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PRACTICAL DERMATOLOGY

Empowerment in Dermatology[☆]



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Abstract The term *empowerment* refers to any process that facilitates behavioral changes and encourages responsibility and making informed choices. The concept has been applied mainly to help patients with chronic conditions achieve therapeutic goals. The aim of the approach in health care is to enhance self-caring and self-efficacy. The term derives from the English verb *to empower* meaning “to give (someone) the authority or power to do something” or “to make an individual or a group stronger or more powerful”. One of the responsibilities of health professionals is to improve patients’ knowledge and their ability to choose between the different alternatives available to them so that they can act accordingly. In this article, we review the various definitions of the term *empowerment*, the tools used to measure patient empowerment, the implications of the concept for the management of chronic disease, and its use in dermatological conditions.

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Empoderamiento y Dermatología

Resumen El término empoderamiento (*empowerment*) se refiere a un proceso que facilita el cambio conductual, favorece la responsabilidad y la toma de decisiones informadas de los pacientes principalmente en patologías crónicas para alcanzar objetivos terapéuticos. El empoderamiento se orienta a fomentar el autocuidado en salud y la autoeficacia. El término proviene del inglés *empower* que significa «dar poder» o «hacer poderoso o fuerte a un individuo o grupo». Es tarea de los profesionales de la salud facilitar los mejores conocimientos y habilidades para que el paciente sea capaz de escoger entre las opciones que tiene al alcance y actuar

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en consecuencia. En este artículo se revisarán las diferentes definiciones de empoderamiento, sus herramientas de medición, las implicaciones que debe tener en el manejo de pacientes con patologías crónicas y su uso en las afecciones dermatológicas.

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Introduction

For some years now, the term empowerment has been used frequently in care models for patients with chronic diseases. The Real Academia de la Lengua Española defines the Spanish verb *empoderar* as an archaic variant of the verb *apoderar* and as a form derived from the English verb *to empower*. The dictionary definition of the Spanish term is "To make an individual or a group stronger or more powerful".¹ The literal meaning would be to "give power", which is not the same as to strengthen or to encourage. Consequently, the correct Spanish term is and should be *empoderar* (to empower).

The origins of empowerment philosophy can be found in the approach to popular education developed in the 1960s on the basis of the work of Paulo Freire.² The participatory approach, which emerged in the field of development in the 1970s, is a process that seeks to reduce the vulnerability and enhance the capacities of poor and marginalized populations in order to promote sustainable human development in these communities.³ In the mid-1980s, a network of women's groups and academics (DAWN) were the first people to use the term to refer to the process through which women could gain control over symbolic and material resources and strengthen their capabilities and roles in all areas.

Initially, the term was used to frame the rights and needs of groups that were vulnerable due to discrimination on the grounds of sex, race, or sexual orientation. Although the term *empowerment* is applicable to all vulnerable social groups or any group that is a victim of marginalization, both its origin and its broadest practical application are found in the field of women's rights.

Today, the concept of empowerment is used in a wide range of contexts. The interpretations of the term come from different disciplines, ranging from psychology and philosophy to the health sciences.

Empowerment and Health

In health care, the term *empowerment* refers to a process that facilitates behavioral change and helps patients to take responsibility for their own health and to make informed choices—mainly in the areas of nutrition, physical activity and adherence to treatment—in order to achieve treatment goals.⁴ The aim of empowering patients is to foster self-care and self-efficacy.

The World Health Organization (WHO) defines empowerment as "a process through which people gain greater control over decisions and actions affecting their health". They go on to say: "To achieve this, individuals and communities need to develop skills, have access to information, and

resources, and opportunities to have a voice and influence the factors affecting their health and well-being".⁵

In 2012, the WHO Regional Office for Europe published Health 2020,⁵ a policy framework document that establishes the strategy and identifies the priority areas for policy action for Europe in health matters up to the year 2020. One of the goals defined by this policy document is to empower citizens and patients.

In the context of health care, the term *empowerment* was first used as a guiding principle that should inform all interventions that promote better health. Later, the approach was used as a way to increase patients' autonomy and participation in decisions about their health. More recently, however, some authors have started using the term to refer to strategies designed to help patients with chronic diseases to participate in and take responsibility for their own care and treatment, in order to improve health outcomes and, as a secondary goal, to control healthcare costs.⁶

Numerous definitions of empowerment exist in the context of health economics (Table 1). They define empowerment as the social process of recognizing, promoting, and enhancing the patients' ability to meet their own needs, solve their own problems, and feel that they are in control of their own lives.

Empowerment is achieved by way of 5 principal steps:

1. Explore which aspects of the condition represent a problem for the patient.
2. Clarify the patient's feelings and the implications of their emotions: What does the patient think and feel about his or her situation?
3. Develop a plan: What needs to change? What options or resources are available to the patient?
4. Commit to action. Help the patient to understand the effort they will have to make and assess their commitment: What will the patient do and when?
5. Evaluate the process. Discuss the results and what the patient learned. Find out whether they encountered obstacles. Decide on the course of action for future interventions.⁷

Through these 5 steps, the empowerment process explores the patient's emotional response to their situation, works on ways to resolve the problems identified, and sets behavioral goals and targets. Obviously, there are certain prerequisites to success in this process and it will not be possible to empower a patient if these are not met:

- The patients must have certain abilities^{8,9}: They must accept their condition and have the necessary intellectual capacity to understand and engage with the disease

Table 1 Definitions of Empowerment.

Definition	Reference
A process of recognizing, promoting and enhancing people's abilities to meet their own needs, solve their own problems and mobilize the necessary resources in order to feel in control of their own lives.	Gibson, 1991 ²⁴
A process involving a helping relationship that enables people to take control and make decisions about their lives.	Rodwell, 1996 ⁵
Empowerment is the process of people obtaining the knowledge and skills that enable them to become active partners with professionals in making informed decision and choices about their own treatment and care and of enabling communities to exert informed influence on the health system.	Farrell and Gilbert, 1996 (cited by Boudioni et al., 2012) ²⁵
Empowerment enables patients to gain control over their health.	O'Cathain et al., 2005 ²⁶
It is the capacity shown by patients with chronic disease to accept their illness and to develop and use specific coping strategies in order to regain a sense of control.	Bulsara et al., 2006 ²⁷
A process in which nurses collaborate with patients towards achieving the goal of disease self-management; this implies that patients actively participate in their care.	Shearer et al., 2007 ²⁸
A process of communication and education between professionals and patients, in which knowledge, values and power are shared, which is seen as a process of personal transformation.	Aujoulat et al., 2007 ⁶
Patient empowerment is achieved when there is an equitable or fair distribution of knowledge, and the patient is involved in a shared decision-making process.	McWilliam et al., 2009 ¹¹
Empowerment reflects a type of support that enables and motivates people to take the necessary steps to manage and improve their health in a self-directed manner.	Bann et al., 2010 ⁹
Empowerment applied to health is the degree of choice, influence and control held by patients over treatment, the disease and their relationship with health professionals.	Anderson and Funnell, 2010 ²¹
The empowerment viewpoint perceives patients as self-determining agents with some control over their own health	McAllister et al., 2012 ²⁹
A process and outcome arising from communication between health care professionals and patients involving the sharing of resources over information relating to illness, which enhances the patient's feelings of control, self-efficacy, coping abilities and ability to effect change over their condition.	Small et al., 2013 ⁸
A process and outcome through which patients gain self-confidence and self-efficacy in order to actively participate in their own health care and, ultimately, exercise power over decision-making concerning their treatment.	Aslani, 2013 ³⁰
It is power that is actualized through a beneficial relationship of mutual trust and respect for autonomy that develops within a dynamic and patient-centered process.	Jerofke, 2013 ³¹
A collaborative approach in which health professionals help patients acquire the knowledge necessary to make informed decisions and whose outcome is a patient who is responsible for the management of his or her illness.	Wentzer et al., 2013 ³²
An empowered patient is able to report changes, develop self-care activities, has the necessary skills and capacity to develop coping strategies and promote self-management independently and feels in control of his or her life.	Fotoukian et al., 2014 ³³
It is gaining the motivation and capacity (skills and knowledge) that patients can use to participate in decision-making, thus creating the opportunity to shift the balance of power in their relationship with health professionals.	Fumagalli et al., 2015 ¹⁴
Empowerment is a process through which people gain greater control over decisions and actions affecting their health; to achieve this, individuals and communities need to develop skills, have access to information and resources, and opportunities to have a voice and influence the factors affecting their health and well-being.	World Health Organization, 2012 ⁵

Adapted from Garcimartín et al.²³

process as a whole (prognosis, risks, treatment options, etc.).

- Empowerment is both a process and an outcome.^{10,11} The empowerment process is a collaborative partnership between health professionals and patients in which the patient acquires capacities and skills through the transfer of knowledge and resources. At the end of the process, patients are better equipped to control and manage

their disease and make informed decisions. The process should be guided by an exchange of information through which knowledge and skills are shared.¹² This goal can be achieved in many different ways: through a verbal exchange of information during a visit with the specialist; by creating materials designed to inform and train patients to correctly interpret clinical information; by teaching patients to cope more effectively with their disease and

to improve their quality of life (and enabling them to pass on their knowledge to other patients); by fostering healthy behaviors that will reduce clinical risks.

Today, on-line resources are very important and, when properly selected, they can and should be an essential resource for patients. In Spain, there are a number of “patient schools” (patient education websites), where patients who have certain diseases or are taking certain drugs share their knowledge and experience with others in similar situations.¹³ To cite just a few, there are “schools” dealing with diabetes, fibromyalgia, anticoagulation therapy, breast cancer, colorectal cancer, Parkinson disease, epilepsy, Alzheimer disease, childhood asthma, food allergies, chronic kidney disease, serious mental illness, and ostomies).

The ultimate aim of the empowerment process is to change the patients’ situation by encouraging them to play an active and responsible role and to participate in the decision-making process.

A patient can be said to be empowered when:

- They understand and have mastered their disease and understand the effects it has on their personal, family, and professional life—in short, its impact on their quality of life and future.
- They are capable of effective self-care measures and of adjusting their treatment regimen as needed, and are aware of the limits that must be respected in their therapy.
- They are capable of making decisions and are satisfied with their health professionals and treatment.
- They are well informed enough to avoid the most common risks and complications of their treatment and know how to minimize those risks.
- They play an active role in their own care, engaging with health professionals to learn more about their disease and its treatment.

Patient empowerment implies making a paradigm shift in care; the challenge is how to introduce this approach into routine practice. It implies changing the current model of patient-physician relationship from the old paternalistic model, in which the patient is excluded from medical decisions, to a model based on an empowered patient. Designing strategies that enhance the patients’ knowledge and understanding is not enough to empower them; if the ultimate goal is to enable the patient to change his or her behavior, motivational strategies will probably also be necessary.¹⁴

Measuring Empowerment

Patient empowerment should be an essential component of health care, implemented through strategies embedded in educational programs and by developing instruments that can measure levels of patient empowerment and their impact on the management of chronic diseases in all domains. The tools used to measure patient empowerment should be designed to assess all the domains at 3 key time points: baseline, during the empowerment process, and after the intervention. Numerous tools have been

designed to measure empowerment in different disease settings (Table 2). Diabetes and cancer are the diseases in which most work has been done to date. For example, Ebrahimia et al. published a study that evaluated outcomes in 103 patients with diabetes randomly assigned to either conventional training or empowerment approach training.¹⁵ At the end of the intervention, they reported that the patients in the empowerment approach group had better results in terms of HbA1c, fasting blood sugar, triglyceride, and total cholesterol levels. The authors concluded that empowerment was an effective strategy for improving health because it increased the patients’ active participation in the management of their condition, helping them to identify their strengths and to take decisions aimed at adjusting their needs and improving their quality-of-life.

Empowerment in Dermatology

There are very few references in the literature relating to patient empowerment in dermatology. However, there are numerous skin diseases in which empowering patients could be a very helpful strategy that would promote a more holistic approach to their care.

Skin cancer, including actinic keratoses, is one such disease. Skin cancer and actinic keratosis are chronic conditions and it is essential that these patients learn that photoprotection must be a lifetime habit. They must also be properly informed about the wide range of treatments available and the potential adverse effects of each option. In this context, empowerment could play a key role in primary prevention (photoprotection) and secondary prevention (early diagnosis), and in improving adherence to treatment and the medical follow-up of these patients.

Other areas of dermatology that could benefit from patient empowerment approaches are atopic dermatitis, acne, urticaria, and psoriasis. Patient empowerment has already been shown to be useful in the management of psoriasis¹⁶ and psoriatic arthritis, at least in terms of patient satisfaction.¹⁷

In fact, psoriasis is the only skin disease for which an attempt has been made to develop a tool to assess empowerment levels. Psoriasis Empowerment Enquiry in Routine practice (PEER) is a questionnaire developed by the Istituto Dermatologico dell’Immacolata in Italy to measure empowerment levels in patients with psoriasis.¹⁸ PEER includes 3 domains: knowledge, experience, and skills. In the study, 240 patients responded to 12 statements by indicating their level of agreement with each one (ranging from “strongly disagree” to “strongly agree”). Based on the results, the authors calculated a Global Empowerment Score (GES)—ranging from 12 to 60 points—by totaling the scores for all 12 items (5-point score). The questionnaire was originally created in Italian, but the published article also includes a version in English, although this not yet been validated for use (Table 3).

The authors reported that men and patients aged 44 years and older had higher GES scores ($P < .05$). No differences were observed between groups with different educational levels.¹⁸ They also reported that patients who had developed psoriasis more than 1 year before the study and those with psoriatic arthritis, particularly the latter group, also

Table 2 Empowerment Measures.

Measure	Setting	Dimension	Reference
Patient empowerment in long-term conditions	Specific: primary care and patients with chronic diseases	Knowledge and confidence in decision-making, and a desire to share and enhance capacity	Small et al. ⁸
Patient Empowerment Scale	Specific: cancer	Coping strategies and self-efficacy	Bulsara et al. ²⁵
Diabetes empowerment questionnaire	Specific: diabetes	Knowledge, self-care, coping	Aghili et al. ³⁴
Diabetes Empowerment Scale	Specific: diabetes	Coping, openness to change, ability to define and set objectives	Anderson et al. ³⁵
Patient Empowerment Scale	Specific: hospital care	Identification of activities that illustrate empowerment and disempowerment in relation to the nurse/patient relationship	Faulkner ³⁶
Patient Activation Measure	Generic	Skills, knowledge, and beliefs in three domains: self-management, collaboration with health care providers, and self-care	Hibbard et al. ³⁷
Patient Enablement Instrument	Specific: primary care	Aspects of perceived control over disease	Howie et al. ³⁸
The Empowerment Scale	Specific: mental health	Self-efficacy, perceived power, optimism about and control over the future, and community activism	Rogers et al. ³⁹
CIDES: Cyber Info-Decisional Empowerment Scale	Specific: tool for patients with cancer who manage the disease using online support communities	Knowledge, participation, decision making	Seçkin ⁴⁰
Genetic Counselling Outcome Scale	Specific: clinical genetics	Perceived personal control (over decision-making and behavior), hope, and emotional regulation.	McAllister et al. ⁴¹
Psoriasis Empowerment Enquiry in the Routine Practice	Specific: psoriasis	Knowledge, experience and skills related to psoriasis	Pagliarello et al. ¹⁸

Adapted from Garcimartín et al.²³

scored higher in the areas of knowledge ($P < .01$) and experience ($P < .001$). Patients on systemic therapy were more knowledgeable about their condition than those on topical treatment ($P < .001$). No differences were observed between patients on conventional systemic treatment and those on biologic therapy.

A number of subjective tools are currently used to measure quality-of-life,¹⁹ habits, attitudes, and knowledge related to solar exposure in dermatological patients.²⁰

These could serve as a starting point for the development of valid and reliable tools adapted to each cultural setting to measure empowerment in dermatology patients. These tools would facilitate the evaluation of educational interventions in the coming years.

Conclusions

Patient empowerment will become an integral part of the management of chronic diseases because it helps to maximize efficiency and value in health care systems.²¹ An active and empowered patient is able to make decisions, satisfy his or her own needs, and resolve problems. Empowered patients think critically and are in control of their

lives and health. In order to achieve this goal, the patient must first acquire the necessary knowledge. An empowered patient has to be well informed and trained and must have a sufficient knowledge to understand the disease and its treatment and to feel capable of carrying out the therapy.²² Health professionals must keep their own professional knowledge up-to-date, avoid clinical inertia, respect the patient's needs, offer their patients the best therapeutic options available, and guide them in their choices. Health professionals are responsible for collaborating in the task of providing the best knowledge and skills (advising their patients on appropriate on-line resources and sharing links to webs or blogs offering reliable information in everyday language). This will empower their patients and enable them to make informed decisions about the options available to them and act accordingly.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

Table 3 Psoriasis Empowerment Enquiry in Routine Practice (PEER)^aEnglish Version of PEER^b

Please mark the answer that best describes your opinion/feeling

Smoking and alcohol consumption improve psoriasis

1 am able to interact with my doctor in decisions about the best treatment

1 don't allow myself to be demoralized by the difficulties that psoriasis creates for me

1 am able to live in a satisfactory manner with psoriasis

1 am genetically predisposed to this disease

1 know what 1 can expect from my treatments for psoriasis

Some forms of psoriasis can damage joints

1 cannot affect psoriasis by my behavior

Psoriasis can be treated very well but it can't be cured

1 can make my doctors understand my condition precisely

1 am able to tell which treatment works best for me

1 am always trying to resolve all of the problems that psoriasis creates for me

Response choices for all items are "Strongly agree", "Agree", "Uncertain", "Disagree", "Strongly disagree"

^a A tool for measuring level of empowerment in patients with psoriasis by Pagliarello et al.¹⁸

^b The original version of the questionnaire is in Italian. The English version has not yet been validated.

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