The Added Value of Therapy in Diabetes: The Education of Patients for Self-Management of Their Disease

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The long-term success of diabetes therapy is strongly dependent on education of the patient. Considerable emphasis and effort has been directed at this dimension of treatment by healthcare providers (HCPs) in the field of diabetology. Education of patients is not aimed at making them more knowledgable about their disease, but to help them better manage their treatment and adapt the diabetes control to the constant changes in daily life. Patient education is a complex process, and many factors may interfere with the patient's understanding. There is growing awareness among HCPs that more knowledge and skill have to be acquired in the field of therapeutic education of patients.

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LONG-TERM SUCCESS of diabetes therapy is impossible without patient education. Considerable emphasis has been placed on this dimension of treatment by heathcare providers (HCPs). This is why today diabetes is probably the model of care for many chronic diseases such as asthma, chronic back pain, neurological conditions such as Parkinson's disease, cardiovascular diseases, etc.

Education of patients for self-management of their diabetes plays a crucial role both in the quality of control of the disease[1-3] and in the quality of life. Patients who are not properly taught will need many more medical visits and may require recurrent hospitalizations, and yet these hospitalizations will have little impact in preventing further crises.[4,5] Because of recurrent insufficient metabolic control, HCPs may show a progressively negative attitude toward their patients, who in turn may also lose confidence in the medical team. Resignation and a permanent negative attitude on both sides are often the result of poor education of patients in the area of self-management of their diabetes.

Patient education is an essential part of medical care, particularly in the case of long-standing diseases. Its crucial role has been fully recognized by the World Health Organization (WHO). In this perspective, in 1991 at the WHO regional office in Copenhagen, the ministers of health of all the European countries signed a resolution for a 5-year diabetes program. In this program, education of patients has been one of the main targets for control of the disease and prevention of diabetic chronic complications. The WHO therefore recognized diabetes as a major health problem. At the European level, ambitious intervention programs are planned. The St. Vincent Declaration stated that every effort should be made to decrease amputations by 50%, blindness by 30%, and renal failure by 30% by 1995. Although this ambitious program could not be implemented in these few years, great involvement in the majority of European countries has been seen. All of these programs required a major investment by HCPs in the field of patient education.[6] The concept of "health for all" promoted by the WHO includes, of course, equal access for all to medical care. So far, this includes diagnostic procedures and availability of medications, but equal access to medical care also implies equal opportunity for patients to be educated in the management of their disease. By far, this latter aspect is not systematically included in the mode of functioning of HCPs. Consequently, not more than 20% of hospitals or ambulatory clinics have an ongoing training program for their patients with diabetes. In the best of cases, in places that have a formal teaching program, one may observe that the education patients receive for management of their disease may vary widely in content and quality. Patients who refuse the program or are in revolt against their disease, those who are poorly motivated, those with a low educational level, or the elderly and the isolated are not integrated into the teaching program as actively as other diabetics.

Proposals for diabetes care must then include the proviso that special attention be given to these types of underserviced patients.

PATIENT EDUCATION

Education of patients is a difficult task.[7] Its efficiency may vary to a great extent according to (1) which aspect of the disease has to be controlled, (2) the extent to which behavioral changes are needed, and (3) the educational strategies needed to help the patient reach the medical objectives.

Medical Objectives for Patients

These objectives will be grouped according to the degree of difficulty.

Easier for the patient to master. These involve the technique of blood/urine glucose determination, insulin injection, and prevention of hypoglycemia in patients who have already experienced severe hypoglycemia.

More difficult for the patient to master. These include sick-day rules for insulin-dependent diabetes mellitus (IDDM) patients, weight loss for non–insulin-dependent diabetes mellitus (NIDDM), and prevention of foot traumas in patients who have lost pain sensation in the lower extremities.

Educational Objectives for the HCP

Easier for the HCP to master. These include giving descriptions to patients (definition of NIDDM or IDDM), listing different kinds of food and glucose-lowering drugs, and teach-

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ing a technique (insulin injection, blood glucose determination, or foot care).

More difficult for the HCP to master. These entail helping patients to understand how insulin works, how excess glucose can lead to development of retinal lesions, kidney problems, and nerve involvement, and how to help patients cope with their disease.

Patients' Involvement

Easier for the patient to master. Patients should be able to give simple definitions of their own disease and about their treatment, describe their own diet, master a technique (blood/urine glucose and acetone determination), prevent hypoglycemic comas, and prevent diabetic ketoacidosis or hyperosmolar decompensation for NIDDM.

More difficult for the patient to master. Skills include translation of blood glucose values into the right insulin doses, control of lability of blood glucose excursions, and prevention of injuries in a neuropathic foot insensitive to pain.

Behavioral changes include dietary adherence, weight loss, and adherence to a correct timetable (insulin injection, mealtime, etc.).

In summary, patient education consists of teaching patients to acquire the right skills and to develop the appropriate behavior to help them control their own disease.

ASPECTS OF THE DISEASE THAT TEND TO DEMOTIVATE BOTH PATIENTS AND HCPS

For patients, diabetes is a silent disease with chronic serious, life-threatening complications. Drugs—particularly insulin—may have serious side effects (hypoglycemia or weight gain); the disease is incurable and needs daily control. Self-monitoring of glucose takes time, and skin punctures to obtain blood samples from the fingertips are painful. This situation easily results in the understandably negative attitudes of patients: "Why bother?" The disease is silent and there is denial about the long-term complications: "Why bother?"

For HCPs, the situation is often no better: they become bored with supervising a chronic, monotonous disease. Patients are not motivated, and one can easily find medical teams that suffer from the so-called "burn-out" syndrome.[8] The fact that diabetes is an incurable disease certainly interferes with the medical identity of each physician or nurse—the dream of solving patients' problems, the dream of curing the disease.

EDUCATIONAL STRATEGIES

Patient education as part of a global therapy for diabetes has its own history that does not coincide directly with the time of major discoveries in diabetes therapy. Although patient education was provided in specific places due to the motivation of charismatic diabetologists as early as 1922, with the use of insulin by Joslin in the United States, Ernesto Roma in Portugal, and Lawrence in England, it was only after the 1970s that patient education became accepted worldwide as an integral part of therapy. It took about 50 years to be recognized. The decade 1970 to 1980 was devoted mainly to the awareness of the therapeutic role of patient education. The American Association for Diabetes Educators was founded in this period. The European Diabetes Education Study Group (DESG) was created in 1979 and reported 2,200 members in 1996; the DESG is part of the European Association for the Study of Diabetes. Thanks to a most generous 14-year educational grant by les Laboratoires Servier and a 3-year grant by Novo-Nordisk, the DESG organized approximately 100 workshops throughout Europe for its members. These were attended by approximately 3,000 doctors and 3,500 nurses. Another activity of the DESG has been to publish several documents and to create specific educational methodologies that have been distributed not only in Europe but also worldwide. As a result, great impact was made with publication of the following series:

1. Teaching letters for the healthcare teams. Twenty topics of significant interest and use for those involved in patient education have been written and distributed. These teaching letters have since been translated into 25 different languages.
2. Another document, a 5-minute "survival kit" for the education of patients by busy physicians, has been published. It should help the practioner to give each patient a 5-minute minimal message important for the daily control of his/her diabetes. However, despite these important efforts, little consideration has been given to the educational methodology of how to train physicians, nurses, and dietitians in the field of patient education. Too little attention has been drawn to the difficulties patients experience while they have to learn about their diabetes and its treatment. The same is also true with the difficulties HCPs encounter when they have to teach patients.
3. In this perspective, the DESG has published a series of educational posters to help HCPs more efficiently master the long-term care of their patients.

EDUCATION IS A PROCESS THAT HAS TO OVERCOME MANY OBSTACLES

Education Has to Be Adapted to Patients' Sociocultural Characteristics

Transmission of the message from the doctor, nurse, or dietitian to the patient may easily be distorted by different factors that are dependent on the patient. Each factor may act like an unseen barrier interfering with the transmission of this message. HCPs, therefore, are not always aware of these unseen barriers when confronted with a patient who has not understood the medical message. It then follows that HCPs expend needless energy, and poor results in the educational process are obtained if these barriers are not taken into account.

Patients' Personal Beliefs About Diabetes and Its Complications

A patient's willingness to comply with the doctor's advice depends on his/her personal appreciation of the disease and its treatment.[9,10] Agreement to comply with a treatment or preventive measure requires from patients the tacit acceptance of four concepts. They have been formulated into four postulates by sociologists under the "health belief model." Although this model deals with the patient's adherence to treatment, it may also explain why an educational program may have different rates of success. According to the health belief model, patients will not be actively committed to their treatment or ready to learn the right skills for self-monitoring unless they are convinced of the following:

1. They are at risk for the complications of diabetes (eg, hypoglycemic coma or long-term complications such as blindness or gangrene).
2. These complications constitute a serious threat.
3. These complications can be kept under control or cured.
4. The psychological, social, and financial cost of the treatment is less than the benefit of the treatment.

These postulates must be accepted en bloc to ensure patients' adherence to the educational program and to the daily obligation of medication and self-control.

The role of health beliefs becomes a major issue in planning community intervention programs in different ethnic groups. Much greater attention should be given in our countries to these beliefs, to follow more closely the representations and medical needs of the many immigrants we treat in our clinics.

Locus of Control

Who is finally responsible for the treatment of diabetes? HCPs (external control), the patient (internal control), or both? Acute medical problems are directly treated by doctors or nurses. In this situation and from the patient's viewpoint, disease control comes from an external locus. But daily management of the chronic phase of diabetes implies that the patient himself directly controls his diabetes. This is only possible through an internalization of the locus of control. Doctors do not sufficiently realize the burden placed on patients when switching from an external to an internal locus of control.

Coping With the Disease

The degree of acceptance of the disease may interfere with or facilitate the patient's understanding and adherence to treatment. Illness weakens people's self-image and places them in a situation of inferiority in relation to others. When self-esteem is too severely threatened by disease, people use a series of defense mechanisms to protect themselves from anxiety owing to their feelings of inferiority. This protection can take the form of a delay of direct entry into the disease state through a series of psychological steps known as the process of acceptance of the disease, or the mourning of health.[11] This psychological progression goes through five phases in which the patient's ability to listen and learn may vary greatly:

1. Denial of reality ("No, it isn't true, I do not have this disease"). During this phase, patients are unlikely to listen and learn, since they are not concerned about the disease.
2. Revolt ("Why is this happening to me?").
3. Bargaining ("OK, I agree to take insulin, but only one shot a day. . . "). During the phases of revolt and bargaining, patients frequently distort and misinterpret the medical information they receive. These are difficult times for the healthcare team, who often are exasperated by the patient's inability to learn correctly.
4. Depression with hope ("I realize I am sick and that I need treatment, but shall I really be able to cope?"). During this phase of emotional decompression, patients show a great demand to learn, a demand that is not always met by the healthcare team that remembers the recent difficulties experienced with the same patient during the previous phases.
5. Finally, in the phase of acceptance, one sees a patient who is receptive, listens attentively, puts the treatment into practice, and accepts suggestions and corrections.

HCPs need to be better observers of the psychological evolution of patients with the disease. Through a more appropriate attitude, they may help patients to cope with their disease more rapidly and to be in a better position to learn the appropriate skill to manage the treatment.

Helping Patients to Comply With Treatment

Because medicine has been initially learned and practiced in hospitals where, for several years, physicians were confronted with the diagnosis and treatment of acute or subacute medical conditions, this group of professionals has never learned or put into practice the various strategies necessary to help patients with chronic diseases to adhere to treatment. This applies even more for prevention of relapses. It is also true that the pressure of work in the medical routine leaves little time to allow patients to describe the difficulties they encounter in following their treatment.

Barriers Due to the Use of Unadapted Educational Methodology

When they teach patients, HCPs use the educational model they have been taught. They copy the classic school model, ie, an active teacher and passive students. To change this behavior is a difficult task, since it requires not only specific knowledge but also a change in attitude. This classic school model favors retention of knowledge and has little effect on skill and no effect at all on behavioral changes. This model is strictly bound to medical logic and does not include the representations and beliefs that patients have about the disease and its treatment.

THE NEED TO PROVIDE FORMAL AND STRUCTURED TRAINING IN THE FIELD OF PATIENT EDUCATION

Which programs should be developed to teach the teachers? Today in Europe, there are no more than 10 schools where students in medicine or nursing can follow a formal course in the field of patient education for the management of their disease. The same is true for HCPs at the level of postgraduate or continuing education. There are, on the other hand, several conferences and workshops dealing with patient education. They are organized for doctors and nurses every year in almost all European countries. Although these meetings promote awareness of the problem, they do not provide formal training for HCPs in the complex field of patient education.

Medical education, from medical school to continuing education, urgently needs new approaches. This holds true not only for medical doctors but also for members of the entire healthcare team. It results from ex cathedra lectures, ie, vertical teaching, which have virtually no interaction between experts and practitioners. Few answers are given for the daily problems encountered by professionals. We have specifically developed interactive workshops held over the last 10 years that aim at responding to the needs of practitioners (the Grimentz summer university workshops, named after a small village in the Swiss

Alps where these workshops are held). Their objectives are as follows:

- Reinforcing the medical approach by bringing together various members of the healthcare team, eg, doctors and nurses, etc.
- Developing the necessary strategies to reinforce the concept of the interdisciplinary team.
- Helping the individual team members to voice the difficulties they encounter in their daily professional activity.
- Helping the members of the healthcare team to find their own solutions, following small group discussions.
- Working with experts who agree to intervene only after participants in the group have defined their needs and their own proposals as to the solution.
- Encouraging experiential teaching.
- Working in collaboration with patients who also participate in the workshops.

HCPs often ask for study courses in the following areas:

- How to motivate patients.
- How to organize a teaching program for patients.
- How to evaluate the efficacy of an education program.
- How to integrate patient education in an outpatient clinic.
- The specific attitudes that help patients to learn.
- How to listen to patients.

Ironically, almost all of these fields are lacking in the curriculum of medical schools.

CONCLUSIONS

Remember these figures: in medicine, 95% of all patients are treated on an ambulatory basis and 80% of them have a chronic disease, whereas 90% of HCPs are trained in hospitals where they are confronted with only 5% of patients, those suffering from acute conditions. This situation remarkably helps the treatment of acute conditions, but it is unhelpful—even counterproductive—for the efficient management and follow-up evaluation of long-lasting diseases. In this perspective, the management of diabetes mellitus represents a model. It is one of the rare diseases in which HCPs try to compensate for what medical schools and their initial training have not been able to provide. Hopefully, the type of management necessary for the follow-up study of patients with diabetes may help the medical system to change. Education of patients and their families, helping patients to cope with the disease, psychosocial support, and more dynamic strategies for follow-up evaluation over the years—this global approach to diabetes is a real challenge for better diabetes therapy and for medicine in general.

Said but not heard
Heard but not understood
Understood but not accepted
Accepted but not put into practice
Put into practice but for how long?

These words of Konrad Lorenz remarkably summarize the challenge to be met by doctors, nurses, and dietitians for better education and follow-up evaluation of patients with chronic diseases.

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