Afterword

This edited book hosts contributions by scholars belonging to many different disciplinary domains and Athenaeums from across the world, all attempting a conceptual foundation of what the promotion of patients’ participation and engagement is and how this may be achieved.

On the one hand, the variety of theoretical and research glances assumed by authors in the different chapters testifies to the richness (and the ferment) of this ongoing literature debate. Furthermore, these research efforts testify the multifaceted nature and the novelty of the patient engagement phenomenon, which is not reducible to only some of its phenomenological manifestations, neither assumable for granted or on the basis of traditional (and developed “there and then”) perspectives and paradigms.

On the other hand, the contributions to this book also cast light on the still fragmented approach of academic research in this area: while important insights already exist, often they are circumscribed to only some aspects of the phenomenon. Wider approaches and theorizations able to cast light on the whole complexity of the phenomenon are missed.

These premises confirm the importance of promoting occasions of dialogue and sharing among scholars in order to better joint research efforts towards the common goal of a theoretical foundation of the patient engagement phenomenon. From our perspective, this edited book can be rightly considered as a first concrete step in this direction: In these last pages we shall summarize the main insights which have emerged from this joint endeavor and offer some “food for future thoughts” in this field.

PROMOTING PATIENTS ENGAGEMENT AND PARTICIPATION: STATE OF THE ART

The chapters of this book discuss what patient engagement and participation are and what may promote it from the micro analysis of the individual characteristics of the patients (at the psychological, medical, sociological and cultural level) that play a role in determining their attitude to being engaged in health management; to the analysis of dyadic relational dynamics (occurring mainly between a patient and his/her formal or informal caregivers) which may sustain or not sustain patient engagement; to the analysis of networks and peer group exchanges of their roles in this process; finally to the analysis of the organizational, structural and systemic elements that may influence patients’ engagement and participation. This book well explained how many elements are play when patient engagement concerned (see Figure 1 for a conceptual summary). This should sensitize the readers against an i-per-simplified approach to the analysis of patient engagement and make them aware of the multiple elements that should be taken into consideration when approaching the problem.
PATIENT ENGAGEMENT: TOWARDS A SHARED DEFINITION

Definitions of patients’ engagement and participation vary in the literature. Although not always moving forward from the same definition of patient engagement, the chapters of this book all share the same logic when considering this phenomenon: patient engagement and participation are conceived an umbrella concept which overcomes and structures other similar ones such as “adherence,” “compliance,” “self-management” or “shared decision making.” According to evidence which has emerged from these book chapters, patient engagement is not solely referable to the dyadic interaction between patients and healthcare professionals; neither it is describable as simply a psychological state or attitude that the patients may or may not assume during their care management. Patient engagement should rather be conceived as the kind of healthcare fruition that the patient may experience along his/her care journey. A fruition experience which characterized by the deliberate decision of playing an active and negotiating role: opting for an engaged approach to healthcare management, from the perspective of a patient, thus, means to take the decision of being an actor (and of being perceived and treated as such by the others actors on the scene) able to co-authoring the plot of his/her care journey. However, becoming an actor of one owns healthcare doesn’t mean to opt for an “anarchic” or uncontrolled position towards care, rather to become aware of the potentiality of one-own role and deliberately choosing when being active, when passive, when partners, when not…of the healthcare systems. Finally, being able to became engaged patients means to better understand one owns healthcare rights, duties, needs and expectations.
PATIENT ENGAGEMENT: PERSPECTIVES FOR THE FUTURE

A lot has been done, but still much needs to be done in order to finally locate the concepts of patients’ engagement and participation and to effectively orient practices. The main consideration is that this book has offered some encouraging first contributions in this direction. The auspice is to move steps forward in a better joint and orchestrated way, and by promoting the dialogue among the different research groups involved in this field.

Foremost one shared consideration which appears key to us to the continuation in this shared endeavor: the importance of opting for a process-like approach to patient engagement and, thus, to its implications for the practice. Patient engagement should not simplistically conceived such as an “on-off” of patients’ status, but it should be recognized as a dynamic trajectory which is mutable, framed and influenced by several psychological, relational, contextual and organizational factors. Patient engagement is a dynamic, volatile, mutable, complex and implies different levels of manifestation and analysis. Furthermore, patient engagement is not “one” and defined “once and for all,” but may change according to the different trajectories of disease and of life; depending on the different socio-demographic characteristics of actors involved and on their possible encounters and exchanges, since patient engagement concerns persons and their human subjectivities. Patient engagement thus must advocate for a humanistic and multidisciplinary approach in order to be further studied and promoted. A long path-way is still ahead: this book intends to be coinceived as a first (important) step in this direction.

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