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THE 21st CENTURY HEALTHCARE CHALLENGES

The ageing population, the rise of chronic conditions and the decrease of economic resources, directly or indirectly impact on healthcare systems.

Healthcare organizations, in the era of “chronicity,” are particularly concerned with the long-term management of patients, especially the elderly ones. While the management of acute conditions is primarily restricted within the traditional hospital or clinic setting for short periods of time, chronic conditions need long-term and integrated approach to care, which implies an enhanced dialogue with the territory, both at the level of formal and informal care (Graffigna, Barello & Triberti, 2015).

More and more social relationships and peer exchanges that happen in the lay community, indeed, play a crucial role in the healthcare process and may constitute a potential resource to improve the effectiveness and the efficiency of healthcare systems. Peers influence patients’ knowledge about health and illness, contribute to shape shared practices of health management, and influence good or bad health conduct. Peers are also a source of pragmatic and emotional support for patients.

Furthermore, the last century Technological Revolution deeply impacted on healthcare systems and on the processes of delivering care. The advent of new technologies, in particular, enabled new processes of knowledge construction and exchange in the general democratization of information fluxes (Deluca & Enmark, 1999; Livingstone, 2004, Riva et al., 2012). This continuous development of technological and bio-medical solutions are not only increasing patients networks and improving doctor-patients communication: they are also alimenting the expectation for longer life expectancy and for a good quality of this renewed time of life (Diener et al., 1999).

Due to the evolution of socio-cultural health values and to the promise of new medical and technological discoveries, today people expect to be in good health and active for a longer period of time. Furthermore, people assess their quality of life not only in term of absence of disease and symptoms, but also in terms of good performance and ability to maintain their work activities for a longer period of time, a private satisfactory life, and active roles in their communities (Barello & Graffigna, 2015). In this light, patients expect that healthcare services not only are able to treat their disease in its symptomatic manifestations, but that they also guarantee the maintenance of a satisfactory private life and the possibility of being positively included in their community, despite the occurrence of a chronic condition (Haber, 2013).

Finally, today’s patients are more aware of their rights as consumers and more literate about their health conditions and available treatment options. They require to be higher involved in the decision making about their care and are willing to deeply entangle all the possible treatment options, their advantages, and their risks (Coulter, 2011).
Healthcare systems, thus, today have to face increased healthcare needs and demand but in a scope of limited economic and human resources. In other terms, healthcare systems are today required “to do more with less” to successfully face their clients’ needs and expectations and to be economically sustainable. This implies the urgency for a deep revision of healthcare systems’ practices and organizational models in order to become better responsive to the present challenges highlighted above (Gorli et al, 2015). In the long run, the survival of the national health systems will depend on the extent to which this goal will be achieved (Baran, Kiani & Samuel, 2014).

PARTICIPATIVE MEDICINE AND PATIENT ENGAGEMENT: A POSSIBLE SOLUTION

Patient participation and engagement in healthcare management is today acknowledged by policy makers and healthcare experts as a valuable option to orient changes and actions of the healthcare systems. Several empirical studies have demonstrated the positive outcomes of a participatory care approach at the clinical, psychosocial, and economic levels (Osborn & Squires, 2012). The participatory medicine approach has given prominence to the patient role in the management of his/her health and have connoted this role with many different terminologies such as “patient participation”, “patient activation”, “patient empowerment”, “patient involvement”. It is notable that, in more recent years, both academic and grey literature have increasingly adopted the term “patient engagement” to indicate the active role of individuals in their healthcare (Barello, Graffigna & Vegni, 2012; Menichetti et al., 2015). The adoption of the term engagement in the healthcare field indicates a renewed partnership between the different actors and institutions (more often a patient and his/her healthcare provider) implied in the health and care management. Patient engagement is related to 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 behaviors is vital to achieve successful health outcomes (Bellardita et al., 2012). Favoring a good psychological and emotional tenure will foster a self-image as active and may improve an internal locus of control over disease, by improving disease prevention and healthy behaviors (Cosgrove et al., 2013). Thus, patient engagement may not only contribute to the reduction of direct costs of the healthcare system, but it also can concur with the (re)orientation of economic resources in the management of healthcare systems to reduce waste of money (Hibbard et al., 2013).

PROMOTING PATIENTS PARTICIPATION AND ENGAGEMENT IN HEALTHCARE: RESEARCH AGENDA

However, many gaps still exist for the implementation of a truly participative medicine able to engage patients and their families in the care management, starting from the lack of a shared definition and of shared guidelines for medical practice. First, the meaning of “patient engagement” is not clear and a shared and a univocal and holistic explanations of patient engagement is still missed in the literature. Carman and colleagues (2013) define patient engagement as a set of behaviors by patients, family members, and health professionals and a set of organizational policies and procedures that foster both the inclusion
of patients and family members as active members of the health care team and collaborative partnerships with providers and provider organizations with the desired goals of patient and family engagement include improving the quality and safety of health care. Other scholars define patient engagement in terms of level of “activation”, by describing an engaged patient as an active agent in the management of his/her own health including developmental stages of 1) believing the patient role is important, 2) having the confidence and knowledge necessary to take action, 3) actually taking action to maintain and improve one’s health and 4) staying the course even under stress (Hibbard et al, 2009). Furthermore, Gruman and colleagues’ patient engagement behavioral framework (2010) defines patient engagement as a set of behaviors including two overarching domains: (1) “managing health” behaviors, which is both the self-management of chronic disease and the adoption of healthy behaviors, and (2) “managing healthcare” behaviors, which can be both patient and “consumeristic” behaviors. Finally Graffigna et al. (2014) offers a psycho-social perspective on patient engagement and define it as a process-like and multi-dimensional experience, resulting from the conjoint cognitive (think), emotional (feel) and conative (act) enactment of individuals towards their health management. In this process patients go through four subsequent positions (blackout, arousal, adhesion and eudaimonic project).

However, patients’ and healthcare professionals’ perspectives about the factors that may sustain or hinder patient engagement have not being sufficiently studied yet. Scientific research in this complex area is still at its beginning and the facilitators and barriers for patient engagement need to be further addressed for finding optimal ways of improving these aspects: currently, there are no clear recommendations on the interventions best effective or which may work best with the various patient populations. Future evidences are needed to orient future education and training of healthcare providers in order to make patient engagement not only an “holy grail” but a concrete guidance for practice.

THE AIMS AND THE STRUCTURE OF THIS BOOK

The broadness of the phenomenon of patient participation and engagement in healthcare is such that only a multi-disciplinary approach can investigate its manifold aspects. Furthermore, the high social expectations placed in additional scientific research in this field require that patient engagement scholars become able to establish linkage between the production of scientific knowledge and its application in the real context of healthcare practices. Favoring the encounter between science and its applications is an increasingly crucial task for healthcare academics and practitioners devoted to the establishment of a really participative medicine.

This book aims to be a first contribution in this direction, by offering some insights both towards the theoretical foundation of the patient engagement concept and for the planning of strategies aimed at sustaining it in healthcare settings.

In order to achieve these ambitious goals, the chapters hosted in the book are authored by healthcare scholars and professionals from around the World and belonging to different disciplines. This editorial project, indeed, was conceived as the occasion to promote a participative “bottom up” process in which different experts may contribute to the development of theory and practices of patient engagement from their different stand-points. The inevitable difficulty related to the effort of putting in dialogue so many different cultural instances and disciplinary domains is - in our opinion - “repaid” by the achievement of a multifaceted discussion of the several crucial aspects implied in the promotion of patient participation and engagement and of their implications for effective healthcare reform.
In order to facilitate the Reader, the book is structured in 3 thematic sections which organize the chapters on the basis of their main thematic focus.

The first section (“Theoretical perspectives”) is devoted to epistemologically set the ground to the following discussions about patients participation and engagement and it proposes some paradigmatic, theoretical and ethical insights for modern healthcare reform.

In particular, Chapter 1, “Habilitation, Healthy Agency, and Patient-Participation” by Lawrence C. Becker offers a philosophical discussion of the ethical principles behind health, healing, agency and participation in healthcare. This chapter critically point at some “given for granted” assumptions of modern medicine and discusses the “light” and the “dark side” of current claims for patients’ engagement and participation. This depth elucidation offers important theoretical and philosophical insights to open the discussion about patients participation and engagement.

Follows in this section Chapter 2, “The patient-centered medicine as the theoretical framework for patient engagement” by Lidia Borghi, Federica Galli, Elena Anna Maria Vegni, which offers an historical excursus about the main paradigmatic shifts that occurred in medical models in order to describe the theoretical roots of the current participative medicine and patient engagement movement. Moreover, the authors discuss theoretical and empirical implications of patient engagement for a patient centered medicine.

The second section of the book (“Individual, relational and social barriers and facilitators of patients participation and engagement”) hosts some theoretical and empirical contributions about the factors that may sustain of hinder patients engagement and participation.

Chapter 3, “Individual, Institutional and Environmental Factors Promoting Patient Retention and Dropout” by Precious Arnan and Emmanuel Adugu, reports evidences from an empirical study devoted to determine factors that shape client dropout and adherence to prevention and rehabilitation in the area of cardiovascular diseases. On the basis of their research work, these authors suggest important implications for practice.

Chapter 4, “Barriers to and Facilitators of Older Adult’s Adherence to Health Recommendations Towards an EngAging Two-way Health Communication” by Rui Gaspar, Samuel Domingos, António Diniz and Roberto Falanga, addresses the factors that may hinder or facilitate the adherence to health and care management of a particularly challenging patients population: older adults. The increasing of ageing and the high recurrence of chronic conditions in this target of the population is making particularly urgent the analysis of specific requirements and needs of engagement of these patients. The chapter, moving from a broad analysis of current literature in this field, offers an interesting systematization of barriers and facilitators related to older patients’ adherence to health recommendations and set some concrete implications for practice.

Chapter 5, “A Relational Perspective on Patient Engagement: Suggestions from Couple-Based Research and Intervention” by Silvia Donato and Anna Bertoni, highlights the importance of taking care of the informal caregivers of patients - and in particular of partners - along the participation and engagement process in healthcare. Chronic patients are often not alone during their care pathway. The role of patients’ partners in the daily management of care or during encounters with the healthcare providers is extremely crucial: patients often relay on their partners to better adhere to health prescriptions, to decode medical communication, to successfully cope with the daily requirement of their healthcare. However often the debate about patient engagement has neglected the study of caregivers’ needs and expectations of engagement. This chapter summarizes the main evidences of the literature on couple relationship
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and bridges them with the debate about patients engagement and participation in order to cast light on promising new lines of research and interventions.

Chapter 6, “The Light Side of Preterm Behavioral Epigenetics: An Epigenetic Perspective on Caregiver Engagement” by Livio Provenzi, Renato Borgatti and Rosario Montirosso, suggests the application of behavioral epigenetics to the study of the biochemical underpinnings of Neonatal Intensive Care Unit (NICU) related stress and care, with a specific focus on caregiver engagement. The authors suggest how interventions aimed to foster the engagement in healthcare of caregivers of preterm infants may have a beneficial clinical impact, also at the biochemical level. This contribute, by critically discussing recent literature in the field, offers a preliminary roadmap to guide future behavioral epigenetic research on the adverse and protective effects of early NICU care of preterm infants based on caregiver engagement.

Chapter 7, “Why do Patients Protest? Collective Action Processes in People with Chronic Illnesses: a Psychosocial Perspective” by Davide Mazzoni and Augusta Isabella Alberici, adopts a social psychology perspective to analyze the individual and interpersonal roots of patients’ collective action and its relationship with patient engagement. The authors argue how patients’ protests and critical actions may be considered as the other side of their active participation in healthcare. Practical and theoretical implications of patients’ collective action are discussed to identify new directions for future research and interventions.

The last section of the book (“Reforming healthcare organizations and practices in the light of patients participation and engagement”) adopts an organizational perspective in analyzing the implications or the potential levers for promoting patients participation and engagement in care management.

Chapter 8, “The patient centered organizational model in Italian hospitals: practical challenges for patient engagement” by Mara Gorli, Elisa G. Liberati, Laura Galuppo and Giuseppe Scaratti, questions the assumption that adopting a patient centered model of care in managing an hospital may directly lead to an improvement of patient engagement. By constructing on the analysis of real cases, the authors point at the contradictions, gaps, hindrances and resistances that may result in an healthcare organization when trying to reform their practices in the light of patient centered medicine and patient engagement.

Chapter 9, “No Entry. Prohibitions and violations in organizational spaces across the patient-staff interface in hospital” by Livia Bruscaglioni, points at the problematic negotiation of spaces in healthcare organizations and discusses how this aspect may be the scenario of interesting (but often counterproductive) power dynamics among different healthcare professions and between experts and patients in the daily management of healthcare. The author, based on real cases of research, discusses how these processes may hinder patients participation and engagement in healthcare.

Chapter 10, “The value of measuring patient engagement in healthcare: new frontiers for healthcare quality” by Guendalina Graffigna and Serena Barello, points at the importance of adopting performance indicators to assess the level of engagement of patients in their healthcare. The adoption of validated scale to measure patient engagement is argued by the authors as the first crucial step to transform patient engagement from a mere claim to a real guidance for practice. The chapter reviews the characteristics and psychometrics properties of the main validated tools existing in scientific literature to measure the levels of engagement of patients and their needs and expectations in order to better manage their care.

Chapter 11, “Accountability and public reporting. Publication of performance to improve quality” by Maria Tanzariello, Sabina Bucci, Walter Ricciardi and Antonio Giulio de Belvis, discusses how accountability, transparency, and public reporting are some key factors in promoting patients participation and engagement in healthcare. In particular, public reporting is one of the major tools in supporting patients’ decisions making process, by providing structure, process and outcome measures. The authors
performed a web-based analysis of the major initiatives of public reporting in order to highlight their main characteristics and properties and to detect actual gaps and directions for improvement in the aim of enhancing patients participation and engagement in healthcare.

Chapter 12, “Could patient engagement promote a health system free from malpractice litigation risk?” by Massimo Miglioretti, Francesca Mariani, Luca Vecchio, suggests how patient engagement in healthcare may be addressed as a possible method for reducing the risks of doctors being sued for medical malpractice. The authors test their hypothesis in two recent studies, and, on the bases of their results, they argument that future initiatives to promote patient engagement may offer a support in this direction.

Chapter 13, “Engagement in Health and Safety at the Workplace: a new Role for the Occupational Health Physician” by Nicola Magnavita, elucidates how ageing working population may be a problem for companies and for their health and safety services that must face the long-term management of active, chronically ill workers. On the basis of these premises, the author discusses how the discipline of occupational medicine must be replaced by occupational health, which not only combats occupational diseases, but actively works to promote the engagement of older workers in health prevention and care management. New directions for research and practices in this field are highlighted in the chapter.

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