

## Patient-Based Medicine and Psoriasis

### Development of Evidence-Based Medicine

The exceptional progress in medicine during the 20<sup>th</sup> century was made possible by two complementary approaches: biological research that enabled better understanding the pathophysiology of diseases, and development of the statistical methods that enabled characterization of diseases and evaluation of treatments. The object of this research was not disease but patients. By definition, it targets broad populations having in common a certain number of clinical and biological anomalies whose origins must be understood. The effectiveness and tolerability of the treatments proposed will also be gauged on broad populations. The level of certainty of the differences observed can be evaluated by means of statistical methods.

This 'evidence-based' medicine must eliminate the background noise created by individual situations. In contrast, it emphasizes the symptoms that the patient shares with those patients who have enabled this disease to be characterized.

### Patient-Based Medicine

Although this approach is necessary for diagnosis and is supreme in its management of acute situations, nevertheless such evidence-based medicine can only bring genuine benefits to patients suffering from chronic diseases if it is supplemented by other medical techniques that allow for this knowledge acquired by study populations to be applied to a particular individual. Each patient, even if suffering from a common disease, differs in the way that the disease is expressed, in his or her response and in his or her tolerance to treatment. By the same token, the patients will differ in the way that disease impinges on their day-to-day life, in the way they perceive the treatment

and are or are not capable of adapting to it. These new medical techniques, which I propose to call 'patient-based medicine', have begun developing in Europe (1-3). It could be argued that this represents the most significant advance in therapy of the early 21<sup>st</sup> century.

These new therapeutic techniques were first developed in medical specialties managing chronic diseases whose impact on the length of life is minimal but whose gravity relates to their, sometimes very serious, effect on the quality of life. In fact, the quality of life cannot be evaluated without shifting the focus from the disease to the patient. In dermatology, these management techniques originated in the context of diseases like psoriasis. This disease does not shorten life expectancy, but often has severe impact on social life, illustrating what is called skin disability. European experts working on this disease have reached a consensus that the severity of psoriasis is connected primarily with the degree to which the quality of life is affected (4). The next most important factor is resistance to available treatments. The expanse of skin surface involved is regarded as less important than the previous two criteria. This is in sharp contrast to the previous approach, which regarded this measurable factor as the main criterion of severity (5).

In the majority of acute diseases, it is the doctor who knows how to assess the gravity of the disease. In contrast, it is only the patient who is qualified to assess the effect of the disease on his quality of life (6). Assessing the severity of this effect is a key factor, since this is what will sanction the use or non-use of powerful and efficacious drugs, which may possibly have adverse

effects. As always in therapeutics, it is the benefit/risk ratio that needs to be assessed, but only patients, with the help of their doctors, can truly judge the reality of that benefit, as the key factor will be the patients' quality of life. Moreover, with chronic diseases specifically, the use of topically or systemically administered drugs will always entail some restrictions and unwanted effects. These restrictions and secondary effects may have an altogether negative effect on the quality of life. Although all too often the case, it would be absurd to replace the restrictions associated with the disease by even more irksome restrictions that may be connected with the treatment.

It is not possible, then, to nurse a chronic disease without the informed and responsible participation of the patient. However, a patient coming for consultation in 2010 is coming to seek a solution, a formula, a prescription; he is not prepared to assess the way in which his or her life is disrupted by the disease, nor to take a critical and constructive look at the treatments he or she can be offered. Patients experience their disease like an external strain, of which medicine must rid them just as one is cured of an infectious disease or appendicitis.

In the course of the successive patient's consultations, this misunderstanding will need to be dispelled and the patient allowed to take ownership of his or her disease and of the treatments on offer in order to lay down the foundations of true therapeutic negotiations that will end not in a prescription but in a choice made by the patient aided by his or her doctor, in a contract of care, ideally signed not only by the doctor but by the patient too.

### Technical approach

This approach will be conducted in four stages; the first is that of questioning. This allows one to assess the individual and the unique context in which the disease is expressed. It is the foundation of what is called the global approach, in which the doctor's attention, following the diagnostic phase centered on the disease, focuses on the patient, on the patient's relations with himself, with the disease and with the treatment. Little by little, one consultation at a time, this dialogue allows the disease to be objectified, made into something that can be acted on, not something merely to be endured. The disease becomes an event that doctor and patient alike are able to consider and work on.

The second stage is that of explanations. The patients have the mechanisms of their disease

explained, what is known about its development and treatment. Together with the patient, any links there may be between what is known of the physiopathology of the disease and his or her way of life are examined, as are the ways in which the various treatments available can or cannot be dovetailed into his or her day-to-day life. This second stage will allow patients to understand how they can control the disease. An important fact is understanding that drugs are there to help, but are no substitute for the patients themselves discovering a decent quality of life, and that in some way they command the wherewithal to master their disease, with the help of their doctor whose role, as always in medicine, is to render himself superfluous.

These two initial stages comprise the overall management, completely informed, though not limited, by evidence-based medicine. The aim of this overall management is to introduce the third and most important stage, that of therapeutic negotiation. Good negotiations are conducted between two people, each of whom in the true sense has a different point of view, both of whom are informed and in a position of equality, seeking together to find the best solution to resolve a problem. The quality of therapeutic negotiation between doctor and patient will therefore depend on the quality of the first two stages. Through these, the doctor will have come to an understanding of the patient's life pattern and can try to argue from within this situation. They will have enabled the patient to have better understanding of his or her disease and better understanding of the various potentials and constraints of the therapeutic tools at his disposal. Patient gains the ability to personalize this information by relating it to his own situation, to his own way of life, and to his own appreciation of values. From one consultation to the next, there will be an understanding that the patient is acquiring the freedom to take control of the disease.

Hence, between a variety of possible, technically sound, therapeutic strategies, negotiations will end in a choice made by or with the patient. This takes us on to the final stage, that of the prescription. In this context, it is not just a medical prescription, but a contract that concludes the negotiations and, ideally, should be signed by doctor and patient alike.

### The stakes of patient-based medicine

It is understood that this new therapeutic approach, which takes on different shapes in different medical specialties, lends itself particularly

well to any disease that fits the description of long-term or chronic disease. Its purpose, by means of a revolution, literally, in the doctor-patient relationship, is to restore liberty to the patient in the face of the relative incarceration engineered by the disease, to which the doctor occasionally contributes. In disorders of the skin, particularly, the onslaught on the self-image often has a serious effect on all social relations, and patients can feel imprisoned inside this distorted image. This transcends the bounds of dermatology; any disease impairing an organ destabilizes the life based on relationships. Whilst care for the organ is important, the relationship also needs nursing back to health. This cannot be done without the active and informed participation of the patient since no one can be 'liberated' against his or her will. With this approach, there are by far fewer compliance problems, since the patient has been able to take ownership of his or her disease and to regain control of it.

For thousands of years, medicine has had only the patient as a target, empathy as treatment and fate as companion. The development of evidence-based medicine and more and more outstanding therapeutic tools has focused everyone's attention on the disease, and on the diagnostic and therapeutic tools. This progress has made it possible to uncover the role of the nervous system (and hence the emotions) in controlling immune, inflammatory and growth responses and cellular differentiation in numerous organs. It is only natural, then, that organ-based medicine concentrating on the fight against disease and disease should rediscover the individuality of the patient. This realization should be the starting point for a much more efficient and status-enhancing division of tasks between specialists and generalists *en route* to a system of global management in which the patient, not the disease, is at the centre. The very advance in evidence-based medicine therefore emphasizes the urgent need to put in place techniques whereby general knowledge can be applied to a particular individual to the best effect, thus encouraging the development of what we call patient-centered medicine.

### **Conclusions on the Future of Patient-based Medicine**

So, is this new approach simply a restatement of medical humanism? By no means! Involved here are medical techniques that are needed for the effective management of all chronic diseases, whatever the nature of the doctor, whatever his or her ability for displaying empathy, and whatever

the patient's wish for dependence. These techniques can and must be taught, and the artificial distinction between technician doctor and humanist doctor should merge amid global approach techniques. Today's doctor must make use of all available scientific knowledge, drawing on his experience to help the patient choose whatever means that will allow him to find his physical and mental balance. It is interesting to note that patients are increasingly attending consultations armed with documentation about their disease obtained over the Internet. The request is clearly worded: 'Here's what I've been able to find out about my disease and treatment for it, and I've come to discuss it with you, doctor'. In other words, today's patient lines up at the third stage, the negotiating stage, not that it exempts the doctor from going back over the first two stages with him again; on the contrary, only this time to much greater avail.

Is such management possible? Under the current conditions for practicing medicine, the answer is NO! These techniques take time and medical time (albeit necessary for any health economy initiative) is not valued these days. If management of chronic disease is to be improved, it is paramount to take the time spent into account and to allow for every doctor one day or half a day a week to bill for his consultation, not on the visit but on the basis of time spent. Needless to say, this will not increase health costs since the 'takings' for this particular day or half-day will remain unchanged.

Does this management alter the way medicine is taught? It is already beginning to do so at the center of the medical degree course: an initial endeavor, called patients-partners, originating in rheumatology, consists of having small groups of students meet patients who have accepted special training. These encounters are designed to heighten students' awareness of managing not only the disease, but also the patient in his entirety.

Yet, continuous medical training is doubtless where this revolution in care will have greatest impact. It is effectively a matter of elaborating new training techniques whereby classic lecture-based teaching, in which an expert comes to teach practitioners, can be supplemented with a completely different approach. Practitioners are asked to tell people about hands-on management situations. Each situation is presented at a continuous training session, and each person suggests different management solutions, providing reasoning for them through the information presented and bringing them together by the technique of adopting a global approach to the patient. The conclusion is

delivered by the practitioner, who explains what management he has selected, for what reasons, and what the results were. This continuous training technique allows medical management to be developed not only for the disease but also for the patient. The first trials based on this new approach are already under way.

Through this new initiative, patients once again become the owners of their disease and hence of their medical records, taking over the responsibility for their own health. Does patient-based medicine reduce medical power? I do not believe so, quite the contrary. By developing knowledge and patients' freedom, it reinvests that power with its true meaning: that of taking care of an equal. By gradually becoming useless in technical terms, as the patient frees himself from his disease, the doctor becomes humanly indispensable.

## References

1. Dubertret L. Therapeutic negotiation in psoriasis. *Rev Prat* 2004;15:35-7.
2. Dubertret L. Patient-based medicine. *J EADV* 2006;20(Suppl 2):73-6.
3. Dubertret L. La medicina centrada en el paciente: una revolución terapéutica. *Actas Derm Sif Madr* 2007;98:297-301.
4. Kirby B, Richards HL, Woo P, Hindle E, Main CJ, Griffiths CE. Physical and psychologic measures are necessary to assess overall psoriasis severity. *J Am Acad Dermatol* 2001;45:72-6.
5. Fredriksson T, Pettersson U. Severe psoriasis – oral therapy with a new retinoid. *Dermatologica* 1978;157:238-44.
6. Lewis VJ, Finlay AY. A critical review of Quality-of-Life Scales for Psoriasis. *Dermatol Clin* 2005;23:707-16.

Professor Louis Dubertret, MD, PhD  
Hospital Saint Louis  
University Paris VII  
Paris, France  
louis.dubertret@gmail.com



Scientific Congress Organization:  
Thomas Ruzicka  
Matthias Volkenandt  
Markus Braun-Falco



We are looking forward  
seeing you in Munich.