
Abstract: Making patients active participants in their healthcare is recognized as a crucial component of high-quality healthcare services, particularly in the treatment of chronic diseases. The growing understanding of the key role of patient engagement in improving healthy behaviours and clinical outcomes has led healthcare to search for innovative ways to foster individuals’ roles in the care process: patient engagement may lead to more responsive services and better outcomes of care by incorporating the patient’s values and preferences into care plans. While, patient (dis)engagement may produce a waste of healthcare resources and poor clinical outcomes, comprehensive patient engagement across the continuum of care still presents a challenging task for hospitals and health systems, as it requires not only redesigning current care approaches, but also working with patients to identify ways to integrate care management into daily routines and activities; with this aim, new technologies may play a fundamental role. Based on these premises, this chapter sets the ground for the topics presented in this book and introduces the main challenges that healthcare systems currently face. Within this framework, this chapter also highlight the reasons why healthcare professionals and managers must regard patient engagement as the key to redesigning healthcare and making it more sustainable at the economic, sociological, and psychological levels.

Keywords: Healthcare challenges; economic pressure on healthcare; demographic change; climate change; technological revolution in healthcare; demand and supply of healthcare; patient engagement

1 Introduction

In this chapter, we offer an overview of ongoing societal and global tendencies that are deeply reframing healthcare. The citizens’ demand and expectations toward health and care, precisely, is continuously evolving, resulting in setbacks of consolidated knowledge and practices related to the traditional management of healthcare organizations and services (Barello et al., 2012; Glaser et al., 2014). The incertitude provoked by this evolving and fluid scenario is putting pressure on healthcare professionals, managers, policymakers, and technological engineers and designers, who are in a desperate search for new insight and advice to innovate healthcare and make it more sustainable and effective (Plsek & Greenhalgh, 2001; Pruitt & Epping-Jordan, 2005).
Moving from this frame, we outline how the concept of patient engagement may be a valuable option to make sense of the evolving scenario in which healthcare systems need to act and to orient changes and actions. Patient engagement, conceivable as a qualifier of the exchange between the “demand” and “supply” of healthcare, has, so far, raised the interest of experts across the world, both inside and outside academia. Several empirical studies have also demonstrated the positive outcomes of patient engagement at the clinical, psychosocial, and economic levels (Graffigna et al., 2014).

However, although greatly promising, patient engagement still risks becoming more of a “fashionable claim” than a concrete course of action. The following chapters of this book offer cues for conceptualizing, assessing, and promoting engagement in health and care by taking on board not only patients but all other stakeholders of this process (i.e., healthcare professionals, caregivers, communities).

Let’s start this promising patient engagement journey together!

2 The Main Challenges of the 21st Century

The 21st Century is faced by challenging changes of scenario that are profoundly affecting western societies and casting light on the urgent need for revisions in policies and interventions.

The Global Economic Crisis recently troubled all western markets and changed the rules of finance and commerce. The crisis not only reduced the economic power of the different populations, but also caused deep disorientation and concern among all key economic players. Classical segmentation of population, based on their consumption power, became inaccurate; consolidated economic and financial models resulted in inadequate explanations, changes, and forecasts of global economic tendencies. As a consequence, the economic and human resources of different businesses and organizations needed to be revised and reduced, resulting in a tremendous effect on the job labour and quality of life of citizens. Healthcare systems are not immune to this overall tendency; across countries, all suffer a general economic pressure, and more and more link clinical decision making to pharmaeconomic evaluations. Healthcare professionals, policymakers, and patients are now challenged to frame their healthcare behaviours and attitudes in light of the financial and economic evaluations of such Conducts, and they are forced to seek a better and more virtuous balance in the framework of “doing more with less.”

Furthermore, the Demographic Change is deeply influencing the structure of present society (Gee & Gutman, 2000). The increase in life expectancy together with the decrease in births rates, are augmenting the prevalence of elderly people in the community. Innovation and continuous advancement of technologies and pharmaceutical achievements are also alimenting with People’s the expectations of a better
quality of life. This aspect claims for a deeper reconfiguration of actual research, intervention, and policy-making approaches in favour of a better consideration of the “life course” of human beings in all its complexity.

Moreover, the last decades have been the scenario of a real **Technological Revolution** that deeply restructured societal and industrial processes (Deluca & Enmark, 1999). The advent of new technologies, in particular, enabled new processes of knowledge construction and exchange in the general democratization of information fluxes (Livingstone, 2004). Moreover, the evolution of technology is notoriously characterized by reductions in costs and dimensions as well as difficult of use (Kurzweil, 2005); therefore, new technologies are becoming more usable and designable for everyone. Finally, more recent studies of new technologies show they are not only mere instruments. On the contrary, they constitute fundamental resources to affect people’s lives and behaviours; for example, promoting strengths, wellness, and health (Riva et al., 2012).

Finally, in western populations **Climate Changes** are leading to increased sensibility regarding the the potential negative effects of human actions on the environment (Arrow, 2007). This renewed sensitivity has oriented a revision of policies and approaches to service delivery and productive processes. In the context of restricted resources (economic, natural, human…), societies have to reduce, or at least revise, their effects on the environment. The value of “green approaches”, the shift toward a reduction in consumption (as opposed to the “consumism” of some decades ago), and the shared appreciation for what is “natural” and “less industrialized” is revising the set of values of today’s citizens in favour of a “return to the origin” of a less industrialized, polluted, and pathogenic way of life. In general, this frames the renewed values and expectations that drive citizens’ demand for health and care services. This represents a change of sensibility, which is a scenario of patients’ attitudes towards their care. Furthermore, healthcare organizations claim to revise the effects of their services delivery on the environment and, thus, are more sustainable and environmentally friendly.

These changes are at the basis of a shared perception of incertitude and disorientation: “reading keys” once effective in orienting policies and interventions, are today experienced as “out of date”, rapidly senescent and no longer sufficient to sustain actions. In other words, the dismantling of modern securities—referring to Bauman’s (2005) conceptualization of a liquid society—is leading societies and their governors to seek new convincing and applicable answers. The awareness of not applying past knowledge and practices to manage the present and, in particular, the future, of our societies is frightening, but also opens the opportunity of really innovating societal and organizational systems to achieve a better way of life. The real risk, thus, is to fail in facing these claims for revision and not being ready for innovation.
3 When the “Demand” for Healthcare Changes: Directions of Innovation

The main societal and contextual challenges underlined in the previous paragraph directly or indirectly influence the volume and shape of the “demand” for healthcare services. Changes in the “demand” that need to be considered for deeply rethinking the ways in which healthcare services should be supplied today. Let’s discuss in more detail the main tendencies that characterize the current “demand” for health and care.

– *The demand of care* is increasing because of the diffusion of chronic conditions. The increase of the ageing population is often related to an enhanced incidence of chronic conditions (Beaglehole et al., 2008; Graffigna et al., 2013; Wiederhold et al., 2013). Moreover, environmental stressors and pathogenic elements present in the daily contexts of life, together with the increased diffusion of unsafe life habits (e.g., unhealthy alimentary habits, smoking, and alcohol consumption) are putting the Western population at the mercy of contracting diseases (Sears, M. E., & Genuis, 2014). Furthermore, the ongoing development of pharmaceutical options are transforming once fatal pathologies into treatable and controllable conditions over a longer period of time, thus, they need to be managed longer by healthcare organizations (e.g., think about the recent advancement in the treatment of some very common solid or haematological cancers, such as breast and prostate cancer, or chronic leukaemia).

The increased epidemiology of chronic conditions constitutes a major burden for Western healthcare systems, which, because of the Global Economic Crisis, are facing reductions in available economic and human resources. While the management of acute conditions is primarily circumscribed within the traditional hospital or clinic setting for short periods of time, chronic conditions require a long-term approach to care, which implies a better synergy ‘outside of the institutional boundaries of hospitals; namely, different healthcare services spread throughout a territory (Bosio et al., 2013). Furthermore, the management of chronic conditions also implies an enhanced dialogue with the “lay community” in which chronic patients are inserted, which represents their primary source of support (pragmatic and psychological). Thus healthcare organizations, in the era of “chronicity”, are not only concerned with the long-term management of the patient (i.e., challenging and burdening at the level of economic resources and workload), but are also faced with rethinking and restructuring their “boundaries” to find a better integration and dialogue with these resources (formal and informal; expert and lay) that are present in the territories to which patients and their families belong.

– *The demand of healthcare is evolving: Not only “resolution of disease” but also “improved wellness.” The continuous development of technological and
bio-medical solutions are not only increasing life expectancy, but are also alimenting the expectation for a good quality of this increased life (Diener et al., 1999). People expect to be active for a longer period of their lives; they expect to be in good health; and they assess their quality of life, not only in terms of the absence of disease and symptoms, but also in terms of good performance and ability to maintain longer work activities, private satisfactory life trajectories, and active roles in their communities. In other words, “health” is linked to a complex and articulated representation that goes beyond the mere request of “absence of pathological condition.” Thus, health is being representationally reconfigured by citizens as wellness, namely the positive balance of physical and mental well-being (Edelman et al, 2013). This radical shift in the conceptualization of health is strongly influencing the expectations that clients (the “demand”) are posing on the healthcare system. The expectation is to receive services that not only treat the disease in its acute manifestation, but also offer an improvement in quality of life and the possibility of keeping some satisfactory private or community activities, even in the presence of a chronic condition (Haber, 2013). In this way, a new set of values is framing healthcare services and their demand: new values are changing the criteria of assessment of services received and affecting clients’ decision making and satisfaction. This leads to a much more challenging and complex scenario in which healthcare organizations have to perform.

- **The increased demand for participation: Health consumerisms, improved health literacy, and consumers’ rights.** Today’s clients/patients are more aware of their rights as consumers and more literate about their health conditions and available treatment options. Furthermore, clients seek a more democratic approach in the relation to their healthcare professionals. They require being more involved in the decision making about their care and are willing to deeply discuss all the possible treatment options, namely their advantages and risks. In other words, healthcare organizations have to face a more “critical demand”. This demand does not overlap with the patient, but implies a larger network of peers, directly or indirectly involved in the care process. Patients are involved in their communities of reference, and their goal is to remain active members. From this perspective, the development of new technologies and new forms of communication foster peer exchanges about health and care (Graffigna et al., 2014) by diffusing health information and offering new exchange spaces where it is possible to share empathy, knowledge, and practices about self-management (e.g., the great diffusion of online communities, blogs, and social networks, devoted to health matters) (Graffigna & Libreri, 2012). Peers influence patients’ knowledge about health and illness, contribute to shaping shared practices of health management, and influence good or bad health conduct. Peers are linked to patients by face-to-face or online communications, and these social exchanges contribute to the construction of patients’ representations of health that are drivers of healthcare decision making and criteria to assess the quality of services received. Thus,
patients, caregivers, and peers, advocate for their right to judge the adequacy of care received. Further, patients rate hospitals and healthcare organizations based on the professionalism of their providers. Patients also organize themselves in social networks to dispense suggestions and advice on health management or to share empathy for illness conditions.

4 Patient Engagement: Improving the Exchange Between Demand and Supply of Healthcare

For several decades, healthcare practices have had a shared and recurring idea that, in order to be effective, they must acknowledge the role of their clients. Particularly, Patient Centered Medicine (PCM). Challenged the previously dominant bio-medical paradigm, and refocused healthcare organizations and procedures from the sole protagonisms of these professionals, to a better consideration of “patients’ voices” in the process. The shift is in favour of PCM sensibility in healthcare, re-oriented care criteria, and objectives toward a better consideration of the entire burden of illness, and not only of the patient’s disease. In other words, PCM advocated for a more holistic understanding of care recipients, not only as carriers of organic dis-functionalities, but as persons deeply involved in a sociocultural context with complex backgrounds of life histories, experiences, and expectations of health and care.

This epochal turning point laid the groundwork for the renovation of healthcare systems by casting light on the complex system of subjectivities that are involved in each process of care planning and delivering. This new representation of healthcare organizations has indubitably contributed to an improvement in the clinical effectiveness and psychological sustainability of care practices. In line with this, healthcare organizations and systems claim to have revised the implicit relational geometries that traditionally have ruled the delivery of services in favour of increased centrality to patients.

The tradition of PCM has helped the healthcare world by better focusing the exchange—not only at the level of actions and performances, but also at the representational and emotional levels—between the “expert” interlocutor (i.e., the healthcare professional/people in charge of planning, managing, and delivering the healthcare service) and the (apparently) “lay” person (i.e., the patient-client of the healthcare service, his/her caregiver, his/her community of reference, etc.). From this perspective, healthcare organizations are being conceived as the arena in which different, but complementary, sets of competences and expertise should dialoguate: those referable to a technical expertise of the disease and of its biological manifestations and those referable to the lived experiences of the illness and its management. The recent technological revolution in healthcare has furthered the importance of “democratizing” the healthcare relationship to better empower the patient at the
level of health literacy and participation in care decision making (Bosio, Graffigna, Scaratti, 2013).

However, changes and evolutions in healthcare sensibility and management, preached by the PCM, have not always been translated into real practice. Although more and more modern Western healthcare organizations have, in theory, adopted the principles of PCM, this has often failed to be acted. Thus, PCM is still far more a fashionable claim or “wishful thinking”, rather than real guidance for practice. As a matter of fact, the idea of achieving a better exchange between experts and lay actors in the healthcare process is often not possible because of hindrances at the pragmatic and subjective levels. Resistance to organizational change is still quite common in the healthcare world, and is even more challenged today by the continuous evolution of the “demand” for healthcare (see par. 2). Even new technological applications to innovate health and care often face important organizational and psychological hindrances in actual healthcare systems; usually, this is related to organization members sharing initial negative expectations about how the technology to be implemented will modify their behaviours and habits (Lapointe & Rivard, 2005).

In a context where the involvement and participation of consumers/clients of healthcare services is a priority, the concept of “patient engagement” may be particularly useful. We propose considering the concept of “patient engagement”, as a qualifier in the exchange between the “demand” and “supply” of healthcare (Graffigna et al., 2014).

The verb “to engage” is evidently polysemic and refers to several meanings, such as the formal agreement between two persons to get married, but also the arrangement to do something or to go somewhere in a certain period of time, and finally to be taken on board, or to be involved as a primary actor in a course of activities (Oxford English Dictionary 2010). However, in all its different meanings, the verb “to engage” implies a dynamic and relational context, in which two parties agree on the goals of an action and on the phase of its process.

Recently, the term engagement has been adopted by the marketing and consumer behaviour literature to describe the (potentially positive) attitude of a consumer toward a brand, product, service, or even media event (Gambetti & Graffigna, 2010). The adoption of the term engagement in the healthcare field is more recent and indicates a renewed partnership between the different actors and institutions (more often a patient and his/her healthcare provider) involved in health and care management (Hibbard et al., 2004).

Overall, the concept of engagement attempts to offer understanding in the complex and mutable context of healthcare delivery and organization that we described in the previous paragraphs. Its final aim is that of giving (back) a leading role to patients and taking them on board for a more efficient and effective process of care delivery. Furthermore, patient engagement can be—from our perspective—the key to systematically reading and making sense of the different organizational, relational, and psychological components in play in the dynamic exchange between the “demand” and “supply” of health and care (Graffigna et al., 2014).
In our vision, the concept of patient engagement qualifies the relation that the patient (“the demand”) established—or may establish—with his/her reference healthcare system (“the supply of healthcare”) in the different phases of the care process. The objective is favouring the autonomy of the patient toward the conscious management of his/her health and illness, following the idea that a good partnership between patients and healthcare providers may lead to several positive outcomes. As we shall discuss in the next chapters, new technologies, if developed according to a true patient engagement perspective, may be an important set of tools and strategies to accomplishing this ambitious revolution in healthcare.

5 The Advantages of Engaging Patients in Their Care

The international literature has outlined several advantages in the improved engagement of the patient in the care process. Here we will examine some of this evidence:

- **Patient engagement allows the improvement of clinical outcomes and of patients’ satisfaction towards the care process.** Patient engagement is related to a better quality of care and patient/health provider relationship, thus improving a patient’s clinical indicators and compliance to recommended therapeutic regimens (Green & Hibbard, 2012). Making people aware of their health service options by supporting them in the decision-making process and engaging them in preventive health behaviours is vital to achieving successful health outcomes (Bellardita et al., 2012). Favouring a good psychological and emotional tenure will foster a self-image as active and engaged and may improve an internal locus of control over disease. These components appear crucial to guaranteeing a better quality of life and more positive health experience. Patients engagement is essential to obtaining quality goals and improved outcomes in terms of disease prevention (e.g., cancer screenings) and healthy behaviours (e.g., weight control, not smoking) (Hibbard, 2008). Patient engagement in the therapeutic process is a crucial element to making the patient feel a part of the treatment plan itself and, thus, to adhere better to the prescribed therapy with a decrease in relapse. Finally, engaging people in health is vital to social inclusion and the maintenance of an active role in society. More engaged and motivated people are active and protagonistic in their communities. Thus, they will be better able to maintain social linkage and strengthen their roles and contributions within society in general.

- **Patient engagement allows cuts in healthcare delivery costs.** From this perspective, patient engagement seems a possible answer as it increases individual responsibility and awareness about one’s health and the risk of unhealthy behaviours. Patient engagement also seems to contribute to fostering sustainable lifestyles and avoiding unsafe conduct (Jordan et al., 2008; Reid et al., 2010; Cosgrove et al., 2013). Furthermore, patient engagement in the therapeutic process
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is a crucial element to make him/her feel like a partner in the intervention itself, which will lead to better adherence to the prescribed therapy and a decrease in relapses. An improved efficacy of therapeutic intervention, thus, would increase organizational and managerial sustainability of healthcare by diminishing the “doctor/service shopping” phenomenon and inappropriate access to healthcare structures and doctors. Patient engagement, in terms of better patient sensitization, knowledge, and empowerment in his/her process of care and cure, thus, seems to be crucial to gaining an efficient balance between the increase of health demand and the reduction in economic resources for the healthcare system in all mature societies today. Furthermore, patient engagement may not only contribute to the reduction of direct costs for the healthcare system, but it also can concur with the (re)orientation of economic resources in the management of healthcare systems to reduce wasting finances (Fisher et al., 2011; Hibbard et al., 2013).

6 Engaging Patients “from Theory Into Practice”: Agenda Setting

Based on the considerations previously outlined, the academic and managerial interest in patient engagement is growing daily as an area of focus for researchers, industries, and policymakers in healthcare arenas worldwide. From the 1st of January to the 31st of August 2014, 867,000 new web indices were found on Google.com with the key words “patient engagement.” Among those, 947 indices were news pages, and 8500 indices were dedicated blogs. During this same period, over 1500 new academic papers that focused on patient engagement appeared in Google Scholar, 197 academic papers appeared in Scopus, and 110 academic papers appeared in the ISI Web of Science. At the policy-making level, the U.S. Department of Health and Human Services recognized patient engagement as a priority for 2013 (HHS Strategic Plan FY 2010–2015). Additionally, at the end of February 2013, the Robert Wood Johnson Foundation, in collaboration with Health Affairs, published a brief policy advocating that “patient engagement is one strategy to achieve the ‘triple aim’ of improved health outcomes, better patient care, and lower costs” (p.1, 2013).

As we explained before, patient engagement constitutes a pivotal element for making patients co-producers of their health, enhancing their care experiences, and obtaining improved health outcomes and lower healthcare costs (Hibbard et al., 2013). On the contrary, patient disengagement risks to lead to the waste of healthcare resources and poor clinical outcomes. However, the healthcare system often lacks in delivering effective interventions that are able to sustain patient engagement and bridge the gap between health and healthcare. A shared and evidence-based modeling of patient engagement is still to come and, consequently, concrete guidelines for practice have not yet been determined. We agree with Zuckerman and col-
leagues (2013) on the need to base healthcare innovation on the deep understanding of patients’ “intimate view of problems and needs” (p. 1113). Unfortunately, to date, studies aimed at giving patients a voice concerning their health experiences and the will to engage in healthcare have been fairly neglected. Many times, patient engagement risks being a fashionable claim rather than a real guidance for practice! In other words, although very promising for innovating healthcare organizations and services delivery, the process of engaging patients still appears a theoretical goal, rather than a real commitment for practice.

In the following chapters, we argue the value of assuming a consumer psychology perspective in reading and conceptualizing patient engagement. We offer some concrete guidelines to orient healthcare professionals, policymakers, and marketing and communication specialists, in assessing the level of engagement of their patients and, thus, in planning and delivering interventions aimed to improve such engagement. Particularly, we discuss the fundamental role of new technologies to making a “engagement revolution” in healthcare delivery possible by underlining that not only patients, but also their caregivers and their networks, such as critical stakeholders and precious resources, need to be considered in this ambitious process.

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