobility levels changed, which in turn influenced his blood sugar values. For instance, if one day he did not move much and his nourishment remained unchanged, then his blood sugar level increased. Thus his treatment modality had to be set reset in order to correspond to his changing lifestyle.

It is especially difficult to ensure compliance with young patients, if diabetes has only just been diagnosed, because of the requirement that their lifestyle has to be changed. Because of the patient's young age, prescribing insulin is unavoidable. In order for there to be a favourable outcome, the physician must know many things about the patient in order to assist him effectively in his daily living. The doctor must know—for example, the patient's areas of interest, his occupation, his level of education—even such things as whether he likes, and how much, (if at all), to go dancing, to stay out at night, whether he consumes alcohol, whether he likes hiking, or playing sport. In certain cases the physician should alert the patient to possible dangers, such as the occurrence of hypoglycaemic events. What must be spelled out in a simple and clear way is the importance of eating more, especially before taking part in such physical exercise as sport or dancing, and when the patient feels his blood sugar level is low. This will still not be all that it is necessary to say or do, however, because these young people are carrying a psychological burden as well, caused by the knowledge that they are different from other young people, and that they must give themselves insulin injections several times a day throughout their lifetimes. If she thinks it is necessary, (though it seldom becomes necessary to force the patient) the physician should request psychiatric counselling, while at the same time maintaining continuous concern and attention. Chronically ill patients, however, must at least try to integrate their illness into their everyday life. They should not, however, be forced or manipulated into assuming the "patient role", which would serve only to constantly remind them that they are different from "normal", healthy individuals. It is very hard for a patient to live a double life: to fulfil all his duties, on the one hand, and to keep convincing himself that he is sick, on the other.

We have found that having discussions with patients about their disease and other problems proved to be beneficial. Nor

did we hold back on praise either, because when the patient had good blood sugar results, some encouraging words would make him proud and confident. It was very likely, that from then on he would do even more to keep his disease under control and would be even more cooperative. We also assured patients that whenever they wished to call us for help or information, they were free to do so at any time. Names and phone numbers were given to patients, which reassured them that the promise to help was genuine. The therapeutic alliance was thus established. Eventually, patients were convinced that physicians wanted the best for them. Patients appreciated and highly valued our efforts. Not only did they express this verbally but also by following all the advices and therapeutic decisions that we had made together.

EVOKING RESPONSIBILITY

HK, 34 year old male, unskilled building construction worker who has been diagnosed with diabetes since childhood. Establishing his therapy wasn't easy, because he didn't keep to his diet while doing his hard physical work. When his blood sugar level dropped, instead of eating more, he just omitted his insulin. He stated outright that he was not interested in his blood sugar level. He had to continue working since he was the father of two children and his wife was unemployed. The problem began when, on certain days, his work was not so strenuous, but even then he didn't pay attention to his eating habits. He was consuming greasy food without paying attention to his carbohydrate levels.

If it is necessary, the physician ought to appeal to the patient's sense of responsibility, but should never resort to coercion. It is claimed that coercion is only right and necessary where the public health is threatened.³ In this case, in order to help the patient and to win his cooperation, we had to appeal to the fact that he was a father. Somehow a message had to be delivered in such way that it would invoke the patient's responsibility, if not towards himself, then towards his own children. He had to be reminded, in case he had been failing to take this into consideration, that his wife had no job, and no qualifications and that therefore he was the only one in the family who could provide bread for his children. His wife and small children needed him very much. If he risked complications from his disease, then he would not be able to perform his work, and thus would not be able to support his family. Our genuine concern and openness about his and his family's future seemed to convince him, because he became more and more willing to comply and our relationship turned into a real partnership.

We believe that at least some attempts should be made by health professionals to explore the reasons for non-compliance, and that they should make some effort to remedy the situation. If not the physicians, if not the health professionals, then who will help the patient to stay alive? Or are the interests of the patient only to be served if he happens to be cooperative and to value his life and health very highly? Some patients say they have not got the financial means to be on a diet. Sometimes this is not true, but is only an excuse. If they are asked what they are unable to buy, they usually refer to diabetic chocolate, which is not really necessary for their daily nutrition. Nevertheless, due to unemployment and/or very low salaries, for many diabetics it is extremely difficult, if not impossible, to buy healthy food.

THE INFLUENCE OF THE HUMAN ENVIRONMENT

AT, 74 year old, retired female patient who has been diagnosed with diabetes for 16 years. Her blood sugar is balanced, she is not suffering from any other ailment according to physical and laboratory examinations. She has had no complaints whatsoever. Suddenly, however, she, who is otherwise rather skinny, complained about a frequent drop in her blood sugar level. After questioning her, it turned out that she was eating very

little, because she doesn't want her diabetes to get worse, though she keeps taking her tablets. It also became obvious that her friends and acquaintances of a similar age influence her behaviour. Instead of listening to us and following our therapeutic regimen, she took notice of her contemporaries' life philosophy of "we only live once". Her friends and neighbours have given her bad advice about what to eat and what not to eat. They said, for example, that she should eat mainly meat, and should never consume carbohydrates.

This, of course, resulted in complications, because such advice, which urges one to consume a lot of protein, leads to obvious harmful effects. Also, various teas that were suggested and which are available in pharmacies as a food supplement, cannot be included in the diet of all diabetics. She drank such teas as a result of the advice of her friends. In ideal circumstances, the patient would ask the opinion of her physician before going out and buying all kinds of food supplements. In the above case, the physician had to begin almost from the beginning, determine the right therapy and normalise the body weight again. It took a lot of explaining to convince the patient about the basic components of a more suitable diet. The time spent on winning the trust and cooperation of the patient has, however, paid off. Compliance was achieved, her disease was brought under control.

AN EXCELLENT RELATIONSHIP

TJ, 54 year old male, painter who has been diagnosed with diabetes for eight years. It is treated with tablets. His work demands hard physical activity. After the discovery of his diabetes, his eyesight worsened and only began to improve following antidiabetic therapy and an appropriate diet. After the patient complained of abdominal pain, an ultrasound examination was carried out and a kidney tumour was diagnosed on the right side. At the physician's request for an immediate operation, the tumour was removed in time. Since then, the patient has been well, his sugar level is normal, and his diabetes is under control.

Following the removal of the tumour, the patient re-evaluated his situation, accepted his chronic disease more willingly and his compliance became so "good" that it was a pleasure to work with him and to see the good outcome of our mutual efforts. There is no doubt that even physicians and nurses need positive feedback: a feeling of success that might well be taken as a reward, or some kind of compensation for the low salaries in Hungary. The Harvard professor, Francis Peabody, said a long time ago, that:

The good physician knows his patient through and through, and his knowledge is bought dearly. Time, sympathy, and understanding must be lavishly dispensed, but the reward is to be found in that personal bond which forms the greatest satisfaction of the practice of medicine. One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient.⁴

In this case, the information was given with empathy and in privacy. The patient was convinced he would not be abandoned and that the medical staff would closely monitor the surgical procedures and would stand by ready to help. It is natural that after having learned the diagnosis the patient will have many questions to ask both himself, and the medical personnel. He will ponder about the diagnosis, about the chances of the operation and what else is waiting for him in the future. Therefore it is necessary to put the patient at ease as much as possible, without giving false hope and unreliable information. That this was achieved has been made manifestly obvious in the patient's sincere, appreciative, and kind attitude toward his physician.

In general, one must avoid using such commonplace phrases as “you see, I told you so”. Something gentler and more effective must be said to those who fail to follow sound medical guidance. Instead of “told you so”, a “sorry, that you were unable to follow our medical advice” could have a much better effect. Most of us don’t like to be scolded as if we were schoolchildren, especially when we have to face the deterioration of our own health. In order to really help the patient, the physician must not put herself in the role of a moral judge who simply implies that “you have been told, now you must bear the consequences”. Yes, the patient has been told, but she may not have been told humanely or convincingly. Or, for hundreds of reasons, the patient may not have been able to change her lifestyle. For example, not every human being is equipped with omnipotent will power and not everybody is able to manage stressful situations perfectly well, or even well. It is easy to blame the patient for failing to achieving the therapeutic goal. The physician’s objective, however, is to treat the patient and to promote his wellbeing, instead of finding out who, when, and how she was at fault.

Therefore, we believe that a real commitment to patients as well as to the art of medicine compels us to seldom give up on a patient and keep challenging non-compliance as if it were an integral part of our mission. In most cases our efforts will succeed, and as a result, not only our patients, but we too, will feel

better. Granted, our salary will not be higher, nor will we necessarily be more highly valued for our moral integrity by others, but our self worth and professional pride may increase to a level where we find more fulfilment in our lives.

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Accepted for publication 17 September 2002

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LETTER.....

Neonatal outcomes and risk/benefit ratio of induced multiple pregnancies

During recent years we have seen and assisted at a significantly increased number of twin births. The main reason for this increase in the frequency of twin births is the increasing number of so called “induced pregnancies”, whether through hormonal stimulation or artificial insemination techniques.

It is well known¹ that twins have high mortality and morbidity rates during the perinatal and the following period. The characteristics of conception and pregnancy can determine the development of several pathologies, including prematurity and intrauterine growth retardation, twin to twin transfusion, cardiorespiratory depression, and respiratory distress syndrome, all of which are very common.

Twin pregnancy represents therefore a biological risk factor and needs a very high level of obstetrical and neonatological management, achievable only in highly specialised and well equipped centres; a very high level of investment in terms of human and economic resources is also required.

A recent study carried out² by the Department of Neonatology at the A Gemelli hospital of the Catholic University of Rome shows a significantly higher incidence of prematurity, low birth weight, severe cardiorespiratory depression at birth, (Apgar 0–3) and respiratory pathology, among twins born from “in-

duced pregnancies” than from those born from spontaneous pregnancies.

Such a high incidence of respiratory pathology and cardiorespiratory depression at birth does not seem to be related to prematurity. In fact mean gestational age and mean birth weight of the neonates with severe depression at birth and respiratory diseases are similar in induced and spontaneous pregnancy.

In multiple pregnancies such results are in agreement with the higher incidence of prematurity and low birth-weight, already observed by other authors,^{3–6} in single newborns from “induced pregnancies”, in comparison to those from spontaneous pregnancies.

Quite apart from any clinical implications this situation leads us to consider the ethics of this situation.

Wider and multicentre studies will be necessary if we are to understand whether the induction of pregnancy is a strategy with an acceptable risk/benefit ratio, or whether the possible above mentioned complications can reduce the benefits for a couple of having children.

Also, it will probably be necessary to examine socioeconomic problems related to clinical and treatment needs for pregnancy or for newborn babies. In fact pre-term babies often make large demands on the therapies in the neonatal intensive care unit, require long times of stay in

hospital, and social support and rehabilitation after they leave the hospital.

This implies a remarkable use of technological, human, and economic resources in order to guarantee their survival and optimum quality of life.

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J Med Ethics 2003;**29**:259

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