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EDITORIAL

The contribution of active patient in chronic diseases, the present and the future of health assistance☆

La figura del paciente activo en patologías crónicas, el presente y el futuro de la asistencia sanitaria

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In the history of medicine, probably no topic has been as commented on as the physician-patient relationship, and In Spain no-one has gone deeper into it than Prof. Laín Entralgo. This relationship, described as early as the Hammurabi Code, has gradually taken shape over the centuries, but some believe that it is now under threat from the great technological advances of our time, shared decision making models, and the reduction of the classical asymmetries in knowledge between physicians and patients.

Since the Declaration of Alma-Ata in 1978 and the Ottawa Charter for Health Promotion in 1986, the World Health Organization (WHO) has encouraged patient participation both individually and collectively regarding health issues. In Europe, the White Paper (2007) emphasized the importance of participation in both individual and collective health processes, in more local and regional contexts. In Spain, the National Health System (Sistema Nacional de Salud [SNS]), through Act 41/2002 of 14 November regulating patient autonomy and rights and obligations regarding clinical information and documentation, included ëxplicit recognition of the capacity of choice and influence of patients, both individually and collectively, through the organizations representing them:. Thus, patients, once mere observers and passive agents (obeying without complaining) according to the traditional paternalistic model, have now become co-responsible agents who learn about their disease and communicate both their experiences and their preferences and decisions.

The term 'empowerment' has been used for some years in this context. The WHO defines it as a ''process by which people gain greater control over decisions and actions that affect their health. In order to do so, individuals and communities need to develop skills, have access to information and resources, and the opportunity to participate and influence factors that affect their health and well-being''.[1] Other terms with a similar meaning which are employed include the following: qualified patient, smart patient, engaged patient, or e-patient / connected patient. Early experiences with smart patient programs were conducted by the British National Health Service (NHS)[2] and Stanford University (USA). In Spain, the Smart Patient Program is an initiative of the Education, Health and Society Foundation, with the support of public and private institutions at national level. In September 2006, the Catalan Health Institute started programs with smart patients in some health centers in Barcelona, with reference to groups of patients with chronic heart failure. Other projects were subsequently created in different Spanish Autonomous Communities.

With regard to ''empowered patient'', I am more in favor of the use of the term ''active patient'', which encompasses both knowledge (power) and personal involvement (commitment), as well as participation (movement) in decision-making and in health self-care.

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Regardless of the different definitions, the main characteristics of the active patient are that he/she[3]:

- Has in-depth knowledge about his/her health or illness
- Has control over his/her health or illness
- Participates in decision-making regarding his/her health in coordination with the healthcare professionals
- Is responsible for his/her health care
- Learns and informs about health matters

In this regard, mention also should be made of the letter from the European Patients' Forum.[4]

There is agreement on the benefits of increasing patient empowerment at both the personal and public health level[5]:

- At the personal level, patient training and involvement in healthcare allows for greater capacity to cope with the disease and even prevent it. The active patient learns and informs at the hands of professionals, other patients, other sources and, together with his/her own personal experience, may become a s̈mart patientn̈ the disease. With this knowledge, the patient increases his/her autonomy to make decisions affecting his/her health, handles symptoms, and controls and manages the disease. This approach results in better disease follow-up and greater adherence to therapy.[6]

- At the public health level, implication in the management of chronic diseases results in savings (reduction of costs associated with the therapeutic process, consultations, emergency room care and hospital admissions) and improved management of the healthcare system.

The capacitation process is characterized by information and education, through the transfer of knowledge and resources, carried out by professionals together with patients in a collaborative/participatory manner, and results in greater patient capacity to control and manage the disease.[7] This information exchange can take place in different scenarios (the consulting room, the waiting room, primary and specialized care) and with different supportive media (paper format, audiovisual, digital).

In turn, the healthcare professional should be trained, activated and motivated to provide the best therapeutic options available and to act accordingly, guiding and respecting the patient's decisions. All these initiatives are complemented by self-care education programs, under the focus of the new paradigm in health education and chronic disease management.[8] In addition to educational activity in chronic disease, the patients and caregivers participate in issues related to safety.[9] The challenge lies in how patient education is incorporated into clinical practice.

When the renowned endocrinologist Dr. Gregorio Marañón (1887–1960) was asked to name the most revolutionary invention in medical history, he answered: the chair. He thus illustrated the importance of evoking humanism in medicine, as the chair allows us to listen, accompany and investigate the patient. The physician and patient of the XXI century would probably answer: the internet. Online resources have become particularly important in relation to the transmission of information. According to Eurostat data, 49 % of all Spanish users of the internet between 16–74 years of age used the Google search engine in 2016 for medical advice - 30 % more than 10 years ago. In the European Union, Spain ranks seventh in the list of countries that most resort to D̈r. Google.̈ The list is headed by Luxembourg (71 %), Denmark (65 %) and Germany (63 %). At the bottom of the list are Romania (29 %) and Bulgaria (24 %). According to Eurostat, the information sought by users mainly refers to injury, illness and nutrition.

E-health is a crucial element in the current Spanish healthcare setting. Many institutions, associations, healthcare professionals, companies and patients demand greater implementation of the advances in Information and Communication Technology (ICT) in the healthcare system as an element that can improve its development and access to its services and benefits. According to the latest European Commission report on digital integration, Spain ranks fifth in terms of electronic health services.[10]

The SEEN, sensitive to the considerable possibilities offered by patient training, and making use of the advantages and widespread use of the internet, has recently opened a V̈irtual Classroom (*Aula Virtual*) space on its website (https://www.seen.es/portal//inicio.aspx), which focuses on the training of patients and caregivers. The Steering Committee of the Nutrition Area, with the participation of multidisciplinary teams from nutrition units with a long history and considerable experience, has developed educational and training materials related to common diseases, which entail knowledge and adequate management by the patient and caregiver. Five modules have been presented in launching this new platform: Disease-related Malnutrition, Dysphagia, Home Enteral Nutrition, Home Parenteral Nutrition, and Bariatric Surgery. Each module is organized into four sections that review the basic aspects of the disease (Knowledge); focus on the symptoms/complications which the patient should be able to identify (Learning); highlight the important work of caregivers (Living with); and address aspects related to quality of life (Self-care). The downloadable material is available in simple and comprehensible language. Videos relating to therapeutic specifications and with patient and caregiver testimonials are also available. The key objectives are to provide rigorous information and to educate patients and caregivers on the appropriate and safe management of chronic diseases related to the field of Nutrition.

Now that chronic diseases constitute our main health problem, the patient should become an active agent in the process. Healthcare professionals and patients should operate as a team and work together to find the best solution for each problem. Using the advantages of technology and thanks to online platforms such as the SEEN V̈irtual Classroom,̈ we are in a position to secure the best possible outcomes. However, patient training through digital media should not make us forget the chair cited by Dr. Marañón, as it constitutes the fundamental and irreplaceable humanistic reference in the physician-patient relationship.

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