

THE ROLE OF THE PATIENT: FROM SPECTATOR TO ACTIVE PLAYER IN THE PATH OF PERSONAL PREVENTION AND HEALTHCARE



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ABSTRACT

The scientific, technological, cultural, and social transformations occurred during the last two decades have pushed the role of patients beyond a paternalistic relationship with the doctor. With the explosion of digital and new information tools available to all, and a growing consumerist view of healthcare service delivery, patients have developed a new vision of themselves in their care pathways. Expertise is increasingly shared and care models are shifting the patient to the centre, allowing a two-way information flow where both patient experience and scientific or medical information have the same value to reach the final outcome. The creation of “expert patient” positions and the involvement of patient interest groups into scientific research and large-scale real-world-evidence projects are further consolidating the involvement of patients into the healthcare paradigm. In this scenario, rethinking and designing interdisciplinary clinical and operational work will be crucial for a well-coordinated management in which patients and their caregivers are an active part of the process.

INTRODUCTION

Patients’ engagement from 1950s to today

The evolution of the “patient at the centre” concept has a history that origins in the doctor-patient relationship and in its initial typically paternalistic nature, due to a gap of knowledge and a social vision of the role of the doctor and the patient that has deeply changed over the centuries (Taylor, 2009).

In the 1950s this relationship was highly asymmetrical: the patient was considered both lacking technical knowledge and unable to decide for himself/herself. The ethical principles underlying the paternalism are the principle of charity, which prescribes the duty to act for the well-being and health of the patient, and the principle of non-maleficence, which states the duty to do no harm to the patient (Veacht, 2009).

During the last decades of the 20th century profound transformations took place. Scientific, technological, cultural, and social progress has amplified the demand for greater autonomy of patients and their caregivers. In the field of healthcare, this has contributed to creating a favourable context for the approval of the AHA Patient’s Bill of Rights by the American Hospital Association in 1973 (APRA). The document shows patients’ right to be placed at the centre of the therapeutic program by providing them correct information, enabling their active participation in the therapeutic decisions with a certain level of decision-making autonomy (Patient and Public Partnership Strategy, 2019-2023). However, this model shows some limitations in the context of the doctor-patient relationship. Indeed, it fails to consider important elements intrinsic to the relationship itself, such as its

disparity and asymmetry, the trust investment or all those virtues of a moral agent which accompany the fulfilment of a duty and which can hardly be enclosed by a signed contract (Interview with Sandro Spinsanti, 2016).

Digitization and the “consumer” patient

The birth of a new technological era, with the development of big data analysis and the constant sophistication of information and communication technologies, has revolutionized many sectors, health and healthcare included (Belle, 2015; Hong, 2018). Additional tools used to foster interoperability of data sets include the combination of semantic web, text-mining methods and ontology (Lopes et al., 2015). Moreover, the collection of assessment data and feedback involves not only the patient, but also his/her family members (Baumbusch et al., 2019). This has created promising new opportunities for the cure and treatment of diseases, personalized medicine included, as well as the challenge related to the difficulty of finding, processing and analysing data and the related ethical issues regarding data protection (Lopes et al., 2015; Lochmüller et al., 2018).

Furthermore, in the literature many works emphasize the importance of guidelines as an instrument to be used to spread knowledge and consequently improve the access to treatments and personalized assistance (Fayet et al., 2018). Thus, the figure of the “expert patient” emerges from precision medicine, focused on the personal characteristics and needs of the patient (Baynam et al., 2016; Bodini et al., 2018; Gainotti et al., 2018).

Precision medicine: the expert patient

Medical paternalism represented an ethical model of behavior no longer adequate and it was replaced by the contractual ethical model that places at the centre the ethical principle of respecting patient's autonomy. Therefore, the doctor-patient relationship becomes a symmetrical relationship.

This involvement favours the creation of a two-way information path, where both patient experience and scientific or medical information have the same value. In this scheme, patients become also knowledge and data generators, creating research, clinical care and treatments. A direct manifestation of this trend is the development of the patient-reported outcome measures which are tools that allow the direct participation of the patient to the clinical decisions (Slade et al., 2018).

The user becomes more and more a protagonist and behaves as an "active player" in the system, as a consumer. This model tends to place the patient at the centre, as an individual with his/her peculiarities and personal experiences. This results in the design of more and more personalized healthcare treatments, therefore implying that health systems take higher responsibility in patient management. Moreover, it makes necessary to provide all information to patients in an optimal manner, so that they can make informed decisions and choices. Taking charge of the patient is becoming less focused on disease and treatment, taking more and more into consideration the patient's experience and perspective to create a system. Hence, a distinctive trend is the shift in the relationship between the patients and health professionals towards a more collaborative relationship.

In this sense, narrative medicine plays a key role. It aims to investigate the experience of the disease not only from a strictly clinical point of view, but also through the narratives of lived experiences: a way to "train" attentive listening, reflection, understanding, and complete the training of future professionals who can learn to take care of people from different perspectives. In this way it is possible for the person to arrive at a shared decision (Fiorencis, 2015).

Communication

Better communication is one of the key elements of this system which requires a constant and free flow of information among all participants, including patients and caregivers.

Part of the patient empowerment process is based on providing information to the patient, who first desires the knowledge and a frank discussion. In their role of experts, patients are encouraged to provide data, assessments and feedback on their personal experiences. At the same time, patient organizations are consulted regarding biobanks and the establishment of specific registers, in particular for rare diseases.

In terms of publishing research results, patient representatives and organizations more and more commonly appear as co-editors of these results. Some peer-reviewed journals, such as the British Medical Journal (BMJ), have established a Patient and Public Partnership strategy designed to promote the co-production of contents and help the progress of the global debate on the engagement of both public and patients.

Another development that strongly places patients at the centre is the multitude of possibilities offered by the use of social media. Indeed, they can be used with the aim of informing and promoting advocacy with undeniable success as well as a fundamental resource to search, produce and share health data.

A further observed trend concerns the ability of patients to travel and choose the location of their centre of reference. From a virtual point of view, the development of the possibility of obtaining telematics prescriptions and the current efforts to standardize patient health records/dossiers in different countries allow the easy movement and sharing of patient data, facilitating the use of extraterritorial health services. These tools make remote assistance, such as telemedicine, possible.

CONCLUSIONS

The progressive and constant aging of the population is highlighting the transition from a health request for a specific pathology to a health request for multiple needs. From the point of view of the management model, this step implies an interdisciplinary clinical and operational work and the necessity for a well-coordinated management in which the person is directly part of the process. In the context of such a radical evolution, such as the one that has been involving the national health system in recent years, it is essential that the staff is and will be adequately trained in order to guarantee a regular high quality of care over time. Homogenizing knowledge and creating synergy between the categories of professionals involved in our health system requires the collaboration of the expert patient. To guarantee integration and continuity of care, emphasis is placed on the skills of all staff working in the health sector in order to ensure the effective management of complex healthcare pathways (Interview with Luigi Mossa, 2011). As a result, the collaboration between multidisciplinary stakeholder groups, in order to formulate new policies, conduct researches or improve treatment options, and the healthcare system is becoming increasingly common (FprCEN/DTS 17288, 2019).

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