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PATIENT ENGAGEMENT IN HEALTHCARE: REDEFINING ETHICAL AND MEDICAL PROFESSIONALISM IN THE ERA OF PARTICIPATORY MEDICINE

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The greatest mistake in the treatment of diseases is that there are physicians for the body and physicians for the soul, although the two cannot be separated. ~ Plato

The doctor may also learn more about the illness from the way the patient tells the story than from the story itself. ~ James B. Herrick

Could you keep your heart in wonder at the daily miracles of your life, your pain would not seem less wondrous than your joy; and you would accept the seasons of your heart, even as you have always accepted the seasons that pass over your fields. ~ Khalil Gibran

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ACKNOWLEDGEMENT

This PhD thesis focuses on patient engagement processes and its implications for care practices seen from a patient perspective. Data for the study were collected during the period January 2012 to October 2014. As a PhD student I was employed at the *Department of Applied Psychology* and here I had my daily routine. For data collection I attended the *Department of Cardiology of the San Paolo University Hospital* in Milan. Finally, further precious insights that have illuminated my data come from fruitful discussion and supervision by the *Institute for Professionalism and Ethical Practice* in Boston. I wish to thank these Institutions for hosting me during these years.

The idea for the study and the outline of methods came from a fruitful encounter with *Guendalina Graffigna* with whom I wrote the initial study proposal. I am forever grateful to her for appointing me to do the study and offering me the opportunity to become a PhD student with her as my project supervisor. She has taught me so much through discussion and supervision and throughout my time as a PhD student she has been deeply devoted to the project. I further wish to thank *Elena Vegni, Elaine Meyer* and *Claudio Bosio*, who became fundamental to discuss and interpret my data from different disciplinary perspectives. Their unfailing belief in my abilities has been crucial in my endeavors and I deeply appreciate the trust they have shown me.

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Serena Barello
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FOREWORD

My pathway to writing this thesis started already during my first job as a clinical psychologist at the *San Paolo Teaching Hospital* in Milan just after graduation in Clinical and Health Psychology, at the University Cattolica del Sacro Cuore, Milano. Even though I enjoyed the clinical work, I pretty soon found myself longing for deepening my knowledge about healthcare research and methodology. This led me into further studies to an executive Master's degree in Qualitative Methods Applied to Social and Marketing Research and a chance to become a PhD student at the Faculty of Psychology of the Università Cattolica under the supervision of a research group experienced in healthcare marketing psychology and research methods.

I started to work at Università Cattolica del Sacro Cuore with Guendalina Graffigna. She introduced me to the patient engagement project: an extensive study on the patient engagement process, levers and barriers. The project focused on barriers and facilitators for effective patient engagement strategies with the overall aim of finding strategies for improving patient health outcomes and reducing healthcare cost . Particularly, I have always been interested in the study of effective patient-doctors relationship which is the unavoidable - but too much often denied - condition for guaranteeing care quality and the patient wellbeing.

Immersing me into a new area of research with brilliant colleagues from so many backgrounds and professions was really stimulating and fruitful. Finding my own focus in this rich research environment was not a challenge. Based on my work as health psychologist the patients and their health providers – their perspectives, participation and opportunities – were an obvious focus to me.

ORIGINAL PAPERS

This dissertation is based on the following original manuscripts:

1. Barello, S., Graffigna, G., & Vegni, E. (2012). Patient engagement as an emerging challenge for healthcare services: mapping the literature. *Nursing research and practice*, *2012*.

2. Graffigna, G., Barello, S., Triberti, S., Wiederhold, B. K., Bosio, A. C., & Riva, G. (2013). Enabling eHealth as a Pathway for Patient Engagement: a Toolkit for Medical Practice. *Studies in health technology and informatics*, *199*, 13-21.

3. Graffigna, G., Barello, S., Libreri, C., & Bosio, C. A. (2014). How to engage type-2 diabetic patients in their own health management: implications for clinical practice. *BMC Public Health*, 14(1), 648.

4. Barello, S., Graffigna, G., Vegni, E., & Bosio, A. C. (2014). The challenges of conceptualizing patient engagement in healthcare: a lexicographic literature review. *Journal of Participatory Medicine*, *6*, e9.

5. Barello, S., & Graffigna, G. (2014). Engaging patients to recover life projectuality: an Italian cross-disease framework. *Quality of Life Research*, 1-10.

6. Graffigna, G., Barello, S., Triberti, S. (2014). Patient Engagement: A consumer-centered model to innovate healthcare. DeGruyter Open

7 Barello S., Graffigna G., Savarese M. , Bosio A.C. (2014) Engaging patients in health management: towards a preliminary theoretical conceptualization. *Psicologia della Salute, 3, 11-33.*

8. Barello, S., Graffigna, G., Meyer, C. E. (2015). Ethics and Etiquette in Neonatal Intensive Care. A Comment on the value of parents' engagement in care, and recommendations for further advancing the field. *JAMA Pedi*atrics Doi: 10.1007/s11136-014-0846-x (*in press*).

9. Barello, S., Graffigna, G., Vegni, E., Savarese, M., Lombardi, F., & Bosio, A. C. (2015). Engage me in taking care of my heart": A grounded theory study on patient–cardiologist relationship in the hospital management of heart failure. *BMJ Open. (in press)*

10. Barello S., Graffigna G. (2015) Patient engagement in healthcare: pathways for shared decision-making. *Neuropsychological Trends*. (*in press*)

STUDY RATIONALE

The life expectancy of patient living with chronic disease has improved significantly in the recent years due to advances in medical sciences and technologies. To address the burden of this growing demand of care, patient engagement is considered crucial as it contributes to improve health outcomes and control healthcare costs. Unfortunately, patient disengagement is associated with several quality deficits that may result in patients experiencing re-hospitalization, adverse events and avoidable suffering. However, many gaps still exist for its implementation starting from the lack of a shared definition and shared guidelines for medical practice based on the direct patients' care experience.

As well as gaps in medical interventions devoted to effectively translate patient engagement principles into clinical practice, there are also gaps in the knowledge about several patient engagement aspects. First, the meaning of patient engagement is not clear and a shared and evidence-based definition of this concept is currently not available in the scientific literature. Second, patients' and healthcare professionals' perspectives of patient engagement are not sufficiently studied. Third, the facilitators and barriers for patient engagement need to be further addressed for finding optimal ways of improving these aspects. Moreover, it is not clear what patients' engagement consist of in the day-by-day medical practice and clinical consultation, and, for this reason, no medical training devoted to foster the patient active role in healthcare is today available.

In order to lay the ground to fruitfully discuss about patient engagement, the author will start by providing a historical overview about the deep cultural changes in the medical values and care conceptions which contributed to a rapid revolution in the history of medicine and care tradition. These changes are also at the base of a cultural shift that led to increasingly value a participatory care environment and the concept of patient engagement which is the main issue debated in this dissertation. Then, we will briefly describe the ongoing societal and global tendencies that are now challenging and deeply reframing healthcare systems all over the world and particularly the role of health professionals in the care process. These challenges constitute the main reasons why - in recent

years - participatory medicine - and the concept of patient engagement - has gained increasing prominence both in government policies, healthcare planning and delivery and in re-projecting the contents of medical education curricula responding to the society's evolving health demand. This thesis argues that in order to assess patient engagement and to recommend trainings for health professionals, the very first step consists in being clear about the particular ways and forms of engagement we are talking about.

GENERAL AIM

In the light of these premises, within the context of participatory medicine, this dissertation will propose a sequential and mixed-method research design generally aimed at improving the knowledge and understanding of patient engagement and its implications for the medical practice and professionalism.

SPECIFIC AIMS

The specific aims of this dissertation are to:

1. improve the knowledge and understanding of patient engagement and patient engagement-related concepts in the context of participatory medicine;

2. explore the experiences and perspectives of patients with chronic diseases in regards to their engagement in the healthcare process;

3. explore the barriers and facilitators to patient engagement realization into clinical practice;

4. discuss the patient engagement implications for the clinical decision making pathways and medical education trainings.

METHODS

To answer the overall aim of this thesis – improved knowledge and understanding – both literature reviews (chapter 2 and 3) and qualitative methodology (chapter 4) were used.

Chapter 1 was aimed to set scene and give the readers an overview of the global cultural and societal scenario that justifies the need to deal with the topic of patient engagement. Chapter 2 and chapter 3 consist in in-depth literature reviews aimed at shading light on the concepts featuring the participatory medicine movement (chapter 2) and, more specifically, the one of patient engagement (chapter 3).

An in-depth qualitative study according to the grounded theory principles was conducted and reported in chapter 4 and was aimed at deepening the heart failure patient's perspective towards engagement in their care in order to build and experience-based model of this phenomenon. The cardiological field was chosen as it offers a privileged observation point for the study of patient engagement in chronic care.

The last two chapters, based on the insights emerged from both the literature analysis and the grounded theory study, were aimed at discussing the implications of patient engagement for the clinical decision making process (chapter 5), and for training health professionals in patient engagement strategies and improving the effectiveness of their communication and relational habits with this aim (chapter 6) (See Figure I).

FIGURE I. STUDY RATIONALE

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pathways towards
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PART I

SETTING THE SCENE: DEBATES ON THE VALUE OF PARTICIPATORY MEDICINE IN CONTEMPORARY HEALTHCARE SYSTEMS

This introductory section will be devoted to set the scene for this dissertation by delineating the main roots of the participatory medicine movement and the increasing attention devoted to the central role of patient within the contemporary healthcare systems and health policies.

Particularly, chapter 1 shall describe the cultural and sociological reasons that led Western governments to prioritize - in the recent years - participatory medicine as the elective approach to care. It virtually goes through the main paradigmatic revolutions that affected the image and values of medicine in the society and the roles that patients and health professionals have respectively played within this history. Finally, it introduces the topics covered in more details in the following chapters.

The author of this dissertation maintains that it is unavoidable to consider the global – both social and cultural - scenario within which the concept of patient engagement has its roots to really understand its meaning and value for healthcare innovation.

- CHAPTER 1 -

SETTING THE SCENE:
PATHWAYS TOWARDS PARTICIPATORY MEDICINE

1. FROM PATERNALISM TO PARTNERSHIP: THE EVOLUTION OF CARE APPROACHES IN THE CLINICAL CARE RELATIONSHIP

> *"To attend those who suffer, a physician must possess not only the scientific knowledge and technical abilities, but also an understanding of human nature. The patient is not just a group of symptoms, damaged organs and altered emotions. The patient is a human being, at the same time worried and hopeful, who is searching for relief, help and trust. The importance of an intimate relationship between patient and physician can never be overstated because in most cases an accurate diagnosis, as well as an effective treatment, relies directly on the quality of this relationship". (Hellin, 2002)*

The last few decades have seen great changes in the relationship between healthcare professionals and their patients (Mead & Bower, 2000; Kaba & Sooriakumaran, 2007). These changes can be mainly attributed to sociological and ethical reframings that deeply affected the meaning and the aims of the clinical encounter (see Figure 1.1). Taking into account these changes across the centuries, the attempt to maintain the human aspects of healthcare might constitute a particular challenge to the healthcare professionals (Aulisio et al., 2000). To attend who suffer, a clinician must have not only scientific knowledge and technical skills, but also an understanding of the whole human nature (Michie et al., 2003) and relational skills specifically acquired to include as focus of the medical practice not only the disease treatment but also the person's care.

It would not be an exaggeration to say that the evolution of medicine in the past few decades has been greater in its scope than in any period of history. This evolution has brought a parallel transformation in the relationship between health professionals and their patients. In the following paragraphs we will describe the main changes the patient-health professional relationship models have gone through, taking into account the ethical and sociological factors that have most influenced the medical paradigms across history.

1.1 A DOCTOR-CENTERED MEDICINE: THE PATERNALISTIC ERA

The patient-doctor relationship is as old as medicine itself. The Hippocratic clinician of ancient times considered it a moral obligation to follow the criterion of beneficence for patients. Even today, we still use a Hippocratic formula to define the principle: *"to aid or, at least, not to harm"*. The Romans reduced this principle to an even more concise formula: "*primun non nocere*", as a principle, not to hurt. This has been the main principle of medical ethics throughout the centuries, and this has also been the criterion that has always – till few decades ago - presided over the relationship between health professionals and their patients (Emanuel & Emanuel, 1992). The Hippocratic clinician is featured by a dominant position in the relationship with the patient, a concept known in our days as paternalism (Rees et al., 2007; Taylor, 2009). By paternalism we mean hard-line beneficence: in treating the patient in the same way parents take care of their children, the health professional cures the patient despite his/her own desires and even against his/her own will. The Hippocratic clinician–patient relationship had substantially a vertical, asymmetric connotation. The clinician, as the father, stands above and makes the final treatment decisions, while the patients must place themselves in the position of sons/daughters who are below the father and obey his orders. Let's think what, even in our day, is referred to as a "good patient" and we will see it refers to patients who submissively

accept the passive role of an infant (Goodyear-Smith, & Buetow, 2001). Till this time, a strongly *doctor-centered model* of the clinical encounter focused on the mere disease treatments held sway, in which the epistemological authority of medical knowledge and practice, paternalistically embodied in the clinician, was given as unproblematic, and relationships through which the doctor knew the patient could legitimately be assumed to be longstanding.

1.2 REBALANCING POWER IN CARE RELATIONSHIP: TOWARDS A RENOVATE PARTNERSHIP BETWEEN DOCTORS AND PATIENTS

"...one of the essential qualities of the clinicians is interest in humanity, for the secret of the care of patients is in caring for the patient". (Hellin, 2002)

From the late 1960s, the doctor-centered model of the clinical encounter came under sustained criticism (Morgan, 2003). There were several reasons that have contributed to bring into question this approach to care (Hughes et al., 2008). Wider cultural and political shifts in the 1960s worked to undermine both the paternalism and the biomedical reductionism of clinical practice (Jayadevappa, & Chhatre, 2011). Patients began to push to be seen as more than passive objects and recipient of clinical knowledge, procedure and treatments, and to demand to be understood and treated as 'whole persons' – and not only as "passive individuals"- , as part of a political shift which began with the critique of over-medicalization in the people's life course (Conrad & Schneider, 1980) and extended to include a holistic impulse that connected the disease condition with a wider pattern of social relations and contexts recognized to be crucial factors to consider when treating the disease itself (May, 1992). This movement led clinicians to understand the value of not merely focus on the disease treatment but also to incorporate in the medical practice the wider consideration of the patient's illness experience as a reading key for the disease

pathways and resolution (Stewart, 2003). This new vision about the individual's role in dealing with the ill-health led to define patients as adults who can, and must, make autonomous and aware decisions that concern their own health and healthcare management (Stiggelbout et al., 2012). From that point on, clinicians could no longer establish paternalistic relationships with their patients nor decide for them. Unless it is proved otherwise, the patient is considered a responsible adult who must make the decisions concerning his/her disease management (Wirtz, 2006). In line with this principles, the highest right in the new patient role is the right to "informed consent" (Krumholz, 2000). The clinician has the information, but the patient, acting as a responsible and aware adult, has the role of decision-maker over the treatment course by giving his/her informed consent. The function of the physicians is not to expropriate the patient's illness/disease. On the contrary, their function is to help the patients (re)appropriate and integrate it in their life course.

1.3 PATIENT-CENTERED MEDICINE: NOT ONLY DISEASE BUT ALSO ILLNESS EXPERIENCE

These deep changes in the conception of the patient-clinician relationship let to the progressive affirmation of the concept of *patient-centered medicine* that emerged in the early 70s, and exploded in the health care research policy arena exponentially in the late nineties (Stewart, 2003; Berry et al., 2006; Levinson et al., 2010). Shifts within medicine were also important: from the 1970s onwards, some elements of academic medicine had begun to co-opt both the theoretical positions (and practitioners) of the social sciences (Strong 1979; Stacey 1991), and to attempt to lay claim to the much wider vision of ill-health espoused by proponents of a biopsychosocial model of medicine (Engel, 1977). In the same light, academic general practice had begun to examine the form and content of the consultation much more systematically thus shading light – and giving prominence – to

the specific effects of the patient-doctor relational features on health outcomes (Roter et al., 1997; Mead & Bower, 2002). Particularly, a series of influential empirical studies engaged in microscopic examination of what physicians did in the consultation, and how they did it (Byrne and Long 1976, Tuckett et al. 1985, Neighbour 1987; Little et al., 2001; Finset, 2014). This led in turn to a growing sense that the medical consultation was about the process of negotiation of two kinds of expertise and knowledge: the authoritative general expertise of the health provider (often conceptualized as "*professional knowledge*"), and the specific and unique experience of the patient in relation to his/her own illness condition (often conceptualized as "*lay beliefs*" strictly linked to the patient unique illness experience) (Beach & Inui, 2006).

In 1993, the Picker-Commonwealth program sponsored a book, edited by Edgman-Levitan and colleagues, to conceptualize different dimensions of patient-centered care. This important work in the arena of patient-centered care emphasizes quality of care as perceived through patient's perspective. Important dimensions of patient-centered care that were discussed were –respecting patient's individuality, coordination of care that is unique to the environment of hospitals and health care facilities, communications between patients and providers, intervention strategies for improving quality of patient-centered care within an institution, minimizing physical trauma during acute care, supporting patient's social and emotional needs, role of families, and continuity of care. Particularly, a patient-centered care approach advocates the use of a democratic, equal doctor-patient relationship differing fundamentally from the paternalistic focus envisaged by doctor-centered one. Society advocated a shift in the doctor-patient relationship from the guidance-co-operation model to mutual participation, whereby power and responsibility are shared with the patient (Kaba & Sooriakumaran, 2007). Byrne and Long (1976) suggested that patient-centered consultations reflect the recognition of patients' needs and preferences,

characterized by behaviours such as encouraging the patient to voice aloud ideas, listening, reflecting, and offering availability for collaboration. In this way, patient-centered medicine encourages much greater a patient active role in care than is generally associated with the biomedical and doctor-centered model.

1.4 PATIENT AS CLIENT OF HEALTHCARE SERVICES: THE CONSUMERISTIC SHIFT

The shift away from the doctor/disease-centered consultation to negotiated consultations that accelerated after the mid-1970s was also encouraged by specific government policies intended to increase professional accountability and to promote the vision of ***patients as active consumers of healthcare***, able to adjudicate and evaluate its content, features and quality (Moran 1999; Herrick, 2005; Wilcox, 2015). But more fundamentally, this shift occurred because within medicine itself there was a move towards more and more enrolling the patient into the consultation in ways that reduced the growing strain on the epistemological authority of medical knowledge (Lupton 1994).

In this context, the shift to notions such as "patient trust" and "patient satisfaction" as proxies for quality of care in medicine (and also to different ways of conceptualizing, assessing and quantitatively measuring these), can be seen not simply as technical moves towards improving the quality of care, but also as ideological moves that set out the frame in which negotiation between clinician and patient in the consultation can be understood (May & Mead, 1999). Consumerism also contributed to modification of the patient's role in the treatment process (Robinson et al., 2005). The role of the patient is starting to shift from being a minimally-informed advice recipient to an active participant, instigating collaborator, information sharer, peer leader and self-tracker engaged in participative medicine; a transition that is underway from paternalistic health care to partnership models where patients are considered as consumers of healthcare services (Herrick, 2005).

According to this new role, individuals are becoming more engaged in a variety of self-testing and self-management of conditions, symptoms, genomics and blood biomarkers, behaviors and personal environmental factors. Like any consumer, the patient may demand quality services. By continuously evaluating the service and sometimes lodging complaints toward it, the patient-consumer can improve the health care system.

These changes are at the basis of a further shift in the care framework as well as the patient is now considered as a critical consumer of healthcare services thus supporting the need for a ***client-centered*** or ***consumer-directed model*** of care aimed at catching the complex system of exchanges that occur between the patient ("*the demand*") and the healthcare system ("*the supply*") (Hardyman et al., 2014; Graffigna et al., 2014). Skyrocketing health care costs and quality deficits can only be addressed through a broad approach of quality-based benefit design. Consumer-directed health plans that are built around better consumer information tools and support hold the promise of making consumers really protagonist of their care, and are thus at the centre of this model of care and comparative and interactive consumer information tools, coupled with provider performance transparency and payment reform, are central to advance accountability and support consumers in getting the right care at the right time (Hardyman et al., 2014).

A final remark should be devoted to the implication of these paradigmatic revolutions in the role dynamics occurring between patient and health practitioners as far as it concerns the medical education about the values and the relational attitudes so crucial in the clinical encounters (Rider et al., 2010). The changing role of medicine in society and the more and more active role of patients and their growing expectations towards their doctors strongly suggests that the also content and delivery of medical curricula have to change in order to address the emerging needs of the contemporary society. These changes have also altered

the focus of health care (panel), which has shifted from the individual to the community, from cure of disease to conservation of health, from acute care to continuous and comprehensive chronic care, and from an individual approach, provided by single primary-care physicians, to comprehensive, community-based care, provided by primary-care teams and sustaining an integrated care approach (Bousquet et al., 2011). We are also witnessing a radical shift from paternalism to management negotiated in partnership between patients and physicians, which encourages concordance and patient enablement (Berry et al., 2003). This obviously has an impact on the ways of interaction between patient and healthcare professionals and calls for continuous improvements in the relational and communicational skills of clinicians which would be trained to sustain the active and responsible role of their "client".

There has also been a move from centralized systems to health services, which are primary care led, and from a reliance on inpatient care to the increasing use of home-based care services (Nutting et al., 2009). Anecdotal care is giving way to evidence-based medicine and, as part of the retreat from paternalism, the importance of revalidation, reaccreditation, and continuous professional development of all medical professionals has become a matter of public concern (Sutcliffe, 2004).

FIGURE 1.1 THE HEALTHCARE PARADIGMS' SHIFT
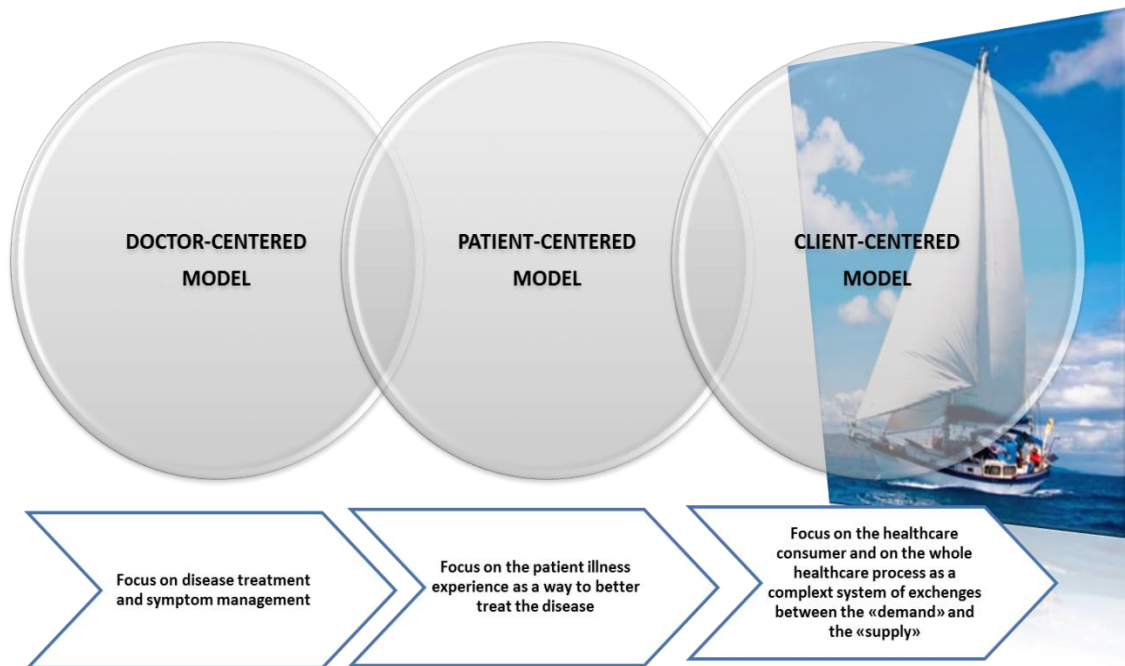
2. WHY DO WE NEED GREATER RESPONSIVENESS TO PATIENTS?

2.1 MEETING INCREASING EXPECTATIONS OF HEALTH AND WELLBEING

The fact that patients' expectations of health and wellbeing are rising faster than the ability of health services to meet them is now a cliché (Koplan & Fleming, 2000). This evidence describes, however, one of the most important ironies of modern health care. Public spending on health care is increasing much faster than inflation in most countries, and effective treatments are available more widely than ever before (Gee & Gutman, 2000). At the same time, public pessimism about the future of health systems is growing. Indeed, the increased aging population is challenging the healthcare system in two ways (Avraam et al., 2014): on the one hand, the general increase of chronic conditions that the healthcare system needs to face (Reinhardt, 2003; Garrett & Martini, 2007); and, on the other hand, the need to manage such conditions for a longer period of time and the guarantee of an

overall better quality of life and address individual's increasing expectation of wellbeing (Bengtson et al., 2012). Politicians recognize this—hence their goal of modernizing the system by encouraging greater responsiveness to patients (Baran et al., 2014). In the long run, the survival of the national health systems depends on the extent to which this goal can be achieved in the next future.

2.2 HEALTHCARE SUSTAINABILITY

The global economic crisis has also recently troubled all Western markets and changed the rules of finance and commerce, even in the healthcare field. 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 (Berwick et al., 2008). 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 and health services practice and delivery to pharma-economic evaluations (Charmel & Frampton, 2008). Healthcare professionals, policymakers, and patients are thus now challenged to frame their healthcare behaviours and attitudes according to the financial and economic evaluations of such conduct, and they are forced to seek a better and more virtuous balance in the framework of "*doing more with less*" (Bertakis & Azari, 2011). Since now increased disability and sickness often accompany the last years of life, the demands for social and health services will increase immensely.

2.3 PUBLIC ACCOUNTABILITY

The high costs of health care and its demands on the public purse have led to calls for healthcare facilities to be more accountable to the public (Fisher et al., 2011). This demand

has resulted in the publication of performance indicators that allow healthcare facilities to be compared (Thomson et al., 2005). These performance indicators are intended to provide information to be used to determine priorities for quality improvements as well as a detailed account of how public funds have been used.

The establishment of new mechanisms to promote choice and accountability - such as the requirement that each hospital and primary care trust publishes a prospectus for patients - will further boost these efforts.

3. PARTICIPATORY MEDICINE: AN IMPERATIVE FOR THE 21ST CENTURY HEALTHCARE SYSTEMS

Basing on the above described care paradigm shifts and societal tendencies that are today shaping the ways of conceptualizing and delivery healthcare services, today's patients are more aware of their rights as consumers and more literate about their health conditions and the available treatment options (Coulter & Ellins, 2007). Furthermore, patients seek a more democratic approach in the relation with their healthcare practitioners. 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 (Davis et al., 2000). Within this scenario, the movement of participatory medicine have grown in importance and today seems to embodied all the value premises that calls for a greater patient active role in healthcare (Coulter, 2011; Barello et al., 2014; Bright et al., 2014; Rider et al., 2014), including policy and practice developments to promote the patients' protagonism in his/her own medical course on the level both of legislation and regulation of health care (Hibbard et al., 2013).

This increasing focus on participatory care approaches is clearly demonstrated by the number of publications per years indexed by the main academic databases that clearly highlights a progressive increase in the yearly number of publication related to this area.

Data showed an overall increasing interest toward this issue ranging from 1 contribution in 1954 to 1904 contributions published in 2014 and indexed with the terms related to participatory care (i.e. patient engagement, patient empowerment, patient involvement, patient participation, patient activation). This is clearly shown by the growing trend of published items over the considered period (Figure 2.1).
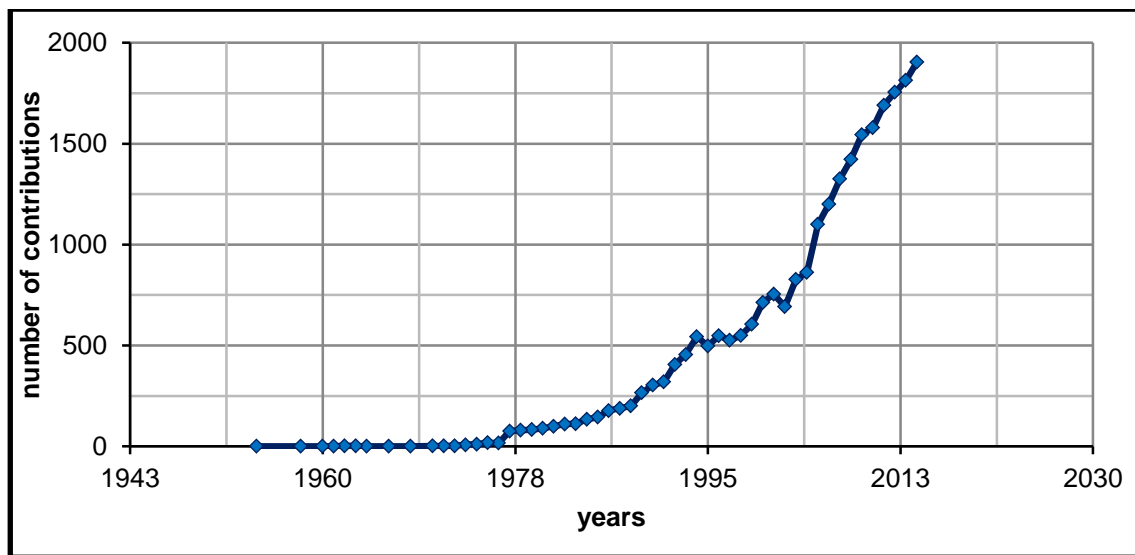
FIGURE 2.1. TREND OF PUBLICATION ON PARTICIPATORY MEDICINE FROM 1954 TO 2014

Participatory medicine has also been prioritized in international policy actions since the World Health Organization declaration of Alma-Alta in 1978 (WHO, 1978), in research programs and also as part of the health professional team (Collins et al., 2007). In the UK, participatory care has been encouraged by several policy papers, e.g., the ''*Public and patient experience and engagement* (PPE)'' (Department of health, 2009), and the ''*Liberating the NHS: No decision about me, without me*'' (Department of Health, 2012) both by the Department of Health. However, a recent editorial published by the British Medical Journal pointed out that part of the political discussions on ''*putting the patients first*'' seem to be ''*rhetorical lip service*'' (Hodkin & Taylor, 2013), thus highlighting the

substantial gap that could be visible between theory and practice of participatory medicine. Furthermore, the topic is on the agenda of influential British think tanks, e.g. the Health Foundation (2014), and the King's Fund (2014). In the US, the Institute of Medicine (IOM) claimed participatory care to be a critical step on the road to achieving better care, improved health, and lower health care costs (Berwick, 2002). The importance of making patient active agents in their healthcare has also been stressed by the 2010 Patient Protection and Affordable Care Act, which led to the formation of the Patient-Centered Outcomes Research Institute (PCORI) (2011). In Australia, putting patients at the center of care is one of the three core principles of the Australian Safety and Quality Framework for Health Care, which was endorsed in 2010. Notable that involving patients in the care process is set as one of the main priority areas for research and policy by the European Commission (Coulter & Magee, 2003; European Commission, 2007; Ahtonen, 2013). Also in Italy, the Ministry of Health has included the promotion of patient and family active role as one of the main action priorities for the NHS (Italian Ministry of Health, 2008) thus revealing in our country a deep increasing interest in this topic. On the international stage, the issue has also been driven forward by various associations and research institutes, e.g. by the International College of Person-centered Medicine (ICPCM), which emerged from the Geneva Conferences on Person-centered Medicine or The Institute for Professionalism and Ethical Practice (IPEP) in Boston, that promote relational learning for health care professionals that integrates patient and family perspectives, professionalism, and the everyday ethics of clinical practice with the aim of including the patient perspective and valuating the patients' active role in the care process (Meyer et al., 2009; Epstein & Street, 2011).

Finally, participatory medicine is today acknowledged by policy makers as a valuable option to make sense of the evolving scenario in which healthcare systems need to act and

to orient changes and actions. Several empirical studies have also demonstrated the positive outcomes of a participatory care approach at the clinical, psychosocial, and economic levels (Osborn & Squires, 2012; Graffigna et al., 2014).

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"* (Gruman et al., 2009; Barello et al., 2012; Menichetti et al., 2015) . 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 et al., 2012; Graffigna et al., 2013; Graffigna et al., 2014; Barello et al., 2014; Menichetti et al., 2015).

However, although greatly promising, today, adopting a real participatory care approach in health management still risk become more of a "fashionable claim" than a concrete course of action also due to the lack of clarity in its conceptualization and lexicon.

For this reason and to address this need for clarification in the object and terms related to participatory medicine, this dissertation is specifically aimed at offering concrete cues for conceptualizing and promoting patient engagement in health and care by circumscribing our analysis to the critical context of the patient-clinician relationship – which is widely recognized to be the very first step to lay the ground for making patients actively responsible for their health (Coulter et al., 2007; Gruman et al., 2010).

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PART II

A CONCEPTUAL OVERVIEW OF PARTICIPATORY MEDICINE

Despite the growing popularity of the label "participatory medicine" and the increasing attention toward a care approach where patients can take an active role in managing their health, there is little consensus about what participatory medicine mans and about its settings of application.

In order to address this lack of shared knowledge and theoretical systematization, this section aims at providing a theoretical overview and shading light on the concept of "participatory medicine" (chapter 2) and, particularly, about the current conceptualizations and meanings mainly associated to the label "patient engagement" which is the most recent key word used in this field (chapter 3).

- CHAPTER 2 –

Participatory medicine:
Its meaning and significance
in the context of caring relationships[1]

As the movement of participatory medicine has increased its prominence in the medical field, this approach to care is increasingly accepted and valued by both academics and policy makers. However, terms and definitions used to describe the active role of patients across various healthcare settings and health disciplines are multiple, often leading to a semantic confusion among healthcare professionals, managers, and policy makers.

In the light of the epistemological revolution occurred within the medical field in the last decades – as pointed out in chapter 1 - this chapter sought to map the extent and nature of research dealing with the most relevant concepts used to define the participatory medicine field (i.e. patient engagement, patient activation, patient participation, patient involvement, patient empowerment) and the extent to which and how these studies have explored the implications of these concepts for the patient-doctor relationship.

Based on the analysis of the included articles, ten different settings in which the active role of patients is discussed by the scientific community emerged. Moreover, when in-depth examining the retrieved concepts' definitions we discovered that these terms covered different aspects of the healthcare process and have effects on different levels. They have also different implications for the patient-clinician relationship's features along the care process.

This chapter is conceived as a "glossary" of conceptualizations related to the active role of patients in their healthcare journey in order to give the readers a roadmap of the main concepts featuring the participatory medicine movement.

Keywords. Patient empowerment; Patient engagement; Patient involvement, Patient participation, Patient activation, Participatory healthcare; Scoping review.

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1. Introduction

As just discussed in chapter 1, today's society is going through deep changes and individuals increasingly expect to attend an active role in designing their own lives, either when healthy or ill (Davis et al., 2005; Leape et al., 2009). This revolution has been labeled "participatory medicine" or "participatory care" (Phillips et al., 2014; Graffigna, Barello & Triberti, 2015). From a research point of view, a growing body of evidences discusses the crucial role of making patients active participants in therapeutic decisions and in managing their own healthcare across different disciplinary field (Gruman et al., 2010; Barello et al., 2014; Menichetti et al., 2015).

Particularly, to adopt a participatory care approach is demonstrated to be essential for those affected by chronic conditions that are frequent and long-term users of health services, accounting for about 80% of GP consultations, 60% of hospital bed days and two-thirds of emergency admissions (Coulter, 2011). It is now widely recognized that effective management of chronic illness entails an active partnership between healthcare professional and patient, in which education and support for self-care should be a key component (Coulter, 2011).

However, although promoting participatory care is receiving increasing attention by both policy makers and academics - according with the increasing call for actualizing the principle of patient centered care -, research and practice in this area seem to be hampered by the variability of concepts and terminology commonly employed to generally describe a patient which is responsible and able to actively manage his/her own health by taking part in his/her medical encounters.

Indeed, as pointed out in chapter 1, a wide set of overlapping terms is used to signify the patient's participative role and this is one of the main reasons why providing an evidence

base for the efficacy and effectiveness of participatory medicine has still remained a challenge. Indeed, while the principle of participatory medicine is gaining momentum in health systems across the world, evidences for its effectiveness in improving patient outcomes and cost reduction remains relatively weak.

Since the epochal turning point promoted by the patient centered approach to medicine (Stewart, 2001), many theories about how the patients can be "taken on board" in the clinical course have been developed. Furthermore, today, as just deeply showed in the previous chapter, several concepts and terms are often used as synonymous in order to indicate the active role of patients in the healthcare process.

In line with this urgent need for conceptual clarification, this chapter is conceived by the author as a "glossary" of the main recurrent concepts related to the patient's active and participative role in health and care management.

In particular, this chapter aims to provide a critical overview of the different concepts related to the participatory medicine movement; to examine the terminology used to describe these concepts and the implications of each term for the patient and health provider's role in the medical relationship.

Our ultimate goal is to lay the ground for a clearer articulation of what these terms mean when used to characterize the patient participative role in healthcare. Thus, this contribution will end by synthesizing the conceptual roadmap of participatory medicine, its innovativeness and its potential for medical practice.

2. GIVING BACK AN ACTIVE ROLE TO PATIENTS: WHAT DOES IT MEAN?

Researchers who have attempted to develop theories and operate interventions aimed at making patient active agents of their care and promote participatory care models, have

many definitions of this concept thus revealing a substantial ambiguity in its attributes and outcomes – often arising from the different researchers' viewpoints laying in different disciplines and/or research perspectives (Barello et al., 2012; 2014).

This literature review[2] unveiled a plethora of terms used to refer to the active role that patients might enact when interacting with their healthcare, often used interchangeably.

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[2] **Methodological note.** This scoping review (Arksey & O'Malley, 2005) was undertaken to map the literature about participatory medicine-related concepts. Scoping methods map ''key concepts underpinning a research area'', particularly when ''an area is complex or has not been reviewed comprehensively before'' (Mays, Roberts, & Popay, 2001, p. 194). Scoping reviews explore the depth, breadth and nature of existing research, draw conclusions about current research activities in the target literature, and identify gaps where evidence is not yet provided (Arksey & O'Malley, 2005).

Relevant empirical literature was identified from searches of electronic databases (Pubmed, Scopus and ISI web of Science) including all of the available literature up until November 30, 2014. To be included, the article had to meet each of the following criteria: discussed and defined the main concepts indicating the active role of patients in their healthcare (i.e. patient engagement, patient participation, patient involvement, patient activation, patient empowerment); and must include conceptual and theoretical discussion about the concepts and their implication for the patient-clinician relationship; was published in peer reviewed journals; was an article or review; and was written in English. Literature was then reviewed in its entirety, and that which did not develop the theoretical or conceptual discussion, such as works demonstrating research applications with minimal theoretical discussion, was excluded. Consistent with scoping study methods (Arksey & O'Malley, 2005), the quality of the literature was not assessed as this could have excluded relevant discussion based on criteria that were not relevant to the purposes of this review.

The search was done performing an open-ended search with the identified terms describing the active role of patients in healthcare (patient engagement; patient participation; patient activation; patient empowerment; patient involvement) – basing on a previous research on this topic (see Menichetti et al., 2015) -, combined with terms related to the field of the patient-health provider interaction in order to collect papers potentially discussing the implications of the active role of patients for the doctor-patient relationship in terms of features and role expectations (patient-doctor relationship; patient-provider relationship; patient-nurse relationship; consultation; visit; interaction).

The initial search resulted in 19250 records in total. After removing duplicate articles and articles without abstract, 10410 references remained. After selecting references by title and abstract, there were 160 left to be judged for inclusion based on their full text. Most of these studies were excluded, based on the inclusion and exclusion criteria. In this phase, 30 studies remained. Screening of the references contained in the review studies yielded another 61 possibly relevant references that were not already included in our database. Ultimately, 40 studies were selected for inclusion for data extraction and analysis.

Each conceptual contribution was analyzed by extracting from each publication using a standard template to allow in-depth qualitative analysis; the information was then examined and summarized, compared to contributions of other works, and analyzed for internal conceptual consistency, completeness and overall contribution to the discussion. This allowed the author to proceed with an in-depht qualitative description of the contributions belonging to each concept of interest. Following a close reading of the selected papers phrases that were used to describe each concept of interest were identified. These first-level concepts were analyzed to produce a secondary level of conceptualization, the emergent themes. Moreover, for each concept of interest the implication for the patient-clinician relationship (i.e. the expected role of patient and of the health provider) were highlighted. By comparing and analyzing these different concepts across the papers, similarities and contradictions could be observed and explored. The concepts, interpretations and themes were aggregated and examined for similarity and consistency. Consistently derived concepts and themes were synthesized from comparisons across the papers and the findings developed into a narrative, exploring the themes, identifying different factors involved and examining the relationship between them.

However each term seems to have its own issues and tells something about the way the authors conceive the roles both of the patient and the health practitioners (see paragraph 2.1). Moreover, a wide number of meaningful settings in which patients may play an active role in their healthcare. These settings differ among each other basing on the different types of patient activities, processes or mechanism occurring; they also involve different types of healthcare professionals and have different aims; and they also underline different expected roles for patients (see paragraph 3).

2.1 KEY CONCEPT IN PARTICIPATORY MEDICINE: A CRITICAL OVERVIEW

When in-depth examining the literature about participatory care (see table 1.2-7.2) we discovered that the concepts related to the active role of patients covered different aspects of the healthcare process and have effects on different levels. They have also a wide variety of implications for the patient-clinician relationship's features along the care process. In the following paragraphs we shall offer the readers an in-depth descriptions of these concepts in order to shed light on their peculiarities.

2.1.1 Patient empowerment

The literature on the patient empowerment concept is multifaceted and diverse, including writings based on educational, organizational, environmental, sociological, psychological and feminist ideologies (Rodwell, 1996) (see table 1.2). The appeal of patient empowerment rests on three different historical and epistemological traditions. It is advanced first on ethical grounds, particularly as a way of increasing individuals' rights and autonomy in patients' decision making related to their treatment options (Jerofke et al., 2013). A second reason for the growing interest in patient empowerment has been the acknowledgment that people should participate in and take responsibility for their health

care in order to prevent healthcare cost wastes (McAllister et al., 2012). Third, from a clinical point of view, patient empowerment is advocated as improving health outcomes because it is considered as a precursor of the patients' activation to effectively self-manage their own health (Asimakopoulou et al., 2012).

In a general sense, "patient empowerment" can be defined as a "process by which people gain mastery over their lives" (Rappaport, 1987). This concept has gained prominence following the Ottawa Charter of 1986, which proposed the "health promotion is the process of enabling people to increase control over, and to improve, their health" and patient empowerment is at the cornerstone of health promotion.

Researchers and clinicians consider, at the roots of this vision, a relational (e.g. doctor-patient) dimension, thus emphasizing the need for a more egalitarian structures and a more equitable distribution of power between health practitioners and patients (Hermansson & Martensson, 2011). Other visions about this concepts refer to a more individualistic view, focusing on the process of informed choice, or on the patient experience of power, control, or higher self-efficacy over the care process (Feste, 1995; Ajoulat et al., 2006). Moreover it is interesting to note that empowerment has been defined both as an intrapersonal and interpersonal process deriving from a fruitful medical partnership: as a primarily personal process, empowerment makes individuals develop and the necessary knowledge, competence and confidence to make their voices heard. Participatory competence (the ability to be heard by those in power), is considered in this perspective as one of the main outcome of this process. Although the findings suggest that empowerment is substantially an intrapersonal process, some authors describe a relation element featuring and triggering it. Gibson (1991), for instance, describes empowerment as a "social process of recognition, promoting and enhancing people's abilities to meet their own needs, solve their problems and mobilize the necessary resources in order to feel that they are in control of their lives";

and Hermasson & Matterson (2012) refer to it as "an ongoing dynamic and social process of acting, creating, confirming, facilitating, listening and negotiating between the nurse and the patient, in which they develop a trustful relationship based on mutual respect and integrity" (p.112). Among these authors' definitions it appears clear how the intrapersonal and the interpersonal processes of empowerment are strictly intertwined.

For what concern the main outcomes patient empowerment, authors report effects on different levels. Among the others, the majority of research showed patient empowerment affecting self-management and decision making patient's skills (Hermasson & Martensson, 2011; Jerofke et al., 2013); health outcomes and quality of life (Connelly et al., 1993; Asimakopoulou et al., 2012); self-esteem and self-efficacy (Connelly et al., 1993); the quality of patient-clinician relationship (Chambers & Thompson, 2008).

Finally, the analysis of the retrieved literature led the author to discover another key related concept: that's patient enablement (Hudon et al., 2011). The patient enablement process is defined as "*a professional intervention aiming to recognize, support and emphasize the patient's capacity to have control over her or his health and life*" (Hudon et al., 2011, p. 12). It is conceived the results of clinicians' empowering behaviors towards the patient. Enablement is a concept in continuity with the patient-centered model, as it shares common attributes with this model such as the contribution to the therapeutic relationship; consideration of the person as a whole; implication and support to decision making.

TABLE 1.2. SUMMARY OF THE STUDIES REPORTING DEFINITIONS OF PATIENT EMPOWERMENT

AUTHOR(S), YEAR	DEFINITION	REPORTED OUTCOMES
Anderson & Funnel, 2010	Empowerment is the antithesis of compliance. The purpose of empowerment-based interventions is to help patients learn to think critically and make informed decisions.	• Effective treatment decision making • Better physiological outcomes
Asimakopoulou et al., 2012	Empowerment is about educating and imparting knowledge and skills and also facilitating patients in developing the tools necessary to successfully manage their condition. It is a philosophy advocating patients taking control and responsibility for their illness.	• Effective self-management • More positive health outcomes • Higher quality of life
Chambers & Thompson, 2008	Empower patients means encouraging them to move gradually away from unhealthy to healthy lifestyles	• More effective nurse-patient relationship • Increase in patient quality of life and reduced use of acute and emergency care services
Connelly et al., 1993	Patient empowerment is a process during which people assert control over the factors affecting their lives. There are four levels of empowerment: participating, choosing, supporting and negotiating.	• Increase in self-esteem and self-efficacy • Increase in sense of mastery • Improved quality of life
Feste & Anderson, 1995	Empowerment education enables people to acquire and/or enhance the social, problem-solving, and communication skills necessary to manage their own health in a variety of life situations.	• Increased ability for goal-setting, identification of barriers, problem-solving techniques, • Better patient's communication skills • Higher rate of assertive behaviours

AUTHOR(S), YEAR	DEFINITION	REPORTED OUTCOMES
Funnell et al., 1991	Patient empowerment is a process whereby patients become activated and have the knowledge, skills, attitudes and self- awareness necessary to influence their own behaviour and that of others in order to improve the quality of their lives.	• Increase in quality of life • Increase in healthy behaviours
Gibson, 1991	Patient empowerment is a social process of recognition, promoting and enhancing people's abilities to meet their own needs, solve their problems and mobilise the necessary resources in order to feel that they are in control of their lives.	• Increase in patient's sense of control • Increase in feeling of hope • Greater patient and clinician satisfaction
Hermasson & Martensson, 2011	Patient empowerment is an on-going dynamic and social process of acting, creating, confirming, facilitating, listening and negotiating between the nurse and the patient, in which they develop a trustful relationship based on mutual respect and integrity. It is a personal process in which individuals developed and employed the necessary knowledge, competence and confidence to make their voices heard and gain a participatory competence.	• Development of trustful care relationship • Increase in patient ability to make informed choices • Development of positive self-concept and personal satisfaction
Jerofke et al., 2013	Patient empowerment is a way to engage patients in self-management of long-term illness in emerging patient-centred models	• Increase in patients access to information, support, resources and opportunities to learn and grow; • Development of effective collaboration with providers, family and friends; • Increase in patients autonomy in decision-making

AUTHOR(S), YEAR	DEFINITION	REPORTED OUTCOMES
McAllister et al., 2012	Patient empowerment is a multi-dimensional construct including: • cognitive control (sense-making - understanding the condition, why it happened, what help & support is available); • decisional control (having some options for managing the condition/risk and able to make informed decisions between options); • behavioural control (able to do something to reduce harm or improve life for self/child(ren)/at risk relatives/descendents); • emotional regulation (reflecting effective coping and adjustment) hope for the future (for self/relatives/future descendents).	• Increase in participants' self-confidence and self-efficacy • Changes in health status and clinical outcomes • More rational healthcare decisions • Decrease in dependence on healthcare services • More cost-effective use of healthcare resources.
Rappaport, 1987	Patient empowerment is a process by which a person gains more power over his or her life.	• Effective decision making • Better handling complications of the disease • Adoption of healthy behaviours
Rodwel , 1996	Patient empowerment is a helping process, a partnership which values self and others, mutual decision making using resources, opportunities and authority, and freedom to make choices and accept responsibility"	• Development of a mutual patient-provider relationship • More effective consultations for patients and clinicians

2.1.2 Patient activation

If we consider its etymology, "activation" means "the act of initiating something" (Oxford English Dictionary, 2012). Indeed, "activation" can be understood as a process thanks to which the parts of a system are brought to an active or passive state, that is, they become able to react to stimuli and increase healthy behaviours (Mittler et al., 2013). In the participatory medicine field, the term "patient activation" refers to the level of "knowledge, ability and confidence in the patients' capacity to manage his/her own health and the interactions with the healthcare system" (Hibbard et al., 2005; Green et al., 2012). Research about self-management of chronic conditions (Stewart et al., 1993; Rosenberg et al., 1997) indicate that greater patient activation can increase satisfaction with care (Blanchard et al., 1990), improve the whole health care process (Kaplan et al., 1989; Epstein et al. 1993), ensure the receipt of guideline-concordant treatments, and potentially enhance health outcomes and adherence to medical prescriptions (Hibbard, Stockard, Mahoney & Tusler, 2004) (see table 2.2).

In 2004, Hibbard defined the concept of patient activation as composed by 4 phases. Moreover, she developed a scale to measure it which is currently the only one available in the scientific debate (PAM, Patient Activation Measure). Patients who have a minimum level of activation (level 1) tend to be passive, not aware of their own role in the health management; the level 2 refers to patients who start to adopt healthy behaviors, such as modifying their eating habits, so that they start to build their own first resources and knowledge about their health condition; a level 3 patient is characterized by autonomy in the symptoms and treatments management, so that he/she is able to develop ad hoc responses to the problematic situations related to the disease. Finally, patients who are at level 4 of activation are able to maintain their new lifestyle behaviors in the long term, even in the context of stressful conditions.

Researchers have generally recognized the patients' personal belief, attitudes, empowerment, and positive feeling towards the patient active role in healthcare as the main enablers of the activation process (Funnell et al., 1991). In these conceptualizations, an effective medical partnership and patient empowerment are considered the very first steps toward promoting patient activation (Ryan & Sawin, 2009).

TABLE 2.2. SUMMARY OF THE STUDIES REPORTING DEFINITIONS OF PATIENT ACTIVATION

AUTHOR(S), YEAR	DEFINITION	REPORTED OUTCOMES
Hibbard et al., 2004; 2008	Patient activation can be defined as "the degree of patient engagement 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	• Better health outcomes • Lower healthcare costs • More effective medical relationship
Ryan & Sawin, 2009	Patient activation can be viewed as a precursor to the engagement in self-management behaviours, as the components of patient activation (knowledge, skills and confidence) are factors that influence the process of self-management behaviour	• Better self-management skills • Higher patients' adherence to treatments
Mittler et al., 2013	Patient activation and engagement in health and healthcare refers to the performance of specific behaviours (self-management, healthcare encounter, shopping and health behaviours) and/or the capacity and motivation to perform these behaviours ("patient activation").	• Increase in healthy behaviours • Increase in patients' adherence to treatments

2.1.3 Patient participation and patient involvement

In the last decade, the ability to take the patient "on board" in his/her whole healthcare process (from medication adherence to participation in clinical research or policy design) and to foster an effective partnership between the patient and the health practitioners through consultations, treatments and continuing care, have been recognized as primary objectives for the healthcare quality improvement (Entwistle and Watt, 2006).

The scientific literature on this topic offers a wide variety of terms to connote this objective (see table 3.2 and 4.2). The terms describing patients taking an active part in their healthcare process mainly includes 'patient participation' and 'patient involvement' (and, more recently, 'patient engagement'). These concepts are often used synonymously (Gallant et al., 2002; Thompson, 2007), without a clear understanding of their differences, despite being problematized individually (Elwyn, Edwards, Kinnersley, & Grol, 2000; Jones et al., 2004). In a notable exception, Cahill (1996) distinguished patient participation from the precursor concepts of involvement (basic, often delegated tasks) and collaboration (intellectual co-operation) and the ultimate concept of partnership (joint venture). Patient participation requires a narrowing of the information/competence gap between health professionals and patients, with some surrendering of power by the professional which conveys benefit to the patient, even if there is no consensus. Early conceptualizations of the patient–doctor relationship outlined a hierarchy of patient control from passivity to participation (Szasz & Hollender, 1956), since when ideas of shared decision-making and patient autonomy have come to the fore (Coulter, 2002). This movement led to more and more valuing the principles of lay people participation in their community, which spawned similar frameworks in healthcare applications, including participatory health programs, participatory patient education (Feingold, 1977), participatory health research (Cornwall, 1996; Rifkin &

Pridmore, 2001) and NHS agenda setting and guidelines development through the patients' involvement (Oliver et al., 2004).

Patient participation/involvement, has been discussed in several contexts. Collective or indirect participation practiced as lay participation in research, formulation of policy, and the design/evaluation of health services (Allen, 2000), or as a parent, or carer (Roberts, 2002). Patient participation may be practiced in, for example, medication adherence, health care and promotion, mental and social care, patient education programs, self-management or self-care (e.g., Lammers & Happell, 2003; Obeid, 2000), and in different situations; for example, discharge planning (Efraimsson, Sandman, Hydén, & Rasmussen, 2004; Jewell, 1996; Roberts, 2002), decision-making in treatment/care (Caress, Luker, & Akrill, 1998; Henderson, 2002; Sainio & Lauri, 2003; Sainio, Lauri, & Eriksson, 2001), bedside reporting (Timonen & Sihvonen, 2000), patient safety programs (Longtin et al., 2010). The meaning of the term has also been explored (Eldh et al., 2004, 2006; Tutton, 2005) and instruments to measure patient participation have been tested and constructed ad hoc (Caress et al.; Latvala, Saranto, & Pekkala, 2004; Ramfelt, Lützen, & Nordström, 2005). Particularly, patient participation or involvement in treatment decision making has received the greatest attention by the scientific community (Guadagnoli & Ward, 1998; Wellard, Lillibridge, Beanland, & Lewis, 2003).

As understandable from the above discussion, the analyzed studies on patient participation are still not congruent regarding definition, elements, and processes (e.g., Gallant, Beaulieu, & Carnevale, 2002). Particularly, patient participation seems to include and be used interchangeably and synonymously together with patient involvement (Anthony & Crawford, 2000; Doherty & Doherty, 2005; Evans et al., 2003; Hickey & Kipping, 1998) and, sometimes, with patient engagement.

Generally, it is notable that contributions addressing patient participation and patient involvement mainly discuss these concepts as strictly connected to the patient-clinician relationship and its implications for the clinical decisional process. Patient participation and patient involvement are described as states relates to being involved in decision-making or expressing one's views on different treatments or in patient safety practices. It includes sharing information, communicating feelings and symptoms, and compliance with nurses' and doctors' prescriptions. Moreover some of the contributions focuses on the clinical and relational competences of the physician, which are fundamental to involve the patient in the clinical decisions. In this sense, communicative and interpersonal abilities are conceived as the main factors fostering or preventing the desirable shared decision making in the care process (Charles, Gafni and Whelan 1997; 1999). Finally, a number of contributions depicts patient participation/involvement as a dynamic process, moving beyond only having a voice, to being involved in evaluation and towards actual planning of care services and delivery. It includes a person-centered philosophy, such as an equal relationship and sharing power and knowledge with a supportive facilitator. Moreover, expressions such as "patient participation" or "patient involvement" might seem to denote the active role of patients in research either as passive participants or subject of a study and active collaborators in the design and conduct of a study.

Reported outcomes of patient participation/involvement are: increased patient satisfaction and trust (Sahlsten et al., 2007), higher patients' quality of life (Henselmans et al., 2013), more positive and direct professional's communication with positive and lasting effects on health (Thomson et al., 2007), reduced patients' anxiety and depression(Henselmans et al., 2013), better understanding of personal unmet needs and patient empowerment (Larsson et al., 2007), improvement in providing, monitoring and evaluating services, better decision making due to access to different views (Forbat et al., 2009), increased trust in services due to

increased accountability of healthcare processes encouragement of sense of independent responsibility (Sahlsten et al., 2007), career promotion for most staff due to positive feedbacks, reduced possibility of patient dissatisfaction and medical errors (Longtin et al., 2010; Vaismoradi et al., 2014).

TABLE 3. 2. SUMMARY OF THE STUDIES REPORTING DEFINITIONS OF PATIENT PARTICIPATION

AUTHOR(S), YEAR	DEFINITION	REPORTED OUTCOMES
Longtin et al., 2010	Patient participation means to involve patients in the decision making process regarding health issues and also it is a strategy aimed at encouraging patients to participate in improving patient safety	• Improved health outcomes • Prevention of medical error • Increase confidence in own capacities • Increased level of health literacy
Sahlsten et al., 2007	Patient participation is an interactional process identified as mutuality in negotiation. Optimal participation by patients requires intimacy and contact, a dynamic interaction between equal partners based on a foundation of interpersonal procedure, therapeutic approach, focus on resources and opportunities.	• Improved adherence and follow-through • Greater patient and clinician satisfaction
Larsson et al., 2007	Participation realizes itself in performing clinical or daily living skills and primarily in decision-making. It is a dynamic nurse–patient interaction process characterised by experiencing an obliging atmosphere, emotional response, concordance and rights	• Increase in motivation to improve the health condition • Better treatment results • Patient empowerment • Greater satisfaction with received care
Thomson et al., 2007	Patient participation is the ideal form of relationship, requires professionals to engage in two-way communication and effectively share the power they undoubtedly have with their patients on the basis of mutual respect and openness.	• Better coordination of care • Better relationships characterized by collaboration and partnership • More effective consultations for patients and clinicians

TABLE 3. 2. SUMMARY OF THE STUDIES REPORTING DEFINITIONS OF PATIENT PARTICIPATION

AUTHOR(S),YEAR	DEFINITION	REPORTED OUTCOMES
Henselmans et al., 2013	Patient participation means to make patient effective communicators in the medical consultation. It implies providers able to providing information, encouragement, modelling and rehearsal .	• Higher patient satisfaction with the consultation • Psychological as well as physical well-being • Provider satisfaction with the consultation • Decrease in consultation duration
Vaismoradi et al., 2014	Patient participation means to make patient active agents in the prevention of errors and adverse events associated with provision of healthcare"	• Increased personal illness coping strategies • Reduced medical errors
Forbat et al., 2009	Patient participation means cooperation for understanding information, as opposed to merely searching for information. It is considered as being trusting, understanding and preserving feeling of control and recognizing responsibility of oneself as a patient .	• Better decision making • Increased patient satisfaction and trust • Higher patients' quality of life

TABLE 4.2. SUMMARY OF THE STUDIES REPORTING DEFINITIONS OF PATIENT INVOLVEMENT

AUTHOR(S), YEAR	DEFINITION	REPORTED OUTCOMES
Vahdat et al., 2014	Patient involvement means make patient active participant in decision making or expressing opinions about different treatment methods, which includes sharing information, feelings and signs and accepting health team instructions	• Higher patient empowerment • Healthcare services improvement • More effective decision making
Forbat et al., 2009	Patient involvement refer to the users' involvement in service design/improvement, policy, research and their own care/treatment.	• Increased trust in services due to increased freedom, knowledge and transparency
Mathie et al., 2014	Involving patients in research means conduct a research with the public or service user than research on patient or public as subject or participant	• Defence of the patients' rights and viewpoint
Entwistle et al., 2014	Patient involvement means engage patients in deciding which treatments would be most appropriate, in self- monitoring and self-managing symptoms and treatments, and in acting to address any concerns about their health or care.	• More positive health outcomes • Reduction in healthcare costs • Higher adherence to treatments
Boelens et al., 2014	Patient involvement means to make patient partners in guideline formation and implementation of consensus information in clinical practice	• An opportunity for patients' dealing with inequalities in health and access to services • Encouragement of sense of independent responsibility
Kidd at al., 2009	Patient involvement is the patients' understandings of their perceived control in managing treatment-related side effects and how this influenced their attitudes toward and roles preferences in their self-care	• Higher patient's quality of life • Better health outcomes
Crawford et al., 2002	Patient involvement refers to the active participation in the planning, monitoring, and development of health services of patients, patient representatives, and wider public as potential patients	• Changes to organisation of care and information for patients

2.1.4 Patient engagement

Upon reviewing the literature (more deeply described in chapter 3), it was evident that there were a number of different conceptualizations at the base of the term "patient engagement". Although the term patient engagement was commonly used in discussions and policy documents related to patients interacting and being meaningfully involved in their health care, it was rarely used – as a specific concept - in the scientific literature (Barello et al., 2014; Menichetti et al., 2015). A lack of consensus and understanding about terminology, the goals and responsibilities of stakeholders were perceived as barriers to achieving meaningful and successful patient engagement. Forbat and colleagues concluded that "one of the greatest barriers to truly integrating patient engagement into health services, policy and research is the conceptual muddle with which involvement is articulated, understood and actioned" (Forbat et al., 2009, p. 123). Not only is the terminology for patient engagement confusing, so is trying to define it. Particularly, the terms 'involvement', 'engagement', and 'participation' were often used interchangeably. However, the concept of "engagement" tries to explore the dialogue between the supply and demand of health services, considering a wider spectrum of patients' activities among different healthcare settings. This is testified by the wider use of the term "patient engagement" across settings at different levels: from patient engagement in medication adherence (Rodriguez, 2013), to patient engagement in treatment decision making (Forbat et al., 2009; Gruman et al., 2009), to patient engagement in safety practices (Maurer et al., 2012), to patient engagement in research (Carman et al., 2013), to patient engagement in healthcare policy design and evaluation (Concannon et al., 2012). Unless this wider and apparently non-coherent use of the term, authors using the term "patient engagement" are similar in examining the patient as a consumer in healthcare environment and thus particularly underline his/her possible actions when navigating the whole healthcare system

(Forbat et al., 2009; Graffigna et al., 2013). Indeed, a consumerist view recognize the patient's ability to make informed healthcare choices that balance the cost and quality of health services delivery (Gallivan et al., 2012). In this view, patients are more actively involved in a relationship of collaborative decision making and empowerment with their healthcare providers and – more in general – with the healthcare network. In virtue of this ability to navigate the healthcare and to manage a more sustainable lifestyle, the patient becomes able to virtuously interface with the entire healthcare system. The pull of retrieved contribution about patient engagement use this terms to refer to different processes related to the active role of individuals in healthcare. Some contribution mainly underline the individuals implications related to this concept describing the benefit that a patients may gain when actively engaged in the care process such as increased health literacy (Gruman et al., 2009), better medication adherence (Rodriguez, 2013) and patient's awareness of health and illness processes (Merriam-Webster, 2012).Other contributions underline the benefits of patient engagement to the health care system in its policy and planning activities (Gallivan et al., 2012; Carman et al., 2013; . Some studies demonstrated the benefits for patients and decision makers at various levels to have patients engaged in face-to-face discussions and decisions concerning healthcare and health product decisions or issues (Gruman et al., 2010; Elwin et al., 2014). The sharing of information, experiences and concerns between patients and decision makers was more than educational; it was also informative for healthcare recommendations. One of the overarching benefits of patient engagement was that it enabled the health system to address the right issues in an appropriate way, design programs, policy and planning activities closely tailored to the needs of both individuals and special populations; achieve better results; and validate outcomes (Merriam-Webster, 2012; Gallivan et al., 2012; Carman et al., 2013). General benefits were found in the literature at both an individual and organizational level included better health and treatment outcomes (Forbat et

al., 2009; Gruman et al., 2010; Graffigna et al., 2013; Simmons et al., 2014), more appropriate and need-attuned services (Gallivan et al., 2012), increased legitimacy and credibility of decision making (Concannon et al., 2012), increased sense of dignity and self-worth (Merriam-Webster, 2012), and improved service user satisfaction (Hibbard et al., 2013). A deeper discussion about the literature dealing with the concept of patient engagement - which is the main object of this dissertation - will be provided in chapter 3.

TABLE 5.2. SUMMARY OF THE STUDIES REPORTING DEFINITIONS OF PATIENT ENGAGEMENT

AUTHOR(S), YEAR	DEFINITION	REPORTED OUTCOMES
Gruman et al., 2010	Patient engagement is a set of behaviours to manage own's own health and healthcare, such as participating in fully shared decisions about treatments.	• Increase in patient health outcomes • Increase in patient self-management skills • More effective decision making
Lequerica & Kortte al., 2010	Patient engagement is a deliberate effort and commitment to working toward the goal of rehabilitation interventions, typically demonstrated through active, effortful participation in therapies and cooperation with treatment providers.	• Effective patient-clinician partnership • Increase in patient health outcomes
Maurer et al., 2012	Patient engagement is a set of behaviours 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. The desired goals of patient and family engagement include improving the quality and safety of health care.	• Improvement in healthcare quality and safety • Increase in therapeutic alliance
Merriam-Webster, 2012	Patient engagement is a person's emotional involvement and commitment to his or her own health and role in healthcare and/or the act of being involved in activities related to one's health and healthcare	• Better psychosocial health • Better perception of illness • Better biological outcomes
Rodriguez, 2013	Patient engagement is the desire, knowledge, skills, and ability to self-manage their disease within the diverse and changing environment of their world	• Changes in attitudes and health beliefs • Self-efficacy • Higher medication adherence • Disease knowledge • Technical skill • Functional health literacy • Better medication management
Simmons et al., 2014	Patient engagement means (1) recognizing and understanding the importance of taking an active role in one's health and health care; (2) having the knowledge, skills, and confidence to manage health; and (3) using knowledge, skills and confidence to engage in health-promoting behaviours to obtain the greatest benefit	• Increase in self-efficacy • Increase in self-management • Increase in self confidence • Increase in symptom reporting • Improvements in self-care behaviours

AUTHOR(S), YEAR	DEFINITION	REPORTED OUTCOMES
Carman et al., 2013	Patient engagement can be characterized by how much information flows between patient and provider, how active a role the patient has in care decisions, and how involved the patient or patient organization becomes in health organization decisions and in policy making	• Changes to organization of care and information for patients • Increase in health literacy • More satisfying decision making
Concannon et al., 2012	Patient engagement is a bi-directional relationship between the stakeholder (the patient) and researcher that results in informed decision-making about the selection, conduct, and use of research.	• Increase in patient's right protection
Elwin et al., 2014	Patient engagement is defined as a collaborative deliberation that takes place when interactions between participants are characterized by curiosity, respect, and empathy. The model presupposes a relationship where the two (or sometimes more) parties 'dance together', figuring out who leads, and in what direction.	• Increase in the patient-doctor relational quality • Increase in effective decision making
Gallivan et al., 2012	Patient engagement refers to "attempts on the parts of organizations such as Health Boards to include a range of (often unspecified) individuals and community groups and organizations, and the 'public at large,' in their activities".	• Changes to organization of care and information for patients
Graffigna et al., 2013	Patient engagement is a dynamic and evolutionary process that involves the recovery of life projectuality - even with the disease. The patient engagement process features four experiential positions (blackout, arousal, adhesion, and eudaimonic project).	• Increase in patient health outcomes • Increase in patient awareness • Increase in patient ability to project their life

3. UNPACKING THE COMPLEXITY OF PARTICIPATORY MEDICINE: AN OVERVIEW OF SETTINGS

As just underlined in the previous paragraphs, the literature dealing with the active role of patients in their healthcare journey remains heterogeneous in approaches, focus and settings of application.

Literature suggests a wide number of settings in which the active role of patients is discussed by the scientific community (see table 6.2). These settings refer to different type of activities and participatory medicine-related concepts. Follows a deeper description and discussion of the emerging settings for the actualization of a participatory medicine approach as proposed by the main authors involved in the current academic debate.

TABLE 6.2. A SUMMARY OF TEN DIFFERENT PARTICIPATORY MEDICINE-RELATED SETTINGS EMERGING FROM THE LITERATURE ANALYSIS

SETTING	MORE FREQUENTLY ASSOCIATED CONCEPT	EXPECTED OUTCOMES	PATIENT'S ROLE/ACTIVITIES	HEALTH PRACTITIONER'S ROLE/ACTIVITIES
Medication adherence	Patient engagement Patient involvement	• Better symptom management • Better health outcomes • Lower healthcare costs	Passive recipient of care and behavioural executor of treatment prescription	Provider of care prescriptions and depositary of the medical knowledge
Self-management, self-care	Patient engagement Patient activation	• Higher health outcomes • Lower healthcare costs	Active learner and co-producer of health management	Expert who is involved in joint processes of patient education and monitoring of health parameters
Patient safety	Patient engagement Patient participation Patient involvement	• Reduced medical error • More effective care process	Proactive agents in safety practice Key player in preventing medical malpractice	Support and encouragement role in legitimizing patients
Shared decision making	Patient involvement Patient participation	• Increase in patient satisfaction • Increase in patient adherence • Improved health outcomes • Higher patient-doctor relational quality	Active participant in the process of treatment decisions Shoppers for high quality services	Modulator of the extent to which the patient actively participates in health care decisions
Rehabilitation	Patient participation	• Increase in social inclusion, • Improvement in patients' wellness	Active participant in social life	Enabler of patient's autonomy and social network (re)building
Health promotion	Patient involvement	• Higher rate of preventive behaviors • Increase in patient autonomy in identifying their own health agenda	Active participant in initiatives devoted to general health promotions	Promoter of empowering behaviors Health coach

SETTING	MORE FREQUENTLY ASSOCIATED CONCEPT	EXPECTED OUTCOMES	PATIENT'S ROLE/ACTIVITIES	HEALTH PRACTITIONER'S ROLE/ACTIVITIES
Research	Patient participation Patient engagement	• Lower rate of patients' drop out • Higher patient-doctor relationship	Recipient/active collaborator in research design and conduct	Researcher
Health system	Patient involvement Patient participation Patient engagement	• Improvement in health outcomes and access to care • Revitalization of community empowerment by establishing local involvement networks to influence health and social care services.	Participant in healthcare planning and delivery	Policy maker
Patient education/ coaching interventions	Patient participation Patient involvement	• Improvement in patient activation • Improvement in functional health status • Improvement in mental health status	Patient as a learner and equal partner in healthcare	Professionals adopt the positions of educators, detectives, negotiators, salesmen, cheer- leaders and policemen
Patient advocacy	Patient involvement Patient engagement	• To move from a NHS that does things to and for its patients to one which is patient led	Building consensus on clinical guidelines Defending the patient's rights	Professionals as equal partners in promoting the patient's voice to be heard

3.1 MEDICATION ADHERENCE

The literature that studies the modalities thanks to whom the patients effectively and actively manage the drug and treatment prescriptions often uses the terms "adherence". The introduction of 'medication adherence' as a MeSH term in 2009 constituted a significant paradigm shift towards recognizing patients as key players in their healthcare. As defined by the World Health Organization, adherence is ''the extent to which a person's behavior- taking medication, following a diet and/or executing lifestyle changes, corresponds with agreed recommendations from a health- care provider'' (Sebate, 2003). Therefore, the validity of the definition and its operationalization in research and clinical practice hinges upon the prove that patient and clinician agreement about the course of treatment is reached in the first instance. In addressing the need for patient involvement in treatment decisions, this definition can be viewed to supersede the concept of compliance and is currently favored by many experts in the field (Lehane et al., 2009) Adherence as a construct is multi-faceted, founded upon patients' understanding of their illness severity, their belief in the efficacy of a particular treatment and in their ability to control their symptoms by utilizing this treatment (Vrijens et al., 2012). In general, they refer to the patients' adaptive behaviors when he/she follows the medical prescriptions and are recognized to have effects on health outcomes and healthcare costs. The main difference between the terms "compliance" and "adherence" relies in the second being more open to an active role of the patient in the communication exchange with the physician in order to make effective and values' sensitive decisions about the care plans. In this sense, the activation of the patient should be promoted. Moreover, he/she is seen as a fundamental actor in the management of his/her own health and also in the communicational relationship with the doctor. However, medication adherence seems to be the contexts in

which a lower level of patient participative role in required as the patient is conceived as a recipient of medical prescription.

3.2 SELF-MANAGEMENT AND SELF-CARE

In the medical lexicon, 'self-management' means the ability of a patient in managing the symptoms, the treatments and the physical, psychological, social consequences of an illness condition. This concept is also related to the achievement of an auto-regulation of a care process, strictly basing on individuals' personal needs and expectations. This state is recognized as the outcome of a process of acquisition of information about disease and its implications. Thanks to this, the patient becomes autonomous in the treatments management. For this reason, the concept of "self-management" evokes a representation of the exchange between the patient and the healthcare system based on the transmission of management competences, and of care practices from the hospital to the everyday life contexts of the individual. Consistently, the self-management becomes one possible positive outcome of a patient engagement process. Moreover, it appears as one of the prototypical contexts where a high engagement level manifests itself, similarly to a high adherence to treatments and a profound partnership between the patient and the physician in the decision making about the care treatments.

Self-care/self-management among patients emerged as a context in which they might act their capability for health and health development. As a health capability, self-care is defined as an action capability whereby the active participation of patients allows them to maintain, promote or enhance their functional ability, limit illness, and/or prevent dysfunction and disability in daily life. It refers to their personal potential to address universal needs, goals and health issues in order to acquire well-being and independence. Self-management is gained by

educating, supporting and encouraging patients – in particular those affected by chronic conditions - to adopt an active role in their own health management. In this context, the patient has mainly the role of an active learner and the physician the one of an expert who has the duty to pass knowledge and skills for effective health behaviors.

3.3 PATIENT SAFETY PROGRAMS

Patient safety has become a crucial context in which patient could enact a participative role since when in October 2004 the World Health Organization (WHO) officially launched a patient safety programs dedicated to "bringing significant benefits to patients in countries rich and poor, developed and developing, in all corners of the globe." This results in various calls to action to make patient active agents in contributing to their healthcare safety, to inform systemic healthcare quality and safety improvements in services' delivery (Wachter, 2012). Patients can play an important role in the reduction of patient safety incidents (defined by the UK's National Patient Safety Agency (NPSA) as unintended or unexpected incidents which could have or did lead to harm for one or more patients receiving NHS funded care). At most stages of care there is the opportunity for the patient to be active in contributing, for instance, helping avoid clinical errors and the monitoring of adverse events (Nieva & Sorra, 2003). There are currently a number of national and international initiatives which support this view, which aim to facilitate patient involvement in safety. Involving patients in safety represents a specific instance of the wider concept of patient participation/involvement in health care. Preliminary studies on patient perceptions of errors in primary care suggest that it is unlikely that patients will view safety issues in a different way to more generic concerns about the quality of health care, though engagement in safety will carry some specific challenges. These may include the fact that some safety-related patient behaviors may be perceived by patients

and clinicians alike as challenging clinicians' professionalism. In addition, while in other areas of patient involvement in health care, patient involvement has been well documented (e.g. patient involvement in clinical decision making), patient involvement in patient's safety is an emerging field of interest with still limited evidence. In this context the physician has the crucial role to encourage patient in taking part in safety practiced and feeling legitimated to alert the care system in case of potential medical errors (McNutt et al., 2002).

3.4 SHARED DECISION MAKING

Shared Decision Making (SDM) is hypothesized to promote active patient participation/involvement in health-related decisions (Elwin et al., 2003) As a concept it refers to a style of communication between a patient and clinician which aims to place patients' preferences and values on a level comparable, although not the same as, clinical information (Elwin et al., 2000). The aim of SDM is to achieve positive outcomes for patients' communication between the clinician and patient and helping patients to select better treatment options (Charles et al., 1997). Many studies identified that SDM impacts on patient satisfaction, patient adherence, patient-doctor relational quality (Briss et al., 2004) but also that SDM faces a number of challenges. For example, patients' actual participation in SDM might be less than they prefer and health care professionals may need guidance on how to implement SDM (Vogel et al., 2008). In this context, patient are recognized to have to role of critical consumer and shopper of healthcare quality services; and clinicians should be able to modulate their decisional style on the basis of the extent to which the patient actively participate in healthcare choices.

3.5 HEALTH PROMOTION AND EDUCATION

Community-based health promotions refer to the com- munities' participation in actions and activities that improve the health of, and reduce risks to, those com- munities. Community members might, for example, be encouraged to participate in more physical activities to improve their wellbeing or to participate in notification and control of infections. More information is needed to support the efficacy of current approaches in increasing community participation. Patient education alone has been largely ineffective in improving adherence. When combined with other interventions, education does enable a patient to participate more effectively in managing care (Roter et al., 1998). The need for education is especially important for patients living with chronic conditions. Complexity of treatment is a factor in poor adherence. Education combined with timely follow-up visits, progress reports, and psychosocial support have produced positive results (Davidson, 2005; Mason, 2005)

3.6 REHABILITATION PROGRAMS

We identified that phrases such as patient participation or patient involvement are used to describe rehabilitation of patients with limited physical mobility, such as stroke patients or patients with intellectual disabilities. The aim of patient participation in this context is to increase patients' participation in social activities and participation is an index of patients' health and effective rehabilitation (Wressle et al., 2002; Talkowski et al., 2009).

3.7 RESEARCH DESIGN AND CONDUCT

Phrases such as 'consumer participation' might seem to denote active involvement of patients in research. However, we identified that in some studies, 'participation in research' referred to recruitment of consumers and community members into research projects as passive

participants and subjects of a study. In contrast to this vision, other studies have considered consumers and community members invited to actively collaborate in the design and conduct of research (Abma, 2005; 2010). Within this domain, members of the public and patients are engaged with the research process in a variety of ways ranging from participation in ethics committees, through to roles on community advisory boards and to undertaking an active role as a co-investigators. Members of the public actively contributing to research may be involved in: defining the scope of the study; recommending, identifying and evaluating the relevant literature; interpreting the findings; checking the consent processes and information sheets; examining the data collection processes; writing up the results; and reviewing outcome recommendations. In this context, patients can serve as ambassadors for high-integrity evidence even where the findings are contrary to generally accepted beliefs.

3.8 HEALTH SYSTEM

Patient engagement in health systems refers to involvement of patients in the healthcare environment at the higher levels of governance (Crawford et al., 2002; Eldh et al., 2006). Patients and families have experience, expertise, insights, and perspectives that can be invaluable to bringing about transformational change in health care and enhancing quality and safety. A variety of clearly defined roles for patients and families to participate as partners in quality improvement and in the redesign of health care needs to be in place in all types of health care organizations. These include hospitals, ambulatory practices, community-based organizations, agencies, and the educational programs preparing the next generation of health care professionals and administrative leaders. Similar partnerships need to be in place for payers, accrediting organizations, and foundations. Both patients and members of the general public can be involved in this kind of activities . Particularly, this context requires patient to be involved into organizational design, governance, and policy making and be critical agents

in health services evaluation. This also implies to make partnerships with patients and families an essential aspect of health care redesign and quality improvement. In this contexts, patient may enact the role of co-leaders and leaders of patient and family education and support groups; members of key institutional committees, such as safety, quality improvement, facility planning, information technology, ethics, and others; members of national health care advisory boards.

3.9 PATIENT ADVOCACY COMMITTEE

Patient advocacy is based on the premise that people have the right to make their own choices about their health care (Mallik & Rafferty, 2000). Promoting patient participation in personal advocacy is considered by some authors as one of the possible contexts in which patient might take an active role in their healthcare by defending their rights and experiential expertise derived from being affected by a clinical condition. In this context patients may have a role as leaders of advocacy groups or members of patient and family advisory councils. In line with this philosophy Hospitals, clinical units, ambulatory programs, and public health agencies are creating paid positions for patient and family leaders to advance the practice of patient- and family-centered care and facilitate the development of partnerships with patients and families (Seal et al., 2007).

4. A COMPREHENSIVE DESCRIPTION OF PARTICIPATORY HEALTHCARE: A SYNTHETIC OVERVIEW

The above described settings and concepts featuring the analyzed literature about participatory medicine can be seen as interrelated rather than being independent from one another. For example, patient empowerment is strictly connected to an active medical partnership between the patient and the health provider which features mutual trust and positive attitude towards shared decision making; patient activation is strictly connected to a patient empowerment status; and participatory actions made by the patients can't realize without being activated in terms of patients' knowledge, motivation and confidence. This interrelation or overlapping of different aspects of participatory care has been described in several conceptual descriptions and is reflected in the analyzed literature. .

A synthetic overview of the features of a participatory healthcare basing on the literature analysis is displayed in Figure 1.2.

FIGURE 1.2. A COMPREHENSIVE DESCRIPTION OF PARTICIPATORY HEALTHCARE
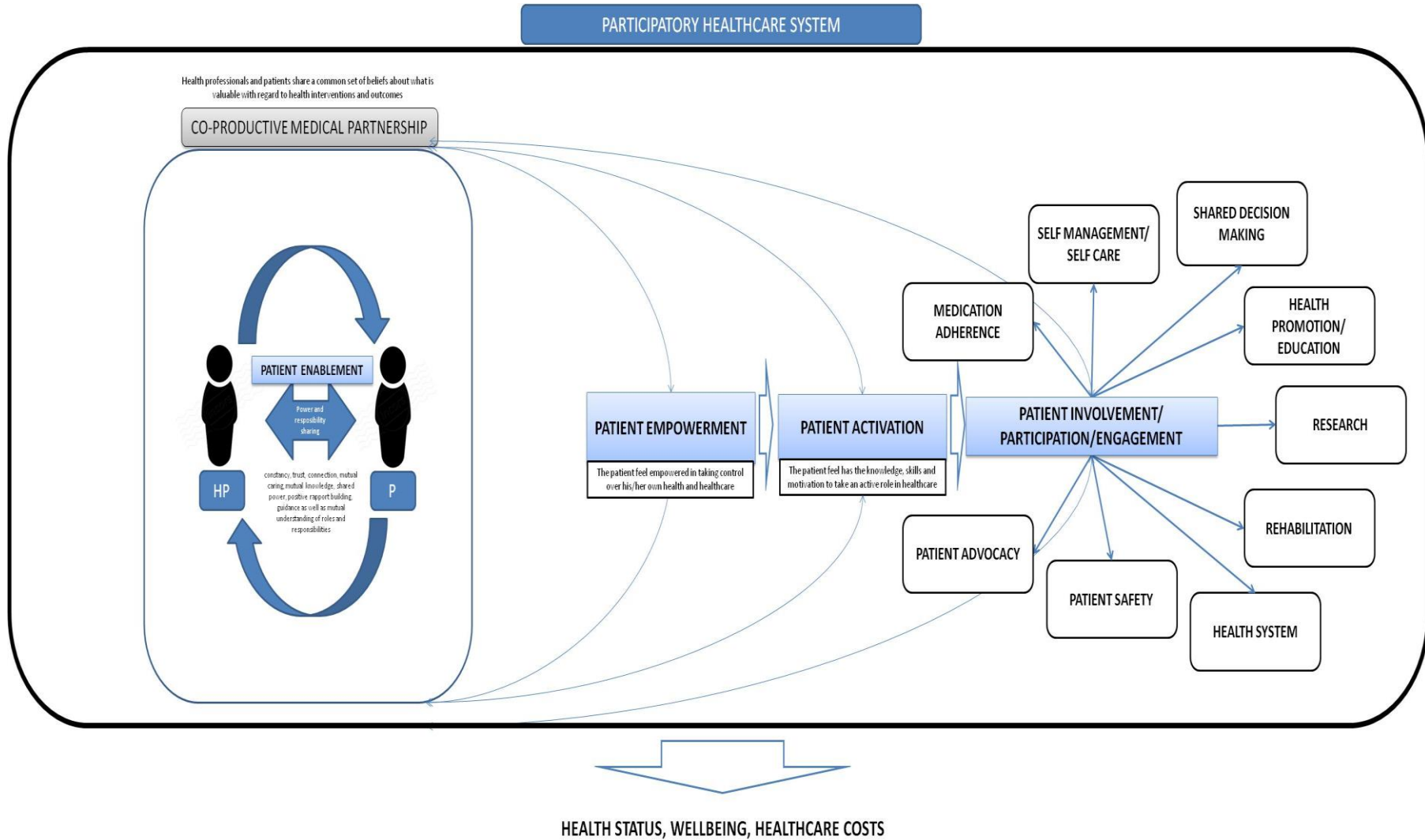
5. DISCUSSION AND CONCLUSIONS

This literature review is though as an extension of what discussed in chapter 1 and was aimed to make clearer the participatory care approach which is today at the forefront of government policies and regulations. It is conceived as a first contribution to address the substantial gap that could be visible between theory and practice of participatory medicine and to take in charge what in chapter 1 has been defined "the challenge of putting the patients first'' that today seems to be ''rhetorical lip service'' (Hodkin & Taylor, 2013).

This chapter discussed the different settings and concepts related to the participatory medicine model of care and proposed a comprehensive description to synthesize the main academic contributions in this area (see figure 4.2). The synthesis highlights that the concepts are different but, at the same time, strictly interrelated. Each concepts is featured by specific outcomes and settings of application butt, on the other hand, they all give their contribution to the realization of a participatory care environment. These results might allow researchers, clinicians, and policy makers to speak the same language and to address the lack of conceptual clarity about the meaning of participatory medicine discussed in chapter 1 and identified as one of the main challenges for its application in the real clinical settings. This can have an impact on clinical practice if everyone is on the same page regarding the delivery of participatory care.

The proposed synthesis can also be used in medical and other health care education to design new curricula that have a stronger focus on participatory care. This is in line with the call of the World Federation for Medical Education for a more explicit coverage of the topic in their Global Standards for Medical Education (Karle, 2010). Furthermore, the research results may constitute an early foundation for operationalizing the different dimensions/concept at the base of participatory care in future research. It can be used to identify gaps in the

measurement of this concept and eventually to develop new assessment tools to fill these gaps and overcome struggles within the measurement of it. This is a prerequisite for a paradigm shift towards a really participatory model of care, as such a shift needs to be evaluated and monitored. This can only be done by sound measurement tools. At the same time, such a shift needs a change of mind or attitude, as pointed out by the World Medical Association (Karle, 2010). This should be considered when implementing a participatory approach to health care in routine practice. Moreover, this work can contribute to the identification of ways in which changes in health care need to be addressed by changes in medical education.

This detailed overview on the academic debate around participatory care also provided some suggestions for detecting the its main dimensions and try to make clearer the boundaries of participatory medicine-related concepts. The definitions of all the terms strictly connected to this care approach (i.e. patient engagement, patient activation, patient involvement, patient participation, patient involvement and patient empowerment) clearly show the presence of specific characteristics and differences between apparently similar concepts. The indiscriminate use of all these terms reflects a lack of clarity of what healthcare systems need to do to achieve the important goal of putting patients at the centre of their care. The critical analysis of the literature in this topic shows that the role of patient into the health-care system is changing. As shown in chapter 1, in a doctor-centered model of care, the patient was conceived as a passive treatment recipient; whereas, today, there is a growing need to consider patients as active partners of healthcare planning and delivery. However, there is still a lack of a clear conceptualization able to translate this shift into clinical practice due to the plethora of terms used to refer to this topic.

We propose to consider the specific semantic role of these terms, because every term has a practical consequence in health-care practice and specific settings of application. To build a shared vocabulary of terms and concepts related to the active role of patients in the health-

care process may thus be envisaged as the first operative step towards a concrete innovation of health-care organizations and systems.

In this framework, the term patient engagement appears particularly promising, not only for its increasing growth of interest in the scholarly debate, but also because it offers a broader and better systemic conceptualization of the patients' role in health care. From this perspective patient engagement may offer theoretical as well as pragmatic insights to innovate organizational strategies aimed at improving the effectiveness and efficiency of health care. We suggest that these strategies should be able to face the current societal challenges, include a clear perspective on the patients' role into clinical practice, and consider different levels of sustainability and applicability (subjective, organizational, and economic). In order to concretely innovate healthcare in the direction of participatory medicine, it is fundamental to tide up the field of existing conceptualizations, and to built a shared and evidence based definition of patient engagement. The following chapter will be devoted to provide a systematic literature review on patient engagement in order to lay the ground for an empirical detection of the direct patient engagement experience in the context of chronic care (see Chapter 4).

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CHAPTER 3

Patient engagement in health management:
a systematic review
of current theoretical conceptualizations[3]

Engaging patients in their own healthcare is now widely acknowledged as a critical ingredient for high-performance health system as it may improve quality of care and reduce service delivery costs. However, despite the increasing debate about "patient engagement" (PE), outlined in the previous chapter as a new frontier in the field of participatory medicine, this phenomenon remains conceptually and empirically under-developed, often used as a synonymous of other terms such as patient involvement or patient participation.

In order to contribute to the conceptual foundation of PE and to make clarity among the scientific debate in this area, the aims of this study are twofold: 1) mapping the current trend of peer reviewed literature about "engagement" in health in term of time frames, disciplinary perspectives, countries more active in the debate, terms mainly used to connote individuals in the process; 2) detecting, comparing and synthesizing the main definitions that are currently orienting the literature debate, by casting light on theoretical gaps and suggesting potential lines for future research development .

The conceptualization of patient engagement is still vague and has changed over time, thus offering a fragmented and partial vision of this phenomenon. The current literature focuses alternatively on different and singular aspects of the patient engagement phenomenon while missing the whole picture of the elements that may hinder or facilitate patient engagement. Our results underline the urgency for a deeper understanding of what patient engagement means in order to develop knowledge useful for innovation both in clinical practice and health policy agendas.

This review suggested to look at "engagement" as an evolving concept that needs for a recover of an "ecological" foundation, mainly rooted in the deeper analysis of patients' perspectives, and finalized to provide insights about this process drivers at the individuals, relational, and organizational levels.

Key words: patient engagement, health management, systematic review.

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1. INTRODUCTION

As pointed out in the previous chapters, to manage these political challenges, healthcare is claimed to deeply revise and innovate their approaches, in the aim of really become patient centered and aligned with their clients' needs and expectations (Stewart, 2003).

With the emerging awareness that patients are crucial stakeholders in the management of their healthcare and medical decision making, the concept of patient engagement, among the others previously described in chapter 2, is increasingly recognized as having a primary role in improving quality and safety of healthcare interventions. Furthermore, patient engagement may contribute to achieve gold standards for healthcare and personal health experiences across the continuum of care (Coulter and Magee, 2003) .

While hospitals and healthcare systems have responded to the call for increased patient engagement, the number of terms and definitions used to describe and capture this phenomenon is growing in its variety thus making this concept generally under-defined. To address the need for a clarification of the engagement borders and to suggest a first tempt of foundation of this concept, in this contribution the authors aimed at critically discussing the extant literature on this topic and at providing a preliminary framework for a wider and more ecological foundation of the concept.

In this chapter, we shall move from the overview of current societal and economic issues that are challenging the healthcare system described in chapter 1, by claiming the urgency for a deep revision of medical paradigms, policies and practices. In this framework we shall discuss how the concept of patient engagement is nowadays addressed by scholars and practitioners as a potential driver of healthcare innovation and improvement.

In order to synthesize the current debate about patient engagement and to provide insights about futures priorities in the health policies agenda, we shall describe and comment on the results achieved by systematically reviewing the scholarly international literature on patient

engagement. We conclude the paper by underlining current gaps in the conceptual foundation of patient engagement and by proposing a conceptual reframing in order to plan a programmatic agenda regarding future lines of research in this area.

Having these premises in mind, the present study aimed at:

1) mapping the current trend of peer reviewed literature about patient engagement in term of time frames, disciplinary perspectives, countries more active in the debate, terms mainly used to connote individuals in the process;

2) detecting, comparing and synthesizing the main definitions that are currently orienting the literature debate, by casting light on theoretical gaps and preparing the ground for a theoretical foundation of the phenomenon of engagement thus suggesting a conceptual reframing in order to plan a programmatic agenda regarding future lines of research in this area.

2. METHODS

2.1 RETRIEVING PROCESS

Our search covered biomedical databases and other sources from January 2001 to May 2014: PubMed/Ovid MEDLINE; Ovid PsycInfo; SCOPUS. We first identified all the papers indexed as "patient "engagement": after having analyzed these contributions, we identified the words more frequently used as synonymous of "patient" when discussing about engagement. After having reached a consensus among the research team members, the search string was thus formulated as "patient engagement" OR "consumer engagement" OR "client engagement" OR "citizen engagement" in health. These words were then chosen to be included in the search string in order to collect the widest variety as possible of perspectives related to this concept in terms of both disciplinary and temporary trends. We chose to search articles which only included the terms "engagement" and not close concepts (i.e. participation

or involvement) in order to maximize sensitivity and conceptual clarity. The search was restricted to only peer-reviewed articles published in English and focused on the health research field (see Figure 1.3).

FIGURE 1.3. STUDIES' SELECTION PROCESS

100%

1286 potentially relevant references identified through the database search

Scopus: 811
PubMed/Medline: 455
Psychinfo: 20

Database cleaning to exclude dublicates → 200 records excluded

1086 records included

Title and abstract screening to select only contributes pertaining to health and considering engagement as the main topic of the contribution → 343 records excluded

58% **753** records included for bibliomentric analysis

Fulltext screening to select only contributes that defines/concepualize engagement → 737 records excluded

1% **16** full text selected and analyzed by qualitative in-depth analysis

2.2 SCREENING PROCESS

Three researchers (SB, GG, MS) were involved in selecting and reviewing the articles. Three steps of screening featured the review process: 1) a first step of title screening allowed to exclude duplicates; 2) a second step of title and abstract screening led to identify those studies that discussed engagement in the health research field and considered it as the main topic of the article. These studies were included in the sample for bibliometric analysis (N=753). 3) A third screening of full-texts led to exclude 737 records because the word "engagement" was not defined or conceptualized.

We finally identified a total of 16 core articles included for in-depth analysis and whose contents are described in table 3.3 and 3.4. These articles were selected as their authors provide in their articles an explicit definition of "engagement" as a specific concept not overlapped with other similar terms such as "involvement" or "participation".

2.3 ANALYSIS PROCESS

The analysis was conducted in two main steps.

1. Firstly a bibliometric analysis (Estabrooks, Winther and Derksen, 2004) on a sample of 753 contributions on different aspects of publications' trend (i.e. key words used; yearly trends of publication; disciplinary frameworks mostly orienting the literature) in order to cover the first aim of the study. The primary assumption supporting the use of bibliometrics is that the exchange and recognition of research evidences are both desired and a key driving force for the advancement of science. Descriptive bibliometric analysis of the retrieved sources was performed to analyze the quantitative trend of publications indexed with "patient engagement", "consumer engagement", "citizen engagement", "client engagement" related to the health research field - over the last 14 –years within the health research field - taking into

account the number of academic articles – excluded duplicates - provided by all the databases considered.

2. Secondly, the qualitative in-depth analysis on a selected pull of contributions (Mahmud, 2004; Davis, et al., 2007; Dearing et al., 2005; Mc Bride and Korczac, 2007; Dunston et al., 2009; Forbat et al., 2009; Hibbard, 2009; Gruman et al., 2010; Schley, 2011; Mulley, Trimble and Elwyn, 2012; Sanders and Kirby, 2012; Carman et al., 2013; Graffigna, Barello and Riva, 2013; Légaré and Witteman, 2013; Mittler et al., 2013; Patel and Rajasingman, 2013) was conducted to deepen the main features of the current definitions of "engagement" debated within the extant literature in order to cover the second aim of the study.

3. RESULTS

3.1 BIBLIOMETRIC ANALYSIS

As showed in figure 1.3, our search retrieved 1286 contributions indexed with the key-word engagement, thus testifying a global interest towards this concept. However, among them the ones that contextualize the word "engagement" in the health field and consider that as the central topic are only 753. The analysis also highlighted a growing trend of published sources over the considered period (see table 1.3). However the literature about engagement is multifaceted and are various the labels that are used to indicate the individuals who should engage in their health management. In particular, although the term "patient" is the most occurring in relation to engagement (N=367) and mainly linked to contributes published between 2005 to 2012, also other terms are frequently used. The strings "client engagement" (N=169) and "citizen engagement" (N=153), for instance, are quite frequent in the literature debate, although more dated, maybe because they refers respectively to the established lexicon used in the humanistic psychology paradigm (Cain, 2002) and in the sociological discourse about the collective benefits of public engagement (Carpini, Cook and Jacobs,

2004). It is notable that the string "consumer engagement" (N=64) is linked to a minor number of sources and mainly from 2005 with a significant increasing of contributions after 2006, such as testifying the introduction of a marketing perspective to frame the engagement concept in the last years.

TABLE 1.3: NUMBER OF PUBLICATION PER YEAR/BY KEY-WORD

Year	TOTAL	*"patient engagement"*	*"client engagement"*	*"citizen engagement"*	*"consumer engagement"*
	N	*N*	*N*	*N*	*N*
2001	2	1	1	0	0
2002	8	3	2	3	0
2003	11	3	3	5	0
2004	10	3	5	2	0
2005	16	5	6	5	0
2006	20	9	5	5	1
2007	27	10	10	5	2
2008	29	14	7	7	1
2009	51	21	10	17	3
2010	53	11	21	13	8
2011	80	34	19	22	5
2012	98	41	28	18	11
2013	135	73	23	25	14
2014	213	139	29	26	19
TOTAL	753	367	169	153	64
	(100%)	(48,7%)	(22,5%)	(20,3%)	(8,5%)

This heterogeneity of terms used to characterize engagement seems to be linked to the variety of disciplines 4 involved in the debate. Medicine is the most productive disciplines by covering the 49,4% of the entire corpus of publications on this theme, followed, in

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[4] Disciplinary fields are based on the Scopus database categorization which labels the research field of the journal publishing each considered contribution.

percentage, by social science (27,3%), psychology (9,4%), nursing (9,1%), health professions (4,1%) and decisional sciences (0,7%).

It is interesting to notice that different disciplinary fields show different preferences of terminologies to address "engagement": medicine, nursing and health professions mainly refer to the individuals as patients – according to a more traditional disease-related perspective (Bensing, 2000). Social sciences mainly mark individuals as citizen thus conveying a critical view of how medical treatment, healthcare finance, and attitudes about health, medicine, and disease play out in broad social and political settings which people are actively engaged in. On another side, psychology tends to define individuals as client, probably in line with therapeutic approaches in which this term was developed to signify a rejection of a medical way of thinking, replacing it with the humanistic language of growth and change. Finally, decisional sciences (such as economics, statistic, mathematics) seem not to have a specific frame of reference when debating about engagement as showed by the scarcity of contributions on this topic. For more detailed data, see table 2.3.

TABLE 2.3. NUMBER OF PUBLICATION ACCORDING PER YEAR/PER DISCIPLINARY FIELD

DISCIPLINARY FIELD	KEY WORDS				
	"consumer engagement"	*"patient engagement"*	*"citizen engagement"*	*"client engagement"*	*Total*
Medicine	39	255	12	66	372
Nursing	9	44	1	14	68
Social Sciences	9	25	132	40	206
Psycology	3	24	4	40	71
Health professions	2	19	1	9	31
Decisional sciences	2	0	3	0	5
Total	64	367	153	169	753

3.2 QUALITATIVE IN-DEPTH ANALYSIS

Among the sample of 753 contribution retrieved through the search string, only 16 papers (1% of the total sample) explicitly give a definition of engagement conceived as a specific concept and not as a synonymous of other more established terms (i.e. involvement, participation, etc.; for a more detailed discussion of different ways to conceive the word engagement in the literature debate, see Barello et al. 2014). However the in-depth critical analysis of these papers illuminated that the definitions provided are partial and various, particularly in regards to the constitutive drivers of engagement addressed. In particular, these contributes can be grouped in two categories that respectively refer to "engagement" as a function of INTRA-individual factors (i.e. emotive, cognitive of behavioral aspects of the patient's experience) or INTER-individual ones (i.e. dyadic interactions between patients and

healthcare providers, multiple and systemic interactions among patients and with their reference healthcare settings).

- Engagement as a function of INTRA-individual factors. These contributions (n=5, see Table 4) were published in the most recent years (between 2009 and 2013), are indexed with the words "patient engagement" and "consumer engagement" and are mainly signed by researchers belonging to the medical disciplinary field. They mainly focus on only one or two intra-individual factors recognized as having a role in shaping engagement, more often with exclusive reference to the cognitive (Legaré et al., 2013; Mittler et al., 2013) or behavioral (Gruman *et al*., 2010) components of the engagement experience. Generally these papers defect in recognizing the role of emotional factors in the engagement process, in line with a lack of a psychological reflections in this area. Only two contributes (Hibbard, 2009; Graffigna, Barello and Riva, 2013, c) propose a more comprehensive conceptualization of patient engagement which jointly consider emotional, cognitive and behavioral elements of this experience.

- Engagement as a function of INTER-individual factors. On the other side, some contributions (N=11) mainly describe engagement as function of inter-individual factors. Among the contributions that describe engagement as function of dyadic relationships, some of them (N=5) focuses on the patient-physician relationship, considered the main context in which "engagement" develops; in particular these authors narrow the concept of engagement within the domain of shared decision making (i.e. Davis *et al.*, 2007; Mulley, Trimble and Elwyn, 2012). Other contributions (N=6), suggest a broader vision of inter-individual factors at the basis of engagement, in particular focusing on the role of complex network of peer-to-peer exchanges (i.e. Dunston *et al.*, 2009) and on the dialogue between

the citizen and the healthcare system conceived as a whole (Mahmud, 2004, Mc Bride and

Korczak, 2007).

TABLE 3.3 INTRA-INDIVIDUAL DEFINITIONS OF "ENGAGEMENT"

Author(s), year	Definition of "engagement"	Disciplinary field	Key-word	*LEVEL OF INTRA-INDIVIDUAL FUNCTIONING*			On/off definition vs processual definition
				emotional	behavioural	cognitive	
Hibbard et al., 2009	Patients' **motivation, knowledge, skills, and confidence** to make effective decisions to manage their health	Medicine	Consumer "engagement"	X	X	X	Processual
Gruman et al., 2010	**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.	Medicine	Consumer "engagement"		X		Processual
Graffigna et al., 2013	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 phases (disengagement, arousal, adhesion and eudaimonic project). The unachieved synergy among the different subjective dimensions (think, feel, act) at each stage of the process may inhibit patients' ability to engage in their care	Psychology	Patient "engagement"	X	X	X	Processual
Légaré et al., 2013	["engagement" is] the process of **individuals' responsabilization that ensures that clear information lead to the best decision** for the person who is seeking the care thus improving self-management	Medicine	Patient "engagement"			X	On/off
Mittler et al., 2013	Engaging **consumers refers to the performance of specific behaviors ("engaged behaviors") and/or an individual's capacity and motivation to perform these behaviors ("activation")** aimed at gaining health	Medicine	Consumer "engagement"	X			On/off

TABLE 4.3. INTER-INDIVIDUAL DEFINITIONS OF ENGAGEMENT

LEVEL OF INTER-INDIVIDUAL FUNCTIONING

Author(s), year	Definition of "engagement"	Disciplinary field	Key-word	Dyadic exchange	Multiple exchange	On/off definition vs processual definition
Mahmud, 2004	It is **a process that led to set healthcare priorities**. It consists in empowering people to provide input in decisions that affect their lives encourages support for those decisions, **which in turn improves the public's trust and confidence in the healthcare system**.	Social sciences	Citizen "engagement"		X	On/off
Dearing et al., 2005	Developing "engagement" means to foster those **client-therapist working alliance** that help the client gain a more realistic understanding of the nature, process, and expected outcomes of treatment.	Medicine/ Psychology	Client "engagement"	X		On/off
Davis et al., 2007	Option for patients to be informed partners in their care, **including a recasting of the care relationship where clinician enact the role of adviser, and patients or designated surrogates** for incapacitated patients serving as the locus of decision making.	Medicine	Patient "engagement"	X		On/off
Mc Bride et al., 2007	It is a process that will allow, at different level, the **wider community to have a say in the future direction of their health** .	Medicine	Citizen "engagement"		X	On/off
Dunston et al., 2009	**Dialogic and co-productive partnership between health system, health professionals and citizen/health consumers** through which these actors become co-productive.	Social sciences	Consumer "engagement"		X	On/off
Forbat et al., 2009	[engage patients means] **working in partnership with service-users** having them inform (i) service redesign/improvement, (ii) policy, (iii) research and (iv) their own care/treatment. It also implies balancing powers among patients and health providers.	Medicine	Patient "engagement"		X	On/off
Schley et al., 2011	Engaging client in the therapeutic encounter means **develop collaboration, perceived usefulness, and client -therapist positive interaction**.	Medicine/ Nursing	Client "engagement"	X		On/off
Mulley et al., 2012	Process of **shared decision making** described as a sequence of three types of conversation: team talk, option talk and decision talk. [engaging patients] means to **create a preference diagnosis which have a unique profile of risks, benefits and side effects**.	Medicine	Patient "engagement"	X		On/off
Sanders et al., 2012	A **collaborative, bidirectional process whereby patients' knowledge and experience is shared in a dialogue with program developers**, health **practitioners and researchers**. It involves actively harnessing the consumer's voice to strengthen the quality, relevance and effectiveness of an intervention.	Psychology	Consumer "engagement"		X	On/off
Carman et al., 2013	**Shared power and responsibility among the actors of the care process** where (i) patient becomes active partner in defining agendas and making decision; (ii) the information flow is bidirectional; (iii) patients act also as representative of consumer organizations.	Medicine	Patient "engagement"		X	Processual
Patel et al., 2013	the [engaged] patients have the ability to balance clinical information and professional advice with their own needs and preferences. It is a **collaborative approach where shared decision making, equal distribution of power and exchange of clinical information** are enacted.	Medicine	Patient "engagement"	X		On/off

Independently from the level of the "engagement" drivers detected, the majority of papers (N=12) (Mahmud, 2004, Dearing et al., 2005; Davis et al., 2007; Mc Bride and Korczak, 2007; Dunston et al., 2009; Forbat et al., 2009; Schley et al., 2011; Mulley, Trimble and Elwyn, 2012; Sanders and Kirby, 2012; Légaré and Witteman, 2013; Mittler et al., 2013; Patel and Rajasingman, 2013) tend to provide a simplified and superficial definition of engagement such as an on/off status, rather than as a process. In other terms, the majority of authors consider individuals as engaged or not, without problematizing possible subsequent phases or gradients of the engagement experience. Moreover, the majority of contributes do not attempt to provide a theoretical foundation of the dimensions involved in the experience of "engagement" and of their logical and/or causal relationship, a part from the following four exceptions.

Hibbard and colleagues (2009) describe engagement as "*the patients' motivation, knowledge, skills, and confidence to make effective decisions to manage their health*". This framework starts from the consideration that level of engagement may affect individuals healthcare choices and disease daily management thus having an impact on healthcare utilization, costs and clinical outcomes. Four gradients of engagement have been identified by these authors, although they are not deeply featured at the psycho-social and clinical level. Furthermore, also in this case, the conceptualization lacks in providing a process-like explanation of the dynamicity that governs the increase of patient engagement.

Gruman and colleagues (2010) for instance, describe engagement as a set of behaviors and actions that allows individuals to effectively manage their health and healthcare in order to obtain the greatest benefits. This definition emphasizes the role of individuals in shaping their behaviors in order to interact in the best way as possible with the healthcare, but appears merely taxonomic and do not offers cues about dynamics occurring when individuals engage

in their health. Moreover, this proposal fail in reducing the concept of engagement to its sole behavioral manifestations.

Carman and colleagues (2013) provide a more dynamic conceptualization of engagement, featured as a continuum of possible interactions between the patients and the healthcare system (i.e. from "consultation" to "partnership" to "shared leadership"). This definition of patient engagement has the indubitable strength of considering engagement as a systemic phenomenon, which is the outcome of actions carried out at different levels of complexity (i.e. individual, relational, communitarian, organizational and health policy). However, also this conceptualization is insufficient since it reduces the "engagement" process to merely the behavioral/conative dimensions of the patient experience and since it doesn't explain what are the dimensions that may sustain or inhibit the passage from one stage to the other of the continuum.

Finally, Graffigna and colleagues (2013) define engagement 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 phases (i.e. "blackout", "arousal", "adhesion" and "eudaimonic project")"*. In their conceptual framework, these authors discuss engagement as a process and they psychologically describe its different phases. However also this model appears weak in explaining the dynamic passage from one to the other phase of the process. Furthermore it lacks in devising the contextual and organizational elements that may sustain or inhibit the patient engagement process.

4.DISCUSSION AND CONCLUSIONS

As pointed out in chapters 1 and 2, we are well aware that the increasing aging society and the multiplicity of emerging people health needs are making urgent a deep revision of medical paradigms. Policymakers and healthcare providers, thus, increasingly believe that encouraging patients to play a more active role in their health care could improve quality, efficiency, and healthcare outcomes. But critics have noted that talking about patient engagement is often a political correct claim more than a scientific discourse grounded in research evidences.

In order to lay the ground to research lines aimed at giving scientific based to the concept of engagement, this paper provides a critical review of the engagement conceptualizations that are currently orienting the debate in the healthcare research. The increasing interest towards this concept is testified by the growing number of contributions indexed with the term patient engagement in the last thirteen years. However, a significant and wide variations in the conceptualizations of engagement emerged, thus illuminating the lack of a shared theorization. As a matter of fact, the present literature debate about engagement mainly tend to an "ecolalic" evocation of the phenomenon, failing in defining and modeling it. In other words, debating about "engagement" often assume the flavor of a rhetorical positioning, rather than of a conceptual foundation. Moreover the lack of a clear and established definition of engagement in its features and boundaries is testified by its frequent overlapping (and misplaced) with other traditional and broader concepts such as "involvement", "participation", "activation" (Gruman et al., 2010; Barello, Graffigna and Vegni, 2012). The vagueness of patient engagement definitions is also amplified by the multiplicity of terms used to connote individuals when engaged in their health (i.e. patient, consumers, client, citizen…), thus testifying different traditions and sensibilities on this concept. For instance,

some authors (i.e. Davis et al., 2007) mainly conceive individuals from a medical perspective thus defining them as patient and valuing their role at the clinical level as the their engagement may improve the quality of the relationship with healthcare providers, enhance treatment adherence and gain better clinical outcomes. Other scholars (Dunston et al., 2009; Schley et al., 2011; Sanders and Kirby, 2012), instead, perceive individuals as "consumers" or "clients" – basing on an marketing vision of healthcare - thus recognizing the importance of engage them in order to reduce healthcare costs and improve their satisfaction towards the received services. Finally, other ones mainly see the individuals as "citizen" (Mc Bride and Korkzac, 2007) thus conveying the crucial role of them in dialoguing with the healthcare systems in order to achieve a real democratization of healthcare. In other words, the analysis of the ongoing literature debate about patient engagement offers a fragmented definition of the engagement concept, often partial and "idiosyncratic", depending on the authors knowledge anchorages and disciplinary traditions. This variations of perspective also suggests that the phenomenon of "engagement" is multifaceted, thus needing a more systematic analysis and foundation, up to now not accomplished yet.

Authors mainly provide a simplified vision of patient engagement nature thus providing definition that conceive it as an on/off status, and thus fail in clarifying its progressive development in time. Only few authors attempt to build a theoretical framework to better connote the engagement phenomenon, that, however, are not holistic description of the phenomenon and that are not fully able of identifying the elements that play a driving role in the process of engagement.

This scares soundness of "patient engagement" definitions seem also to be function of the scarce examination of the patients' perspective. Our results highlighted that the "voice of patients" in defining what engagement is and what may favor it are still absent in the literature debate, thus suggesting the need for more research focused on the patients' care experience.

Basing on these results, we suggest to look at engagement as an evolving concept that needs for a recover of an "ecological" foundation in order to give insights about its dynamic nature and about its drivers at the individuals, relational, and organizational levels (see figure 2.3 for a diagram of possible implied levels in the engagement process). We believe that a re-uptake of a subjective and experiential perspective which values the direct voice of patients involved in the process of engagement could allow to build a really grounded foundation of the concept of engagement. Furthermore, this can help in drafting guidelines for planning interventions able to foster engagement at the different phases of the patient experience. More efforts should also be oriented to unveil the role of cultural and contextual factors in shaping patient engagement in their reference healthcare systems. To not adequately recognize the influence of culture on the patient engagement experience may lead to the mistaken assumption that patient engagement interventions developed in one country can be transferred to another simply using the same clinical protocols and guidelines.

Given the actual state of the literature debate, the path to reach a sound and shared conceptualization of engagement is still at its beginning. However, although the under-developed state of the literature around this topic and the consequential lack of clarity around the concrete meaning and operative strategies for engaging patients in their health, the contextual contemporary call for a participatory healthcare aimed at constructing beneficial outcomes both for patients and the whole society, imposes multidisciplinary and cross-national joint research efforts to be successful in this important endeavor. In this frame, the role of psychology has to be considered central in orienting research lines towards a systematization of the plethora of concepts related to the active role of patients in their health. Up to now, indeed, there is not clarity not only pertaining the concept of engagement, but also as to regard other more renowned constructs such as involvement, participation, empowerment. Indeed, we can observe a fragmentation in their conceptualization that

depends on the theoretical background that has led authors to conceptualize them. On this basis, in order not to risk to making the active role of patients a mere "fashionable claim" we hope for a deeper integration both among disciplines and paradigms in order to really addressing the patients' increasingly willingness to participate in decisions that affect them and their demand for higher-quality standards in the delivery of healthcare services. Moreover, research on the direct patient experience specifically devoted at detecting their perspective on the engagement phenonomenon should be desirable to promote an evidence-based modeling useful to fill the gap between theory and practice. With this aim, chapter 4 will try to address this gap and will provide a first tempt in this direction.

FIGURE 2.3 PATIENT ENGAGEMENT: A PROPOSAL FOR A FRAMEWORK FOR UNDERSTANDING THE CONSTITUTIVE ELEMENTS AND DEVELOPING RESEARCH AND INTERVENTIONS

Socio-cultural and economic context

(i.e. social norms; cultural scripts; political and istitutional conditions, economic situation, cultural barriers; recognition of the social determinants of health…)

Health Systems /Healthcare Organizations

(i.e. organizational structure/culture; roles and teams implied in the patient management; infrastructures; coordination and integration of care across clinical, ancillary, and support services and in the context of receiving "frontline" care.…)

Healthcare providers

(i.e. professional skills; communication skills; listening attitude; decision support; …)

Productive Communication and Relationship

(i.e. Respect for patient-centered values, preferences, and expressed needs; sensitivity to nonmedical and spiritual dimensions)

Patient

(i.e. emotional, cognitive and behavioural dimensions of the engagement experience;…)

Community resources and policies

(i.e. peer networks; lay exchanges; social groups; norms and cultural habits; involvement of family and friends in decision-making and awareness and accommodation of their needs as caregivers; Information and linkages with community to reduce no-shows and help patients achieve self-management goals

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PART III

PATIENT ENGAGEMENT: TOWARDS A CONCEPTUAL FOUNDATION, ITS RELEVANCE AND IMPLICATIONS FOR INTERVENTIONS

As discussed in the previous sections, engaging patients in healthcare is recognized to be essential in order to improve outcomes for patients affected by chronic conditions which require long-term treatments and continuous interactions with the healthcare services. It is also vital when it comes to respecting a person's right to self-determination and meeting legal aspects of care.

However, there is a lack of agreement about the meaning of this concept and no research has been devoted to detect the direct patients' experience about being involved in their healthcare and medical course.

In chapter 4 we return to questions originally posed in the sections 1 and 2 which were aimed at reviewing the distinct contributions and insights afforded by the current academic literature on patient engagement in this dissertation. These questions are: what does it mean patient engagement? What are the facilitators and barriers of patient engagement?

In providing some answers to these questions, we will present the results of a two-year long grounded theory research aimed at deepening the patient engagement experience and at providing an evidence-based model of this phenomenon. This in-depth and context-based research intended to offer some insights and reflect upon the multi-faced nature of patient engagement starting from detecting the experience of whom we consider the "*crux of the matter*" of this complex phenomenon: that is the patient. Moreover, we know that patient engagement is particularly relevant among patients suffering from chronic illness. In this study we deliberately chose to focus on patients affected by heart failure which could be conceivable as a prototypical condition among the chronic disease.

We maintain that a better understanding whether factors are associated with patient engagement among patients with heart failure can be insightful for improving care in this and in other chronic fields with the appropriate adaptations linked to the specific characteristics of the care pathways which are unique for each chronic condition.

- CHAPTER 4 -

"Engage me in taking care of my heart": a grounded theory study on patient-cardiologist relationship in the hospital management of heart failure.[5]

In approaching the study and practice of heart failure (HF) management, authors recognize patient-doctor relationship to have a central role in engaging patients in their care.

This study aims at identifying the features and the levers of HF patient engagement and suggestions for orienting the relational dynamics occurring in the clinical encounters.

Using a grounded theory approach and following the theoretical sampling principles, we conducted 22 in-depth interviews (13 HF patients, 5 physicians and 4 caregivers). Data were collected and analyzed using open, axial, and selective coding procedures. All interviews were conducted in a university hospital located in a metropolitan area of Milan, Italy. Patients aged ≥18 years with New York Heart Association (NYHA) Functional Class of II or III were eligible to take part. Patients were recruited primarily through their referral cardiologist.

HF patient engagement process develops in four main phases that are characterized by different patient's emotional, cognitive and behavioral dynamics that contribute to shape the process of patient's meaning making towards health and illness along their care. The emerging model illustrates that HF patient engagement entails a meaning making process enacted by the patient after the critical event. This implies patients' ability to give sense to their care experience and, to their disease, symptomatology and treatments and their changes along their illness course. Successful patient engagement may also be related to a positive shift in the ways in which patients perceive self and life and experience empowerment to realize their life potential, thus improving quality of life (QoL). Moreover, patient engagement is a powerful concept capable of reflecting significant psychosocial changes that promote patient QoL along the care process. There appears to be theoretical and empirical justification for a broad definition of QoL.

Doctors are recognized as crucial in fostering patients engagement along all the phases of the process as they contribute to provide patients self-continuity and to give new meaning to their illness experience and promote patient's QoL.

Keywords. Patient engagement; grounded theory; chronic care; heart failure; patient-doctor relationship

1. INTRODUCTION

Heart failure (HF) affects about 2% of the Western population, with the prevalence increasing sharply from 1% in 40-year-old individuals to 10% above the age of 75 years (Guha & McDonagh, 2013). HF is a complex clinical syndrome of symptoms that suggests impairment of the heart as a pump supporting physiological circulation. Over recent decades the capacity of health professionals to address the burden of HF has increased through the introduction of novel pharmacological agents, technological devices and non-pharmacological strategies (Krum & Abrham, 2009). However, these treatments are often complex and require infrastructure and support to promote adherence and optimize patients' health outcomes. This fact makes the patients' capacity to effectively engage in their care a crucial factor for obtaining positive health outcomes and reduce cost of care. Optimal outcomes and quality of life for patients with heart failure depend on engagement in effective self-care activities (Evangelista et al., 2008; Zambrosky, 2003; Rogers et al., 2000). Literature suggests that high-quality doctor-patient relation have been linked to higher levels of patient compliance with treatment plans, enhanced self-management of disease, greater recall of important treatment information, and improved general mental and physical health status (Jerant, 2014). Studies (Rogers et al., 1999; Alexaner et al., 2012) have showed that the ability of doctors to engage patients in effective care relationship is likely to make a difference in whether the consultation reinforces or discourages health actions that will maximize a HF patients' capacity to live positively with a chronic condition. Thus, the failure of health professionals to engage patients as effective and skilled self-managers of their health can lead to poor clinical outcomes (Alexander et al., 2008). Self-care is a complex set of activities and unfortunately most clinicians are not adequately prepared to assist their patients to engage in effective self-care (Moser et al., 2012). Although pockets of excellence exist in HF management and there is a growing consensus that engaging patients is an essential component to the successful

management of heart failure (Buck et al., 3012; Seto et al., 2011; van der Wal et al., 2006; van der Wal et al., 2010; Wang et al., 2011; Lee et al., 2011), significant heterogeneity emerges in defining HF patient engagements' goals and how to achieve them. In order to optimally manage their condition patients with heart failure need a good knowledge of their condition, its typical symptoms and the significance of any changes in their symptoms (Zambroski, 2003). In addition patients need to understand the purpose and likely side effects of their drug therapy. Furthermore, living with heart failure is recognized to have physical, emotional, cognitive, social, and vocational consequences that affect the patients adjustment to the illness (Europe et al., 2004). Adjusting to the illness involved changing one's lifestyle, being aware of one's physical ability and disability, developing coping strategies, and adjusting to medication (Buetow et al., 2001). Failure in patient doctor relational quality might impair patients self-management skills as well as their promptness in seeking medical treatment in the light of changing symptoms, and might be the cause of the patients' lack of compliance to the healthy diet and drug therapies prescribed (Yu et al., 2008). A recent review showed that when patients experienced poor quality of care they reported lack of confidence in care providers, confusion, delays in seeking care and were deterred from maintaining positive self-care practices (Jeon et al., 2010).

Furthermore, unless the acknowledgment of the crucial role of health providers in fostering patient engagement in healthcare (Field et al., 2006; Evangelista et al., 2008), currently no study was deemed to explore the perspective of HF patients when engaging in their health management and what is the role of their doctors in this process. Surprisingly, the extant scientific literature on this topic highlights an absence of the "direct voice" of HF patients about their health engagement experience. Moreover, studies aimed at discussing patient engagement mainly involve patients with chronic diseases (i.e. diabetes, hypertension, asthma) that are not featured by frequent episodes of exacerbation and acute symptoms

leading to recurrent hospitalization such as HF. Those studies don't provide evidences about the levers that allow patients to effectively advance in the process of engagement with their disease management.

In the present research we aimed at investigating the features of the engagement process in the case of HF patients that constitute a prototypical clinical population in the field of chronic care, characterized by an unexpected acute event that has a deep impact on the patients identity and emotional response. On these basis, this study was aimed at investigating the levers of the HF patient engagement process and, in particular, which features of the patient-doctor relationship are needed to enhance it.

2. METHODS

The study was qualitative in its nature and designed according to the methodology of Grounded Theory (Charmaz, 2006; Bryant & Charmaz, 2007). GT is a qualitative research methodology aimed at developing theoretical explanations of emerging psycho-social phenomena grounded into data (Corbin & Strauss, 2008). In this study, it was essential to understand how the process of HF patient engagement evolves and which dynamics – specifically related to the patient-doctor relationship – may foster it. Grounded Theory generates in-depth and context-based knowledge from the participants' unique perspective, informing the development of tailored and context-based interventions, which may, in turn, be more likely to lead to successful and sustainable programs. Our study report conforms to COREQ criteria for reporting qualitative research (Tong et al., 2007). For major details regarding the fundamental components featuring grounded theory studies see table 1.4.

TABLE 1.4 MAIN FEATURES OF A GROUNDED THEORY STUDY

COMPONENT	STAGE	DESCRIPTION
Openness	*Through the study*	GT emphasies inductve analysis. Induction moves from the particular to general: it develops new theories of hypothesis from many observations. GT studies tend to have a very open approach to the process being studied.
Analyzing immediately	*Analysis and data collection*	In a GT study, the researcher do not wait the data are collected before starting analysis. In Gt studies analysis should start as soon as possible, and continue in parallel with data collection.
Coding and comparing	*Analysis*	Data analysis relies on coding - a process of breaking data down into much smaller components and labelling those components - and comparing -comparing data with data, case with case, event with event, code with code, to understand and explain variation in the data. Codes are eventually combined and related to one another - at this stage they are more abstract, and are referred to as categories or concepts.
Memo writing (and drowing diagrams)	*Analysis*	The analyst writes many memos throughout the project. Memos can be about events, cases, categories, or relationships between categories. Memos are used to stimulate and record the analysts' developing thinking, including the comparisons made.
Theoretical sampling	*Sampling and data collection*	Theoretical sampling is central to grounded theory design. A theoretical sample is informed by coding, comparison and memo-writing. Theoretical sampling is designed to serve the developing theory. Analysis raises questions, suggests relationships, highlights gaps in the existing data set and reveals what the researchers do not yet know. By carefully selecting participants and by modifying the questions asked in data collection, the researchers fill gaps, clarify uncertainties, test their interpretations, and build their emerging theory.
Theoretical saturation	*Sampling, data collection and analysis*	Qualitative researchers generally seek to reach 'saturation' in their studies. Often this is interpreted as meaning that the researchers are hearing nothing new from participants. In a grounded theory study, theoretical saturation is sought. This is a subtly different form of saturation, in which all of the concepts in the substantive theory being developed are well understood and can be substantiated from the data.
Production of a substantive theory	*Analysis and interpretation*	The results of a grounded theory study are expressed as a substantive theory, that is, as a set of concepts that are related to one another in a cohesive whole. As in most science, this theory is considered to be fallible, dependent on context and never completely final.

2.1 STUDY SETTING AND PARTICIPANTS

Theoretical sampling was used both in the recruitment of participants and in data collection (Mills et al., 2006). Theoretical sampling allows researcher to progressively recruit subjects according to the emerging evidences in order to collect insights to corroborate those findings. According to this sample strategy, a patients with differing experiences of heart failure (basing on their functional class, risk factors and time from diagnosis) and with different attitude to their health management (basing on the level of patient activation according to the Patient Activation Measure score obtained in the screening phase, see Hibbard, 2005) were involved. Theoretical sampling guided the selection of further participants and led to involve some hospital cardiologists and caregivers in order to collect further insights to corroborate the results emerging from the patients' sample. Heart failure is a complex problem, with a high rate of treatment failures and re-hospitalizations, and therefore is more optimally managed with the guidance of specialists, we decided to interview hospital cardiologists. Moreover, data emerging from the patient's interviews showed the pivotal role of public hospital cardiologists for the patients involved in the study. GP are mainly consulted for general health advices and not for specialized consultations. We stopped sampling when we reached data saturation that is when no new emergent themes were generated from interview data (Bennet et al., 2002). Patients were recruited among hospital ambulatory out-patient, in an Italian university hospital on the basis of the following inclusion criteria: 1) hospitalized with HF at the recruitment site; 2) New York Heart Association (NYHA) Functional Class of II or III (Miller-Davis et al., 2006) at least six months before the time of recruitment; 3) able to speak and understand Italian. Exclusion criteria were (1) age below 18 years, (2) cognitive impairment based on a MMSE (Cummings, 1993) score of greater than 24 and (3) impaired vision or hearing, as documented in the medical record or by observation, such that neither an

interview nor completing written forms was possible. The hospital cardiologists who accepted to collaborate to the study were specifically asked to identify more able patients in self-management (NYHA functional class II or III) as we would like to collect successful stories of patient engagement in order to better understand the factors that foster or hinder them to effectively engage in their care. They were also requested to ask the patients whether they would participate in an interview. If the patient agreed, the researcher would then give the patient more information about the study, reassure the patient that all participation was voluntary, and ask for a written informed consent. In order to avoid the potential stress of the hospital environment, the interviews took place in a university office within the university hospital were the study was conducted. The Patient Activation Measure (Hibbard et al., 2005) was administered to each patient that accept to be involved in the study to assess his level of activation towards his/her health and healthcare. Patient Activation Measure is is a 13-item measure that assesses the patient knowledge, skill, and confidence for self-management. It is a valid and reliable instrument tested also in the cardiological field.

This measure allows to build a sample basing on different levels of patient activation to collect a wide range of patient engagement experiences. These differences were taken into account to build the conceptual model emerging from this study.

Physicians were recruited in the same hospital where the research took place. To be included they had to: 1) be experienced in caring for patients with cardiovascular diseases; 2) have at least 3 years of clinical experience in this clinical field. Caregivers were purposively selected basing on clinicians' suggestions. To be included caregivers had to: 1) be the primary caregiver of a HF patients; 2) for at least 2 years since diagnosis in order to be sure collect informative experience of caregiving. All participants provided informed consent after that the purpose of the study was thoroughly explained. The institutional review board of the San Paolo University Hospital (No. 12904) approved this study.

2.2 DATA COLLECTION

Interviews took place at the site of recruitment in a university office and were collected from October 2013 to February 2014. Interviews, which were audio taped with the participants' permission, were semi-structured and lasted in average 45 minutes. Researcher didn't previously know the participants of the study both patient and doctors/caregivers. In line with the iterative nature of grounded theory, data collection and analysis occurred concurrently (Charmaz, 2006). Interviews were transcribed verbatim, read/re-read and analyzed throughout the course of the study. During the data collection process, the interview guide became progressively focused so that concepts constructed from data analysis could be pursued and ideas explored (Table 1).Integrative diagrams and memos were also written throughout the process in order to better illuminate data analysis. Demographic (gender, age, marital status and socioeconomic data) and clinical information (NYHA functional status, time from diagnosis, risk factors for cardiovascular disease) were also collected. A psychologist expert in qualitative methods (SB) conducted in-depth interviews to elicit patient's extended narratives about their illness journey, their ways of coping with heart failure, their health engagement experience and the role of professionals and informal caregiver in sustaining it (see Table 2.4). According to the theoretical sampling strategy, the interviews from the patients leads to selection of other participants – such as cardiologists and caregivers - based on the problems that are unveiled through the progress of the research process. Cardiologists and caregivers were asked to discuss data emerging from the patients' interviews and to describe in their perspective what does it mean patient engagement in healthcare and what factors may hinder or foster its realization.

TABLE 2.4 INTERVIEW GUIDE FOR PATIENTS

Content areas	Questions
Living with heart failure	1. Please, can you describe me your illness journey from the diagnosis up today 2. What are, if existed, the main events that features your illness journey?
Coping with heart failure	3. Overall, how well do you feel and think you are able to manage your failure?
Heart failure and Quality of Life	4. What are your difficulties in managing your disease and the medical prescriptions to cure it? 5. How does your health condition impact your QoL? 6. Has your QoL changed since your diagnosis? 7. What does QoL mean to you at this moment?
The patient engagement experience	8. Please tell me, in your own words what does it mean for you being engaged in your care? 9. What are the factors that, in your experience, may facilitate or hinder your involvement in medical decisions and disease management? 10. What are the features of the relation with your physician that facilitate your engagement? 11. What is the role of your family/informal network in supporting you in being more active engaged in you care? 12. What kinds of support and resources would be most helpful to support your engagement with your care?

2.3 DATA ANALYSIS

Data analysis was independently conducted by two researchers (SB, GG) and took place alongside data collection, to allow a progressive focusing of interviews and testing of tentative hypotheses. Integral transcripts were analyzed according to the procedure of constructive Grounded Theory (GT) analysis (Charmaz, 2006). Grounded Theory requires three sequential phases of coding: a first analysis step named "open coding" that implies a preliminary identification of concepts that fit with data; a second analysis step, named "axial coding", that consists in the progressive aggregation and condensation of codes into broader

categories; a final analysis step -"selective coding" - consisting in the abstraction from data and in the interpretive detection of connections among categories in order to find the "core category"(i.e. the pivotal concept that articulates the whole process under investigation) (Charmaz, 2006). Diagrams and memos written along the data collection were also analyzed according to the Grounded Theory principles and contribute to build the emerging theory. The complex and systematic featuring GT coding procedure was aimed at describing the elements implied in the development of the patient engagement experience. Data analysis was assisted by the computer package QSR NVivo 10 (Gibbs, 2002) that allowed the systematic treatment of data, keeping explicit track of all coding steps. NVivo 10 allowed the researchers to build a theoretical model of HF patient engagement by exploring and statistically weighting associative connections among emergent categories. Integrative diagrams and memos collected throughout the process were used to guide thinking and three of the authors (SB, GG and EV) had several meetings to discuss their analytical insights and interpretations. After iterative discussion over many weeks between SB, GG and EV, a consensus on themes was finally reached. Two cardiologists not included in the interviews were finally asked to review the clinical coherence and relevance of emergent themes as key informants (Morse et al., 2002).

3. RESULTS

22 interviews were collected. 13 patients were recruited. Their mean age was 68 years (range 54–85). Six lived alone and presented risk factors for developing cardiovascular diseases. Other interviews were addressed to 5 physicians experienced in managing cardiovascular diseases and 4 caregivers involved in supporting a cardiac patient in managing his/her own

care (see Table 3.4 for a detailed account of the final sample). None of the potential participants refused to be involved in the study.

TABLE 3.4 SAMPLE CHARACTERISTICS

Patients N=13		
	Male N=9	Female n=4
Age		
Under 65 years	5	1
65-74 years	3	2
75-84 years	1	1
NYHA functional status		
II	6	4
III	3	0
Time from diagnosis		
6-12 months	3	1
1-4 years	3	1
5-10 years	2	2
11-20 years	1	0
Risk factors		
Hypertension	1	1
Heredity	3	0
Hypercholesterolemia	0	1
Low physical activity	1	1
Obesity	1	0
Smoking	1	0
Multiple risk factors	2	0
Level of Patient Activation		
1	1	0
2	3	1
3	3	1
4	2	2
Marital status		
Married	7	3
Living alone	2	1
Annual family income		
Up to € 20000	3	1
€ 20000 – € 50000	5	2
More than € 50000	1	1

Physician N=5		
	Male N=3	Female n=2

Age

	Male N=3	Female n=2
Under 40 years	1	1
40-60 years	2	1

Professional experience (years)

	Male N=3	Female n=2
6-10	1	1
>10	2	1

Caregivers N=4		
	Male N=3	Female n=1

Age

	Male N=3	Female n=1
Under 50 years	1	0
50-80 years	2	1

Status

	Male N=3	Female n=1
Partner	2	1
Son	1	0

3.1 COPING WITH HEART FAILURE: PATIENTS' TRAJECTORIES IN CRITICAL EVENT RESPONSES

Heart failure (HF) and its treatments were described by patients as having a large impact on their quality of life (QoL) and illness adjustment strategies. In the patients' perspective, coping with HF, is a complex process that consists of six sequential experiential phases (Figure 1.4).

FIGURE 1.4 THE PATIENT'S ADJUSTMENT PROCESS AFTER THE CRITICAL EVENT

The patient's reaction after the critical event
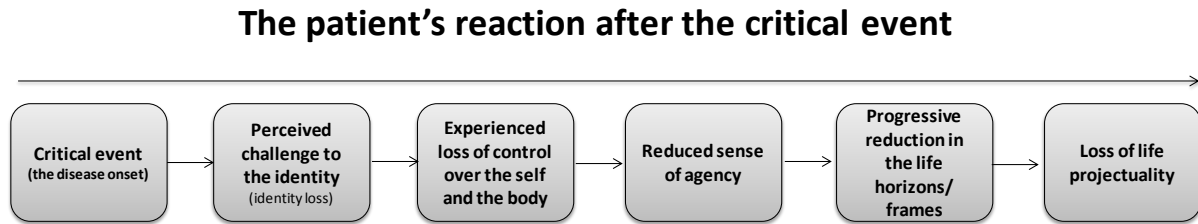
At diagnosis and/or at other times when the chronic condition had been perceived as particularly aversive (i.e., unexpected symptoms, sudden change in life habits), patients described an increased awareness of the seriousness and permanency of the disease. According to data, across disease conditions, shock was experienced as the patients' immediate reaction to the *critical event*. As the patient became conscious of the condition, he or she experienced feelings of powerless to change the situation and an adverse response to the new health condition, which was characterized by thoughts such as *'Why me?'* and emotions indicative of distress and denial. However, the individual chronic population considered in this study differed from one another relative to the kind of critical events that were considered stressful.

This feeling was exacerbated by a perceived crisis of the individual's established identity, arousing thoughts such as *'I am not the same as before'*. This *sense of identity loss* was frequently associated with feelings of powerlessness and difficulty in reframing the role of the patient in the family and in society, which was expressed as difficulties in having an active role in family functions. The patients reported experiencing a shattering of self and a need to reconstruct a meaningful sense of identity in line with the many changes that had occurred in their lives to recover a sense of power over the events. Thus, enormous effort was invested in

appearing 'normal' despite the conflict this process invoked. This finding implies the presence of a tension between the private self and the public identity and contributes significantly to the burden associated with living with a chronic illness.

The results of the present study also showed that the reactions of patients changed over time both with respect to their features and emotional intensity. Gradually, patients acknowledged their diagnosis as something to be dealt with and lived through.

In addition, the critical event was experienced as causing acute emotional imbalance and affected the individual's ability to tackle everyday activities due to the experience of *losing control over themselves* . This loss of control featured different manifestations depending on the specific health condition: for instance, stroke or HF resulted in the perception of a loss of control over the body and its symptoms, whereas diabetic or cancer led to a perception of a major loss of control over social roles. This condition also caused patients to experience a *reduced sense of agency* , resulting in a lack of self-efficacy over disease management. Patients described their range of choices or possibilities as limited by their health condition.

Moreover, they could not attend effectively to other aspects of their lives because they felt overwhelmed by their illness. These outcomes result from the progressive *reduction in patients' life horizons/frames* , which is related to the limitations of living with a chronic disease.

The patients described themselves as completely overwhelmed while reflecting upon the potential impact of their chronic condition on daily life, and they thought about the effects of their diagnosis on their future. Consequently, patients lacked confidence in their futures and became incapable of making plans both in the short and in the long term. In conclusion, the chronic condition limited patients' ability to envision their futures and caused a general *loss of innate human life projectuality*. Life projectuality is a key component of people wellbeing and it means that they have meaning and purpose in their lives.

3.2 THE PATIENT ENGAGEMENT TRAJECTORIES: A FOUR PHASES MEANING MAKING PROCESS

This study showed that the HF patient engagement process develops in four main phases thus confirming previous evidences emerging from a previous study on diabetic patients. These phases are characterized by different patient's emotional, cognitive and behavioral dynamics that contribute to shape the process of patient's meaning making towards health and illness along their care. The passage from a phase to another is featured by patient's identity reconfiguration turning points that led individuals to progressively accept their new status (i.e. as patients) and to interlace effective care relationships with their doctors.

Particularly, our study revealed the crucial role of cardiologists in helping them to effectively engage in their self-care. This process also features the progressive reconnection with valued aspects of the self (featuring the patient's life before the disease onset) and the development of new and meaningful identities according with the new health condition. This allows patients to provide self-continuity and, at the same time, to give new meaning to their life experience (see Figure 2.4). To illuminate the study findings presented below, we have selected representative participants' quotations that illustrate both typical responses and the diversity of views expressed.

FIGURE 2.4 THE HEART FAILURE PATIENT ENGAGEMENT PROCESS
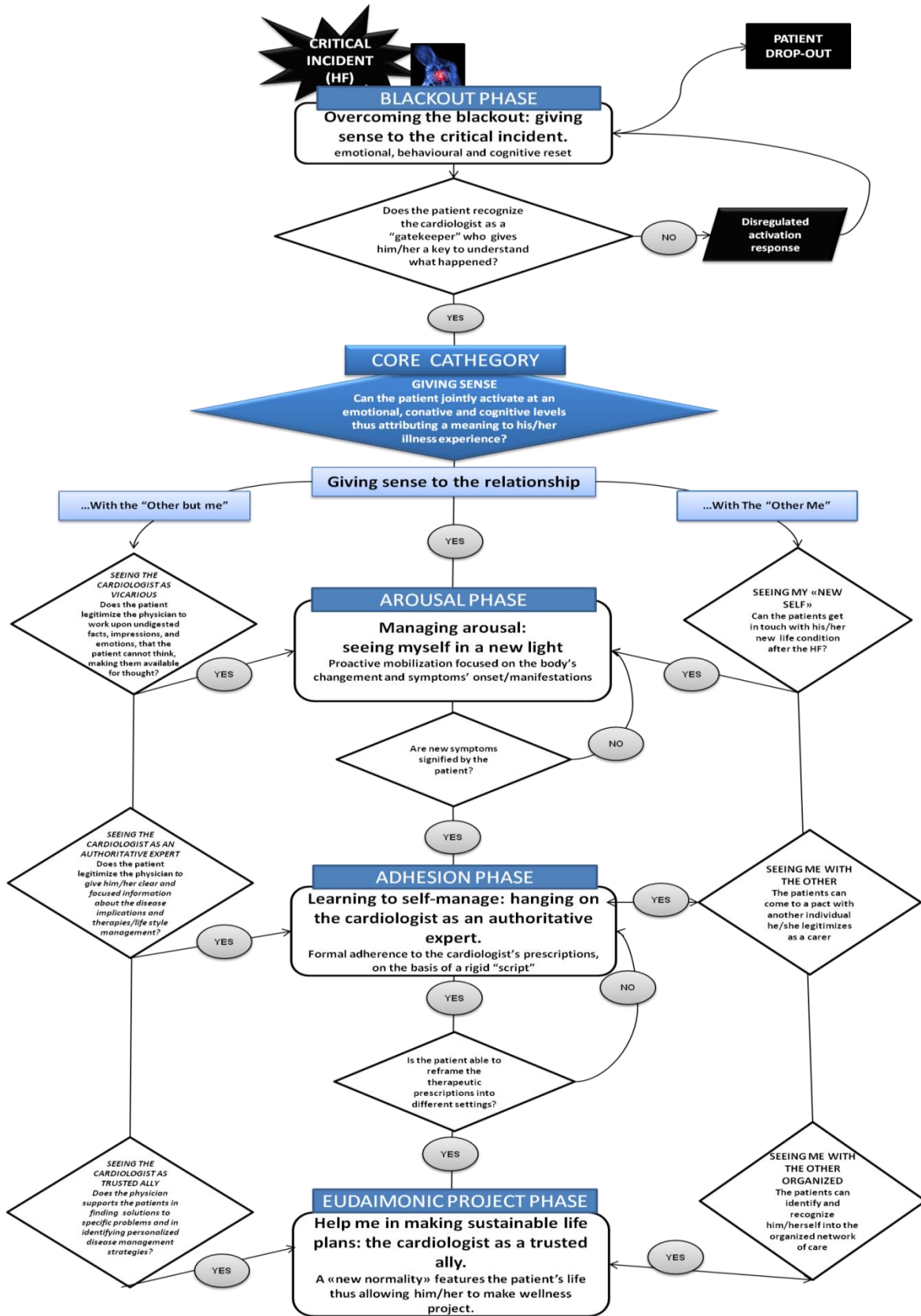
3.2.1 Overcoming the blackout: giving sense to the critical incident

In the phase of "blackout" patients fall in an initial state of emotional, behavioral and cognitive blackout determined by the critical event (i.e. the heart failure) that is described as unexpected and out of their control. They feel like "in suspension" as they are looking forward to a ruling from someone.

The critical event is depicted by patients as distressing and unacceptable because they have not acquired effective coping strategies to manage yet their new health condition and they are not aware about what happened to their body. This patient's status contributes to make the diagnosis often denied and signs and symptoms minimized. In this phase patients feel also blocked in acting and managing their diagnosis as they are generally uninformed about its nature and the exacerbating causes.

"When it happened, I felt like in a black out…I felt as my head was a black box with troubles in focusing on everything."

(55 year-old female patient with NYHA Class III HF)

" You know, maybe it is taken for granted, but it is not that the heart failure, one day, calls you and tells you that it is coming! It is totally unpredictable!"

(54-year-old male patient with NYHA Class II HF)

To overcome the emotional confusion connected to the disrupting critical event, the patient declare to need for clear information to realize what happened. Moreover, when patients get the diagnosis their emotional reaction is often an expression of shock, isolation and grief. In this situation the physician is asked to support them by making an empathic response.

"[…]at the beginning, after the diagnosis, patients seems to be frozen. Their horizon is totally absorbed by the thought of not being able to explain themselves what happened to them. Their horizon is totally dark."

(Physician)

"When I was diagnosed with heart failure, I feel totally paralyzed and the only think I wished in that moment was to understand and have an explanation about what happened to my body, to me, to my life."

(54 year-old female patient with NYHA Class III HF)

"I should have gone to hospital sooner with the shortness of breath and swollen ankles. But I didn't think it was anything serious. I just didn't know. I never heard of it . . . And what happened really at first, it comes on very gradual."

(74-year-old female patient with NYHA Class III HF)

"In that moment I can't understand what my doctor told me…the medical jargon is too difficult when you have no idea of what health failure is!"

(56 year-old male patient with NYHA Class II HF)

Patients refer that this informative action is expected from their referential hospital cardiologist which becomes, since the moment of the diagnosis, the privileged interlocutor for the patient along the care process. The physician who carefully listens to the patient and provides the needed information allows patients to enter the engagement process. In this phase the physician is considered as a "gatekeeper".

The doctor is a catalysts for the patient's advancement in the engagement process by providing him with the key to read and to understand what happened to his body. If patients can't legitimate the physician in this role they tends to enact dysregulated emotional and behavioral responses often ending with the patients' care dropout. In this phase, informal caregivers are mainly under shock as well as the patients and can't really act as supportive figure to help their loved one in effectively managing the disease.

"At the beginning of the journey [with the disease] the doctor has to make you feel safe and should hang around with you and giving the key to understand what happened before understanding what will be."

(54 year-old male patient with NYHA Class III HF)

"I needed to be reassured...and to understand that what I was feeling was not strange or wrong... I only wanted doctor told me that it was normal."

(60 year-old female patient with NYHA Class III HF)

" I think it is important that between you and your physician a compassionate relation sets up. Patients need for human relations not for I mean, I would like a physician that make you feel welcomed; that is close to you and show you that he(she is genuine interested in you and in your health condition. This is the essential condition to led to patients to take care of his/her own health."

(54 year-old female patient with NYHA Class III HF)

"I can't do anything for my husband,,,I was like shocked"

(caregiver, wife)

3.2.2 Managing arousal: seeing myself in a new light

In the subsequent phase of "arousal" patients feel scared by having been diagnosed with heart failure. This emotional condition makes them hyper attentive for every symptoms their body produces. Symptoms are conceived in this phase as a "*alarm bell*" that makes patient worried and risks to activate them in dysregulated emotional responses.

"When I perceive a new symptom from my body, I feel really scared and I am in a tizzy."

(60 year-old female patient with NYHA Class III HF)

"Symptoms make me feel worried and rather than going to my doctor I would like to escape."

(54 year-old female patient with NYHA Class III HF)

Patients have more information than in the previous phase about what happened to them and the causes of their condition although still stereotypical and superficial. Moreover, they still feel behaviorally unequipped to effectively manage their new condition. In this phase, the physician is conceived by the patients as a "vicarious" or "protective father" that should help patients to work upon facts, impressions, and emotions that are difficult to cope with. This allows the patients to test behavioral caring patterns and learn to manage emotional response to cope with the new health condition.

"I met a doctor really careful in explaining me everything I asked her. Once, I experienced a stab and I right away thought of death. Fortunately I took courage and I told her my worries, She told me that it was not an alarming symptom even if she understood my concerns. This made me immediately feel well".

(54 year-old female patient with NYHA Class III HF)

Individuals seems to enter in contact with their new self and role (as a patient) and legitimize the health professional as who may supply them when coping by themselves with the new condition is not possible for them. Patients' level of awareness about the disease and its impact on the self and their ability to develop a trusted connectedness with healthcare providers and influenced their perceptions of heart failure. This helps patients' to develop skills to integrate new knowledge, effectively behave in managing the medical prescription. In this phase patients revealed how they were challenged to integrate new information, adhere to complex medication regimens and life style changes, and navigate an ever-changing health system. In this phase, caregivers act like a nurse thus taking care of the disease management related activities that the patient is not able to do by him/herself.

"I know that everything takes time. But is so frustrating because I don't know what doctor, what form to give who, and there's different doctors for everything that tell you many many things and I often can't remember anything when I go out of the visit room ."

(75 year-old male patient with NYHA Class II HF)

"When I am at home, in front of the pillars and try to do everything as my doctor told me…it is not easy and I often fail in doing exactly what I should do."

(54 year-old female patient with NYHA Class III HF)

"I completely assist my father when he has to take medications or need to go to the doctor for the follow ups…even if I need to be strongly guided by the doctors because I am not so confident with this disease"

(caregiver, son)

3.2.3 Learning to self-manage: hanging on the cardiologist as an authoritative expert

The "adhesion" phase comes when patients have enough knowledge and behavioral skills to effectively adhere to medical prescriptions and feel sufficiently confident in their own emotional strength to cope with their health condition. The label "adhesion" was chosen as it well suggest the act of sticking to something, either literally or figuratively: in this case the patient totally rely on their cardiologists advices. Patients described how they transitioned into regular care by learning to assimilate the diagnosis of heart failure and its medications into their daily routine without losing their sense of self, relationships, jobs, or their normalcy. Successfully moving through this process entailed developing self-confidence and gaining personal insights. In this phase patients seemed to have a good understanding of what was happening to their heart, but had still little comprehension of what many of their heart medications were intended to achieve. Moreover, they can't enact medical prescriptions when some contextual conditions vary (i.e. when they go to holiday).

"For example, when a patient coughs and this symptom annoying him, he tends to focus his attention on this body signal even if for us (doctor) it doesn't care. Then this symptom becomes a sort of trigger that leads patients to indiscriminately search for information to solve the problem. However, they often are not equipped to search for the right information and to find the right source of information because they have not acquired the right skills to distinguish a severe symptom from an innocuous one."

(Physician)

"I always follow what the doctor tells me. Everyone is good at something different and I am not a health specialist. I know it is modern to have something to say about everything, even something I am not good at, but, in this moment I can't and this is not my case".

(70 year-old male patient with NYHA Class II HF)

In this phase, patients succeed in understanding and managing new symptoms basing on the physician counseling and on the increasing awareness about their body's signals. Patients revealed the need to hang on the cardiologists' authority and prescriptions conceived as a «lifeline» waiting for the time when they will be able and self-confident to self-manage. Other sources of information such as the internet, friends, neighbors, support groups are used as means to collect information to be discussed with the physician. The physician is perceived as an authoritative expert and this allows patients to feel confident and not alone when engaging in self-manage not only drugs but also physical activities, healthy diet regimen, stress management and effective symptom monitoring. It is notable that patients refer to the cardiologist as the main point of reference for their global heart failure management and don't make use of other source of information to manage their disease. GP are sometimes asked to give them general health advices.

"No! I leave myself on doctor' hands because for this

he went many years to school!"

(70-year-old male patient with NYHA Class III HF)

"I prefer not to go on the Internet…because it is so confusing…my doctor [the cardiologist] makes me quiet and thanks to him I succeed in staying healthy!"

(75 year-old male patient with NYHA Class II HF)

It generally leads them to employ positive coping strategies and to accept the guidance of an authoritative figure as a reliable point of reference. Rather than seeking knowledge to support self-care, participants still preferred to relinquish responsibility for management to their physicians even if they recognize to have a role in maintaining their health. The vast majority of patients expressed a 'blind' or strong faith in their physicians to make decisions on their behalf and would follow professionals' advice regarding self-care without seeking knowledge of HF.

"I have a role in my care and I always have had my own responsibilities in obeying them."

(74-year-old female patient with NYHA Class III HF)

"I am not a substitute of the doctor, but I think to be able to help my husband with his treatments because in these years I learned a lot of things such as how to maintain a correct diet and to do what make me healthy!"

(74-year-old female patient with NYHA Class III HF)

Further, the caregivers, that till now are not perceived by the patient as a solid anchor, at this stage become sufficiently skilled to facilitate the process of patients' engagement by supporting them both at an emotional and practical level. In this phase, the caregivers are able to provide an effective support to patients as they have gained a valid repertoire of disease management skills to deal with the unpredictable and sudden variations of the patients.

"....my wife asks me to help her when she has to go to the doctor...I usually take notes of drugs and dietary suggestions....then I emotionally support her when she goes down..."

(Caregiver, husband)

3.2.4 Help me in making sustainable life plans: the physician as a trusted ally

After having finally accepted the disease, a "new normality" features the patients' life thus allowing him/her to make life plans – sometimes thus passing from the "adhesion" to the "eudaimonic project" phase, which may be considered a full engagement status (see Figure 2.4). Inspired by the positive psychology movement, we used the term "eudaimonic project" to indicate a general state of wellbeing well-being that could be achieved through the patients' personal development and growth and through finding meaning in their lives. In this phase, the doctor is required to support the patients in identifying tailor-made and context-based disease management strategies and help the patients in making renewed life plans. The patients in this phase described their doctor as a "trusted ally" they rely on and to whom they asked counseling on demand. The doctor succeeds in this role if he is able to provide the patient a vision for the future and help the patient to reframe care prescriptions into different settings.

"Yes, I do help the doctor because I live with my medical condition and I am experienced. I have had it for years. I know my problem, I know myself and I know my body, so I would report anything new or different that would help the doctor."

(54 year-old female patient with NYHA Class III HF)

The patient, in this phase, becomes an experienced testimonial of good self-care practice able to become in turn a caregiver of others similar to him/her. To pass from the adhesion to the eudaimonic project phase the patient need to recognize him/her-self as an autonomous and skilled actor within the healthcare context.

Finally, this phase of full engagement features patients that have become co-constructors of their health, and capable of enacting a meaningful health management which allow them to make improve their quality of life. Patients have now fully elaborated their health condition and have accepted that the patient self is only one of their possible selves. They are also able to recognize their internal resources useful to project satisfactory life trajectories for their future.

"For me as a person, them taking care of me and me making a commitment to do it was wonderful [...] I wanted to be engaged in taking care of my heart. I felt it was more of a two way thing [...] I felt I was making a big contribution to my recovery [....] I felt empowered and hopeful for my future."

(75 year-old male patient with NYHA Class II HF)

In this phase patients are able to effectively activate to search for focused and updated information about their disease conditions and medications. This allows them to give full sense to their health experience; moreover they have fully elaborated the impact of their health condition on their daily life and are able to effectively enact healthy behaviors at due time even when contexts change. Patients that reached this status have also developed a new perspective towards their disease that now can be thoughtful and integrated in a wider life project. Informal caregivers enact the role of a "life buddy" life buddy, who share with the patients the whole life experience beyond illness. The main need of the caregiver in this case is that to discover a new life projectuality with his/her loved one and to be supported in a renovated social inclusion.

"My husband became autonomous and now he can see again our future."

(Caregiver, wife)

"We now need to look at our future, unless my disease"

(75 year-old male patient with NYHA Class II HF)

3.3 Life projectuality as a driver for patient engagement and quality of life

Living with a chronic illness is an ongoing, continually shifting process in which people experience a complex dialectic between themselves and their healthcare context. Based on our data, while patients go through their care experience, they gradually adjust to the burden associated with living with a chronic illness. They also find means to maintain their desired identity and to return with renewed hope and optimism to a perspective of wellness. In our view, this process might be considered as a pathway to recover the patient's lost life projectuality.

This process has also implication for the patient QoL that seems to assume different meanings at different times while the process of patient's adjustment to illness go on. Along the medical course, individuals change their internal standards of what constitutes health or other aspects of quality of life, adjust their values and priorities, and redefine what they think is important to maintain an acceptable quality of life in the face of declining health.

FIGURE 3.4 PATIENT ENGAGEMENT IN HEALTHCARE: PATHWAYS FOR GATHERING QUALITY OF LIFE BY RECOVERING LIFE PROJECTUALITY.

PATIENT ENGAGEMENT PROCESS

"I am an ill body"   *"I am a patient"*   *"I am a person"*

| BLACKOUT | AROUSAL | ADHESION | EUDAIMONIC PROJECT |

ACHIEVING QoL

DISEASE-RELATED QOL

side effects' control
and clinical stability

HEALTHCARE-RELATED QOL

fulfilment of
healthcare needs

EXISTENCE-RELATED QOL

renewed life
projectuality

Are symptoms under control?
Are side effects and treatments tolerable?

Is there symmetry between what the patient expects and
what healthcare gives him/her?
Is the relationship with the healthcare provider satisfying?

Can the patient see his/her future?
Can the patient make wellness plans despite living with a
chronic condition?

THE SWITCHING MODEL OF QoL

In light of the patient engagement model described above, in the early phases of the engagement process, patients perceive themselves as an "ill body". They are completely absorbed in their illness experience and often experience difficulty attending to the needs of their life due to a focus on the management of their disease and its treatments. As a consequence, for these patients, QoL mainly means control of side effects and clinical stability (*disease-related QoL*).

"Suddenly, after having been diagnosed with COPD, I was ok on the condition that the symptoms were tolerable enough and the treatments didn't invade my life too much,"

(68-year-old HF patient)

"Just after the diagnosis, when my symptoms were under control, I felt like my life was also in balance and it was easier for me to control and feel my body"

(63 year-old HF patient)

As individuals journey through the engagement process, they gradually start to perceive themselves as patients, or, in other words, as individuals with an illness experience. They also acquire control and confidence towards their disease condition and their focus shifts from disease control to health promotion. In line with this shift of perspective, a patient's QoL depends mainly on fulfillment of the patient's healthcare needs. The wellness of a patient is closely associated with the experience of a healthcare system that is responsive and attuned with the care expectations of the patient. In this conceptualization, a positive and trusting relationship with healthcare providers contributes to the wellbeing of patients (*healthcare-related QoL*).

"When my doctor said: 'It is a great that you could control your blood sugar', I understood that I was an empowered patient. Because I was living well with diabetes and could control it and because I was sure that my healthcare was there when I needed something".

(71 year-old HF patient)

Finally, when patients are in the final phases of the engagement process and start to reconsider themselves as whole persons despite their disease condition, QoL is conceived as a renewed ability to make realistic life decisions that are fitting with the impact of the disease on their life (*existence-related QoL*).

"My disease changed my approach towards life and caused me to question my goals for living. Before that time, I was just a lazy person with no clear goal in my head. But, now I'm very successful because I have tried to do the best with my time, love myself much more than before, and as a result, I'm happier and healthier now."

(56 year-old HF patient)

4. DISCUSSION AND CONCLUSIONS

This study focused on heart failure patients considered as a privileged observatory for developing insights about the process of individual's engagement in chronic care. It was devoted to fill the theoretical gap – deeply described in the introductory chapters (1,2,3) – concerning the lack of a shared and evidence-based definition of patient engagement starting

from the patients' perspective. Thus, this research showed how patient engagement within the heart failure care setting is developed, maintained or inhibited. Heart failure patients describe their engagement in healthcare as a process-like and multi-dimensional experience resulting from the conjoint cognitive, emotional and conative enactment of individuals towards their health management. These experiential dimensions play specific driving roles in the subsequent phases of the process (blackout, arousal, adhesion and eudaimonic project).

Yet, the model that emerged illustrates that patient engagement is based on a meaning making process enacted by the patient after the critical event (heart failure). This implies patients' ability to give sense to their care experience and, to their disease, symptomatology and treatments and their changes along their illness course. Moreover, data revealed that the possibility for patients to enter the process of engagement is connected to their capacity to make meaningful their relationship with the *other me* (that is his/her new identity as a patient) and with the *other but me* (that is the other/s involved in the care relationship mainly the cardiologist) (see Figure 2.4).

Our results show some similarity with other conceptualizations of patients engagement currently present in the literature that we have discussed in chapter 2 and 3. Hibbard (2009) describes engagement as "*the patients' motivation, knowledge, skills, and confidence to make effective decisions to manage their health*" thus highlighting the importance of fostering patient's ability to improve their health literacy and enact healthy behaviors. Also, Gruman (2009), conceives patient engagement as a set of behaviors and actions that allows individuals to effectively manage their health in order to obtain the greatest benefits from their healthcare. The model emerging from this study, although confirming the relevance of both the cognitive and behavioral components of the engagement process, clearly casts light on the crucial role of the patients' emotional elaboration of their disease engage in their care. Our results find confirmation in previous frameworks that represent phases of cognitive readiness for

behavioral change (Prochaska et al., 1992; Simpson & Joe, 1993; Simpson, 2001; Johnson et al., 2006). According to these approaches, a staged view of patient engagement suggests that a full engaged status is the final element in a series of cognitive, emotional and behavioral changes and disease-related events and experiences (Mowbray et al., 1993); and that patient success at any point in the process may depend on success in earlier phases. We hypothesize that patients need to sequentially pass through each of the identified phases of the process on the way to becoming effectively engaged in their health management. These phases have some similarities with the stages of change in the Transtheoretical Model (Neimeyer et al., 1993), which includes pre-contemplation, contemplation, preparation, action, and maintenance stages. The Transtheoretical Model emphasizes motivation and readiness but not explicitly deal with issues of emotional elaboration and disease acceptance. This model mainly focuses on the behavioral and cognitive factors at the base of patients' ability to self-manage. In our model, instead, individuals' emotional elaboration plays an essential role in how they cope with situation of illness, thus influencing their engagement towards their health. The transition from sporadic engagement to regular and effective behaviors to manage their own health, involved confronting a variety of meaning making actions, each of which contributed to the individual's subjective perceptions about the impact of heart failure on their identity and everyday life (Levine & Reicher, 1996) as shown by previous studies (Yu et al., 2008). When heart failure interfere with the healthy individuals' established identity the person tends to regard him/herself as a not fully functioning individual such as an inhabitant of a luminal space that narrow his/her identity to the one of a patient. Reconstruction of a positive self not only limited to the patient one contributes to mitigate the disruption of the heart disease and facilitate them in the recovery of a "new normality" thus allowing patients to recover a wider quality of life.

Moreover, our data casted light on the complex and challenging nature of patients' engagement trajectories when approaching their disease management and the crucial role of the patient-doctor relationship in fostering it. To deepen the role of the care relationship in promoting the engagement process, further research may be also devoted to understand the role of family caregivers in supporting it.

To trigger the process of engagement, the cardiologist should play the role of a "*gate keeper*", a sort of "*relational catalyser* ", for helping patients to activate the meaning making actions that sustain the passage from a phase to another. A physician who "*gives the patient a key"* to understand what happened and functions as a "*emotional container*" for the patients, could be a catalyser to get this process off the ground. These evidences are consistent with the ones developed in previous research on diabetic patients which clearly underlined the importance of accompanying patients in the elaboration, acceptance and incorporation of their disease (and its treatment) in a new, achievable plan for present and future life trajectories on the bases of their subjective experience of health engagement.

The diatribe around the dialogue among paternalism or partnership in the patient-doctor relation finds some answers in our results that suggest the need for a paternalistic approach to care in the early steps of the engagement process as patient in these phases showed a strong preference to defer decision making to their health provider, because it allows them to take the time to understand the nature and causes of their disease and gradually learn to deal with its implications on their life. On these bases, it will be important to find ways of engaging patients only whet it is an acceptable status and not an unwanted burden for them (Coulter, 1999).

Our results also suggest the need for considering the patients' direct experience of engagement with their disease management in order to give the patients the power to choose their position towards the doctor and, more in general, towards the healthcare (Graffigna et

al., 2013). According to the our results, patient engagement may allow individuals to experience a feeling of active participation in their lives via a renewed sense of authorship over life events.

Moreover, the finding that advancement in the engagement process orients the healthcare needs and care priorities of patients are also important in revising current conceptualizations of quality of life. Indeed, as emerged by our research, the meaning of QoL to heart failure patients appears to change during the engagement process as health priorities and needs undergo modifications (see Figure 3.4). In figure 3.4 we propose an adaptation of the patient engagement model developed on HF patients by integrating findings about the quality of life (QoL) shift along the engagement process. It is interesting to note that while the patient's position along the engagement process changes, also the patient perception and meanings attributed to his/her QoL vary. This results appears in line with the literature on response shift and may be a further confirmation of this processes of appraisal (Schwartz & Rapkin, 2004; Rapkin & Schwartz, 2004; Schwartz et al., 2006; Sharpe et al., 2005).

This mechanism is based on the fact that human beings actively construct meaning from their environment, and display a range of cognitive and emotional mechanisms to continually adapt to changing circumstances. Also people evaluation and meanings related to their QoL are highly individual with patients varying considerably in what they consider important for their QoL over time and in response to changing circumstances. In our study, this phenomenon finds confirmation as well as the meaning of QoL shifts from a dependence on effective disease management to the possibility for patients to make wellness plans. When patients are in the final phase of the engagement process — the "eudaimonic project phase" — QoL means a recovery of life projectuality, which is consistent with the WHO's definition of QoL as the "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and

concerns" (1995). This result supports and makes valuable the healthcare systems efforts towards fostering patient engagement in healthcare.

To sum up, this study offered insights towards the dynamics that feature the heart failure patient engagement experience and casted light on the individual and relational processes that occur when this process develops. In particular our results strongly highlights the crucial role of physician in fostering the engagement process as they behaviours may reinforce or challenge the patient's ability to engage in the healing process. Moreover, making patients autonomous in managing their care means that the doctor should gradually lead the patient to acquire the skills and confidence to effectively engage in the care process. This means also to attune communication style and adopted vocabulary to the level of patients' experience and understanding of their disease condition – as suggested by other studies in this field (Barello & Graffigna, 2014; Williams et al., 2002; Castro et al., 2007; Graffigna et al., 2013).

It is hoped that our model and the its practical implication for the patient-doctor relationship may be helpful to clinicians for thinking in a fresh way about encounters with patients and about their role in fostering their health engagement. This also implies the need for attuning the patient-doctor relations to meaning making process enacted by HF patients along their engagement continuum. This model also well underlines the importance of not merely foster the patients' health literacy and provide behavioral education. Whereas, patients should be supported in their process of emotional elaboration of their illness experience and identity reconfiguration in order to keep the maintenance of their daily life in spite of the disease (Falk et al., 2007) and to achieve a positive quality of life. To achieve psychological adjustment, patients need to face the reality of being chronically ill and make efforts to change their lives to adjust to the new circumstances imposed by their illness. The process of adjustment to a chronic illness signifies the integration of the burden of disease management into the broader

"modus vivendi" of the individuals to renew their wellness plans (Park, 2010; Theofilou, 2012). Thus, effective engagement in healthcare suggests a gradual change in patients' broader cognitive-emotional representation of the disease, including the recovery of a sense of control over the body (Stephens, 2011; Bury & Gabe, 2013). Successful patient engagement may also be related to a positive shift in the ways in which patients perceive self and life and experience empowerment to realize their life potential.

Future research might be aimed at deepening the results by studying the experiential perspectives of the other actors involved in the healthcare For instance, to better understand the possible role of the general practitioners and physicians of other specialties (i.e. especially in diabetes and renal care) in managing heart failure patients' may be valuable for translating this study's implications from the hospital settings to the ambulatory care. Other countries also have specialist nurses and heart failure patients come into contact with other professionals such as physiotherapists or dieticians and these are missing from your results. Basing on our data, the main figure present in the patient engagement experience is the hospital cardiologist. It is possible that this results may depend on cultural and organizational specificities.

This point suggests the need for further cross cultural investigation to test the transferability of this model in other healthcare systems. Moreover, in order to improve the study evidences, a more articulated data collection and analysis according to patient's age and comorbidity – including also patient affected by advanced heart failure (NYHA IV) - would be worthy. Also deepening the perspective of lay caregivers and their role in supporting their loved one's engagement in healthcare would be powerful to detect possible "environmental" levers or barriers to effective engagement. Finally, it would be notable to extend this study by

collecting stories of dissatisfaction with care services and health providers in order to better

address patients' unmet needs when engaging in their care.

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PART IV

PATIENT ENGAGEMENT IN PRACTICE: SENSITIZING PATIENTS AND HEALTH PROFESSIONALS IN ADOPTING A PARTICIPATORY CARE MODEL

Following the research results presented in chapter 4, this final and concluding section will provide reflections and discussions upon two possible lines of application of the insights developed by the theoretical and empirical studies previously described in this dissertation.

Particularly, the author shall discuss and offer theoretical viewpoints about the implications of the patient engagement model developed in field of cardiovascular care (1) for the process of shared decision making in the medical encounters; and, (2) for the development of a communication skills training for health professionals which is aimed at sustaining an effective patient engagement basing on the research collaboration developed with the Institute for Professionalism & Ethical Practice of the Harvard Medical School (Boston, US).

The following chapters are strictly based on the research results concerning the area of cardiovascular diseases and suggest lines of intervention in this specific clinical field. For these reasons, an adaptation of these reflections to other clinical fields is desirable but it is still ongoing and has to be tested with further research.

- CHAPTER 5 -

Promoting patient engagement in medical consultation: pathways for shared decision-making [6]

In the previous chapters we have discussed how questioning about "how to talk with patients" and how to make them engaged in healthcare decision making is currently a policy imperative for Western healthcare systems. Making patients active participants of their care process and adopting a shared decision making are increasingly advocated as an ideal model of medical consultations, as far as it has the potential to deliver better health outcomes and a more efficient use of resources retaining patients' autonomy and self-determination. However, beyond the evident plus of patient engagement in healthcare, it should be also considered that clinicians – in their daily practice - are commonly challenged by the diversity of situations that arise when they attempt to engage health consumers in clinical decision making. Indeed, consistently with our research evidence showed in chapter 4, engaging cardiovascular patients in daily clinical practice asks health professionals to be able to recognize that patients' different clinical status and engagement dispositions might require different relational styles. Clearly, different situations require different communication approaches and doctors should be trained to adapt their relational style according to the specificities of such situations. This chapter will be devoted to discuss the opportunities offered by an "engagement-sensitive decision making" in order to orient clinicians' relational skills and decisional style according to cardiovascular patients' needs at each phase of the health engagement process. Insights for medical education aimed at improving doctors' relational strategies to improve cardiovascular patient engagement will be also provided

Keywords. Patient engagement; shared decision making, patient-doctor relation; medical education; medical communication

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6. Adapted from: **Barello, S**., Graffigna G. (2015) Patient engagement in healthcare: pathways for shared decision-making. *Neuropsychological Trends*. (*in press*);
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1. INTRODUCTION

As just discussed in the previous section of this dissertation, patients and consumer advocacy groups are more and more expressing increasing interest in realizing true partnerships with their clinicians and in being engaged across the care process, with real-time access to their own medical records, to science-based comparative effectiveness information, and to health care delivery environments built to enhance both safety and personalization of medical care (Barry et al., 2012). Patient engagement in healthcare, as one of the six major initiatives of the National Priorities Partnership of the National Quality Forum in US, is recognized to sustain the creation of more informed and engaged patients as active and responsible decision makers in the care process (Cassel & Guest, 2012).

Doctors and managers are thus increasingly more committed to actively engage patients in the whole care process − thus favoring an effective and productive exchange between demand and supply of health services. In particular, if we consider the setting of the clinical consultation - as well demonstrated by the patient engagement model described in chapter 4 and its implication for the patients' quality of life - patient engagement finds its best realization in a two-way active partnership between the patient and his/her health provider(s) in making decisions about treatments plans and in finding the best solution to obtain a satisfactory quality of life.

In this chapter the author will discuss the usefulness of the heart failure patient engagement model (see Chapter 4) to orient both clinicians and managers when they relate with patients. We advocate the need for considering the engagement phase the patients are passing through in order to successfully communicate with them and to promote high-quality and satisfying clinical consultations and effective treatment plans. This chapter has also the mission to show to the reader the relevance of the patient engagement model also for planning educational

interventions for doctors that help them in practicing communication models which are truly aligned with the patient's engagement needs and expectations.

1.1 PROMOTING PATIENT ENGAGEMENT IN SHARED DECISION MAKING: IT TAKES TWO

Patient engagement in medical decision-making is described - at least in theory - as the best philosophy and decisional style, whereby clinicians engage patients as equal partners to make choices about healthcare, based on clinical evidence and patients' informed preferences and care expectations (Cassel & Guest, 2012; Judson et al., 2013). Today, both patients and health practitioners recognize that patients themselves are in the best position to evaluate the trade-offs between the pros and cons of alternative medical courses (Makoul & Clayman, 2006). Moreover, patient expectations about their role in care choices and treatment decision making have been influenced by living in a society where patients more and more play the role of active and critical health services consumers. Ready access to health information and treatment options via new technologies – such as the Internet - has increased in time (Baker et al., 2003). Moreover, social movements - such as women's movement - have emphasized the primacy of patient's autonomy and have actively challenged the medical class (Holmes-Rovner et al., 1996; Charles et al., 1999). Actively engaging patients is also recognized to help meeting demands for accountability as clinicians can be more open about decision making (O'Connor et al., 2007).

Furthermore, although evidence about the effects of engaging patients in decisions on clinical outcomes is far from being conclusive, treatment compliance and self-management of long-term chronic clinical conditions has been shown to be greater where patients mutually agree decisions with their doctors (Barry & Edgman-Levitan, 2012). The strongest evidence for patients' engagement in decision making also comes from studies on the use of decision support tools. An increasing body of literature suggests that an enhanced participation of

patients in decision making leads to consistent improvements in patients' health knowledge and more accurate perceptions of clinical risks, leading to increased confidence when confronting with decisional tasks (Couët et al., 2014). Finally, cost savings are founded and clinicians are less involved in legal arguments (Duncan et al., 2012). Given these extraordinary premises about the positive implication of patient engagement in decisions on patients' health, who reads may ask why involving patients in decision making is so challenging and so difficult to make a routine practice? The answer to this legitimate question probably is that beyond the uncountable and demonstrated value of this decisional style, this model poses important challenges to clinicians. Let's see them together. To be implemented, patient engagement in decision making requires doctors to help their patients in understanding what the reasonable care options are, then eliciting, informing, and integrating the patients' informed preferences as they relate to the available options. However, according to the patient engagement model and the specificities of each phase for the patients' mindset towards his/her management, engaging patients in decision making could be effective only if both patients and doctors are committed to the process and when the patient emotional and cognitive status matches with the skills required by such an active decisional style. There are patients that prefer not to be told too much about their illness, and patients' own preferences for joining in decision making have been found to be weak, showing even more decline when they were asked to consider increasingly severe illnesses (Fraenkel & McGraw 2007). Moreover, the emotional stress and anxiety of severe clinical diagnosis or hospitalization may further affect patients' judgment, cognitive functioning, emotional availability to participate as skilled and aware partners in shared decision making (Gaston & Mitchell 2005). Considering all these aspects together might introduce complexity for doctors in providing the best communication and relational style for each patient when having to take a critical decision along the medical

course. such a complexity, furthermore, makes patient engagement difficult to be translated from theory into practice, and the lack of clarity about how to communicate appropriately according each patient's features might contribute to clinicians' documented failure to really apply a participatory approach in decision making. Probably, in order to be effective in engaging patients in decision making, clinicians should consider to overlap between the different relational and communicational approaches and flexibly combine them to improve their patient-centered practice along the unique patients' illness journey.

2. TOWARDS AN "ENGAGEMENT-SENSITIVE" DECISION MAKING STYLE: A PROPOSED HIERARCHY OF DECISION MAKING STYLES

Patient engagement in medical decision making could be a challenging act as *"interacting with the healthcare system can be understandably unsettling for any patients"* because of uncomfortable feelings that may inhibit patients in accomplishing this task (Judson et al., 2013). We would like to extend this reflection relating it with the nuanced phenomenon of patient engagement that is a process-like experience resulting from a conjoint cognitive, emotional and conative enactment of individuals towards their health (see chapter 3). As known, the unachieved synergy among these dimensions may inhibit the patients' ability to engage in the whole process of care, comprised the decision making component. Across this process, patients go through subsequent phases that are strictly linked to the disease course and the patients' elaboration of their illness experience. According to this process-like view of patient engagement, individuals may be differently akin to be engaged in shared decision making along their illness journey and might require different decision making styles according to their emotional, cognitive and behavioral mindset (see figure 1.5).

FIGURE 1.5 A HIERARCHY OF ENGAGEMENT-SENSITIVE DECISION MAKING STYLES

ENGAGEMENT-SENSITIVE DECISION MAKING STYLE

SHARED DECISION MAKING ZONE

| BLACKOUT | AROUSAL | ADHESION | EUDAIMONIC PROJECT |

PREFERRED DOCTOR-PATIENT RELATIONAL STYLE

paternalism

doctors are expected to perform information management, assess options, and make treatment decisions for patients by informing them and augmenting their health literacy and basic behavioral skills for disease management.

consumerism

doctors are expected to give information to patients who then make their own decisions. The doctor is a technical expert that provide information and facilitate the patients' decisions

sharing

doctors are expected to help patients 'on demand' in order to construct, check and prioritize their preferences in order to encourage reflection and co-create decisions.

PATIENT PREFERRED ROLE IN DM PROCESS

INFORMATION EXCHANGE
Patients can acquire basic knowledge and skills and need only some information relevant to understand their clinical condition and psychological implications.

HCP should pass the patients a limited range of input regarding their health and basics skills for navigating the healthcare systems. No real choice is presented here – patients must take control over their health will be experienced

DELIBERATION
Patients are able ti face formal discussions about treatment options and need to receive information about various self-management alternatives.

HCP should discuss pros and couns of deling with each within the patient's psychosoacial context and should provide a contunuo assistance to facilitate the patient's decisions and choices.

DECISIONAL CONTROL
Patients have the power over the final selection of treatments and care plans. He/she is able to outline a self-care plan on the basis of the discussions carried out in the consultations or they choose to invite the HCP's viewpoint on what action is best to take

Patient need to be supported in making the ultimate, informed decision for themselves and in gain a renovate sense of social inclusion

As just discussed in chapter 4, patient engagement is a dynamic and evolutionary process featuring four experiential positions (*blackout*, *arousal*, *adhesion*, and *eudaimonic project*) that involves peculiar ways of interaction, roles and power dynamics between the patient and the health provider that strongly depend on the phase of the process the patients is passing through. To illustrate and discuss the dynamics occurring in medical consultations in which different decision making styles are appropriate, we will consider three clinical cases – based on real patient's histories collected in the empirical study described in chapter 4 - that exemplify the situations of cardiovascular patients in different states of the patient engagement model and their preferred role in decision making.

For a consultation to be patient engagement-sensitive, we propose that healthcare practitioners need to both give patient information and choice about how and how much to be involved in make a treatment choice, and also support them in implementing this information with an ultimate goal of being in control over their care. To this end, a hierarchy of decision making style is suggested according to a process-like vision of patient engagement that implies different levels of engagement in the care process.

2.1 Level 1: Paternalism and information exchange

Let's consider that in the early post-diagnosis phases– namely the phases of blackout and arousal of the patient engagement model –, many patients may be not ready to make decisions due to negative emotions and/or fatigued cognitive functioning (see Figure 2.5).

In this phases, some information relevant to the patient's health should be provided. The healthcare practitioner should present patients with a range of, primarily didactic, input regarding their disease condition and emotional implications. This is evidence-based information provision at its most basic level. For instance, if we consider the case of heart

failure patients, this would be akin to a health practitioner describing heart failure, its risks/outcomes both at the physical and psychological levels, and introducing some basic aspects of self-care.

FIGURE 2.5 DECISION MAKING STYLE WITH A PATIENT IN THE BLACKOUT PHASE.

"HE IS IN BLACKOUT": THE CASE OF JIM

Clinical condition:
Let's consider Jim, who is 77 years old. He was affected by hearth failure 3 years ago and has ulcerous colitis. He has just been diagnosed with early-stage prostate cancer. He is shocked and scared by the diagnosis and can't believe to have cancer because no one in his family had ever this disease. He has no information about this kind of cancer features, risks, treatments and ways of management. He is really worried for the consequences on his life and he doesn't know what to do.

Decision to take:
After an initial treatment consultation with a urologic surgeon and a radiation oncologist, **Jim needs to interpret complicated medical information to make an informed treatment decision. Patients can chose among different management options: active surveillance, hormone therapy, surgery, and radiotherapy.** Jim is totally blocked and feels not to be able to take a good decision.

Preferred decisional style:
Jim is passing through the "blackout" phase of the model and he completely relies on his oncologist's advices because he feels to have no skills to decide. Observation is a reasonable alternative for some patients with early disease, usually those who are elderly and have important comorbidities. He expects his doctors takes his care responsibility and suggests him the best treatment options according to his clinical and age profile. Jim desires a **mere information exchange with his oncologist** within a **paternalistic decisional style.**
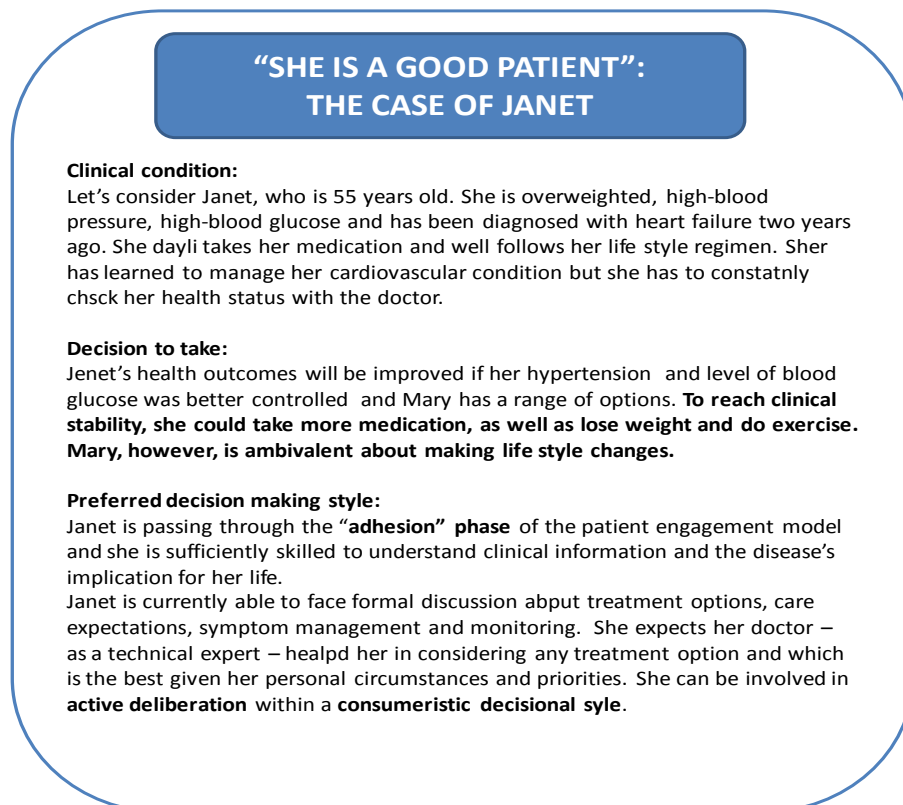
In these phases paternalism should be the preferable patient-doctor relational style. In line with the patients' expectations, doctors are expected to perform information management, assess options, and make treatment decisions for patients by informing them and augmenting their health literacy and basic behavioral skills for disease management. Regarding the patient role in decision making, this phase of the patient health engagement process should require a mere information exchange: patients, in this way, can acquire through the dialogue with

clinicians basic knowledge and skills to start navigating the healthcare systems without the responsibility of taking decisions about care plans.

2.2 Level 2: Consumerism and deliberation

In a more advanced phase of the process – the "adhesion" phase - patients are more available to be involved in decision regarding their treatments but still need to be encouraged in taking part and requires to be empowered in their ability to co-produce their health (see Figure 3.5). In this phase, information should be provided to patients as in the first level along with the idea that there is potentially choice between different treatment courses. The patient should be here introduced to the idea of having choice over how and whether they manage their disease condition.

FIGURE.3.5 DECISION MAKING STYLE WITH A PATIENT IN THE ADHESION PHASE.

"SHE IS A GOOD PATIENT": THE CASE OF JANET

Clinical condition:
Let's consider Janet, who is 55 years old. She is overweighted, high-blood pressure, high-blood glucose and has been diagnosed with heart failure two years ago. She dayli takes her medication and well follows her life style regimen. Sher has learned to manage her cardiovascular condition but she has to constatnly chsck her health status with the doctor.

Decision to take:
Jenet's health outcomes will be improved if her hypertension and level of blood glucose was better controlled and Mary has a range of options. **To reach clinical stability, she could take more medication, as well as lose weight and do exercise. Mary, however, is ambivalent about making life style changes.**

Preferred decision making style:
Janet is passing through the "**adhesion" phase** of the patient engagement model and she is sufficiently skilled to understand clinical information and the disease's implication for her life.
Janet is currently able to face formal discussion abput treatment options, care expectations, symptom management and monitoring. She expects her doctor – as a technical expert – healpd her in considering any treatment option and which is the best given her personal circumstances and priorities. She can be involved in **active deliberation** within a **consumeristic decisional syle**.

A consumerist style of decision making seems here to be the best way of patient doctor interaction. Doctors – considered as technical experts that provide information and facilitate the patients' decisions – are here expected to give information to patients who then make their own decisions. In this phase deliberation is the expected role for patients which are now able to face formal discussion about treatment options, care expectations, symptom management and monitoring and also share with doctors responsibilities about care plans.

2.3 Level 3: Sharing and decisional control

A proper shared decision making zone probably comes when the patients are in the phase of "eudaimonic project" and have finally acquired knowledge, skills and emotional balance necessary to effectively and wittingly engage in their healthcare management, thus making renewed wellness plans for their future life (see figure 4.5).

FIGURE 4.5 DECISION MAKING STYLE WITH A PATIENT IN THE EUDAIMONIC PROJECT PHASE.

"LET ME TAKE CARE OF MY HEART": THE CASE OF LUCAS

Clinical condition:
Let's consider Lucas, who is 63 years old. He was diagnosed with hearth failure ten years ago. He daily takes beta blockers and antihypertensive drugs. Two months ago his clinical condition worsened and he been diagnosed with advanced heart failure. Due to his long experience with this disease he knows that

Decision to take:
Lucas's health outcomes will be improved if he better controls cardiac functions . **To reach clinical stability – due to the gravity of his health status - he could consider two options: therapies that only reduce the risk of sudden cardiac death (i.e. ICD), or advanced surgical therapies to exchange disease (i.e. transplantation).**

Preferred decisional style:
Lucas is passing through the "eudaimonic project" phase of the model and he is **totally aware of his clinical condition and associated risks**. Lucas is well informed about pros and cons of both alternatives and want to share with the doctors what main counts for his life quality. Lucas **feels empowered to take control over the final decision** after having discussed with the clinicians his priorities and desires within a **shared decision making style**.

Here, information, choice and tools to make an informed choice are given to patients with the ultimate aim of the patients themselves making the final treatment decision that is appropriate to their psychosocial and contextual circumstances, according to their eudaimonic life plan. Doctors are here supposed to share decisional actions with the patients which should be helped 'on demand' to construct, check and prioritize their preferences thus encouraging reflection and co-create decisions. Patients are here akin to take decisional control due to the fact that they feel to have the power over the final selection of treatments and to take the most of responsibilities about care plans.

2.4 What is the point of the proposed hierarchy of decision making styles?

In this chapter we have argued that in order to be truly engagement-sensitive, the preferred role of patient in information management and treatment choice, and the way that these issues can be handled within the medical consultation need to be clearly assessed and determined. We thus proposed a theoretically-driven hierarchy of decision making styles built upon the insights derived from the heart failure patient engagement model described in this dissertation (see chapter 4). As showed by considering the clinical cases provided, the patient engagement model might allow to highlight specificities in the relational dynamics that feature the patient-clinician encounters along the care process of cardiovascular patients and helping health practitioners in orienting their communicational behavior. This process-like modeling of patient engagement potentially leads to reshape the medical encounters by posing the bases for a true and sustainable partnership between patients and doctors along the natural change of the patient's illness experience. In this perspective, while the process of patient engagement evolves, the patients' expectation towards the relational style of their doctors changes too, thus implying a continuous realignment of roles and power dynamics (Rodriguez-Osorio & Dominguez-Cherit, 2008; Barello et al., 2014). As shown, the last position of the engagement

process (i.e., *eudaimonic project*) culminates in the patient capacity to gain a positive approach to the disease management and to adopt a more active role in medical decision making. In this position he/she perceives him/herself as a person (not only as a patient) and is able to construct an effective partnership with the clinician. This can be considered the actual "shared decision making" zone, where the clinician may consider the patient a real partner in decisional tasks.

Moreover, this broader conceptualization of patients' engagement is suggestive of richer guidelines to orientate patient-centered medical communication skills and power dynamics in the patient-physician encounter within the cardiovascular patients' care. A real "patient-centered communication" includes sharing of information, but it also focuses on fostering relationships, managing uncertainty, favoring the patient's awareness, acknowledging and responding to the patient's emotions, and enabling self-management practice. The clinician who would embrace this perspective will align his/her relational style and communicational behaviors with the patient's agenda and engagement disposition well enough to encourage patients to get involved in active and shared decision making in the right moment. We thus suggest that clinical consultation in the cardiac care which would be effective in fostering patients' engagement should not be reduced to the mere enhancement of patients' overall health knowledge. Rather, engaging patients in medical consultations and decision making should also include specific communicational actions aimed at scaffolding patients and passing those behavioral skills necessary to accommodate different models of decisional styles. Moreover, we suggest that patient should be educated to participate in decision making and can't be pushed to be actively involved in decisions regarding their health if they are passing through an engagement phase that is not suitable to that decisional style. Patient engagement is a fluid concept and the hierarchy of decision making style proposed in this

chapter could be a concrete tool for physician to help them monitor the way they manage information and choice in their consultations when dealing with patients affected by cardiovascular diseases. Here we have outlined specific, qualitatively different ways of enacting decision making and we hope that health practitioners would choose to test it out in their daily practice.

3. ENGAGING PATIENTS IN DECISION MAKING "FROM THEORY INTO PRACTICE": AGENDA SETTING FOR MEDICAL EDUCATION

According to the insights inspired by the patient engagement model described in chapter 4, as far as it concerns the patient-doctor relational features, we advocate the importance of preparing patients for a shared decision making clinical encounter, partly by changing attitudes towards engagement, partly recognizing the not always appropriateness of this decisional style. We also suggests that interventions should be delivered in two stages: firstly sensitizing patients, followed by enablement to shared decision making (see figure 5.5). Patients should attend a sensitizing intervention that clearly explain them the meaning of taking a shared decision and the effective ways to do that. Once patient has made an informed decision to be involved and has clear in mind the benefits related to a shared decisional style, the focus moves on to patient actual enablement to shared decision making. This might be done through help patients taking part in a two-person setting of health decision making, by offering appropriate decision support tools and question prompt lists. Importantly, the interventions need to be promoted from within the organization and the patient should perceive that both the healthcare organization and the clinicians consider patient engagement a core value of their practice. Many clinicians in their routine clinical practice may dismiss the above recommendations as impractical, given the considerable time needed to complete

the communication processes outlined above. The diverse tasks of physicians involved in chronic patient care might limit the capacity to conduct thorough prognostication, communication, and decision making for different patient engagement preferences and expectations. Yet, the unique role of clinicians demands that they assume the primary responsibility for "diagnosing" the best relational style for each patient along the care process thus really promoting what we called "engagement-sensitive decisional style". As such, the routine conduct of these activities must be efficiently integrated into routine care. The more clinicians perform patient engagement − in the ways and time suggested by the patient engagement model -, the better they will be at making it a natural part of their routine practice of care.

Unless the cited controversial pints, a good message is that the promotion of patient engagement appears likely to continue both in clinical practice and policy making initiatives. Doctors appear receptive to this practice, and willing to acquire the relevant skills to enact it. However, strategies for wider implementation of patient engagement could address how consultations are scheduled in chronic patient care, and raise more consumers' expectations or desires for involvement (or un-involvement) by assessing their level of engagement according to the patient engagement model presented in Chapter 4.

FIGURE 5.5 DOCTORS' COMMUNICATION PRIORITIES TO ENGAGE PATIENT IN SHARED DECISION MAKING.

PATIENT'S SENSITIZING

PATIENT'S ENABLEMENT

DOCTORS' PRIORITIES IN COMMUNICATION BEHAVIOURS

- Listen to the **patient desires and expectation** and legitimize each choice in regard
- Make the **patients aware about the importance of sharing their illness experience** to best tailor the medical course
- Give the **patients basic information about their condition** and allow them to understand their available options
- **Educate the patients about the practice of shared decision making**—what it is, what to expect, and when and why it is appropriate
- Explain that **there are two experts in the medical consultation** and that the doctor is not expert of the patients' own illness experience— show the patients the **different but complementary knowledge and expertise**
- **Challenge attitudes that patients have not the power** to decide for their own health
- **Redefine believes around what it means being a good patient** and reassure patients that their participation will not affect the quality of received care
- **Promote social acceptability of an "active patient" in healthcare**—confirm that clinicians want patient participation
- Build patients' belief in their ability to take part in medical consultation as active agents of the medical course

- Help patients to **actively take part** in the shared decision making process
- Provide patients appropriate **decision support tools**
- Suggest patient to **prepare question prompt lists**
- Make the patients aware that shared **decision making is in line with the healthcare organization's core values**
- Constantly **check the patient's availability to be engaged** in decision making and legitimize the times in which he/she can not

4. DISCUSSION AND CONCLUSIONS

This chapter showed how engaging patients in their health care across daily clinical practice requires health practitioners to be able to recognize that different clinical situations require different approaches and to be skilled enough to adapt and, where needed, integrate diverse methods and styles of patient-doctor communication. As showed in the clinical cases used to describe the decisional style more attuned with the phases of engagement the patients are passing through, the biological reality of chronic diseases - such as the cardiovascular ones - makes communication and decision particularly difficult since these clinical conditions are often characterized by unpredictable periods of acute illness, followed by improvement in symptoms and function. Attending to this uncertainty involves both acknowledging the cognitive aspect of the conversation (e.g., explaining to patients and families the unpredictable nature of illness and recognizing the inability of modern medicine to accurately predict life expectancy), while simultaneously addressing the complex emotions associated with the "roller coaster" of chronic conditions (e.g., fear, anxiety, and uncertainty). Second, the chronic nature and unpredictability of clinical courses featuring cardiovascular diseases require that communication be viewed as an evolving series of dynamic conversations that take into account the overall level of engagement of the patient, and the shifting balance between benefits and burdens of any treatment or test that is either currently being used or that is being considered. Patients' preferences towards engagement in their health decisions may change over time as their illness progresses and their health engagement experience changes, which further highlights the relevance of an ongoing patient-doctor dialogue and of the continuous attunement of doctors' communicational behaviors. Considering the specificities of each phase of the patient engagement model, a patient-doctor relation merely oriented to shared decision making alone could be inappropriate. Leading patients in being

actively involved in decisions regarding their health is an uncountable hard tasks for doctors. The patient engagement model presented in chapter 4, as showed in this part of the dissertation, might contribute to make this task easier both for clinicians and policy makers who are involved in the care of cardiovascular diseases. Moreover, it may be a sort of "relational compass" able to detect the cardiovascular patients communicational needs and priorities at each phase of the process. Different phases of the model call for different decision making styles and relational attitudes. Identifying the appropriate application of those ways of patient-doctor interactions according to the patient engagement phases, alone and in combination, would assist clinicians in achieving a true patient-doctor partnership in clinical practice. Furthermore, the breath and detail offered here - unless in the area of cardiovascular care - might be helpful in disseminating research results to healthcare professionals, and in reviewing barriers or obstacles to using research evidence in practice.

Finally, it is equally possible, and in many cases desirable, to integrate different models of patient engagement in decision making as an ongoing process along the patients' illness journey. In line with this reflection, enhancing patient "engage-ability" in medical daily practice would require educational interventions targeted at both clinicians and patients. Patients need to believe that they can and should be engaged in decision making and speak out, and clinicians should be trained to understand what matters most to patients. Tackling structural and process barriers, such as appropriate time and place to do shared decision making and tools to do it, is amply suggested. Notwithstanding, unless we address the patient engagement phase and its implications for the patient's availability to be engaged in decision making through appropriate interventions, active patient engagement in healthcare is unlikely to become a reality.

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– CHAPTER 6 –

The "Patient Engagement Training Program": promoting health professionals learning in patient engagement. An educational protocol

As we discussed in the previous chapters, health professionals' understanding of their patients' health beliefs, values, and preferences is a fundamental feature of patient-centered care. Our research results described in Chapter 4, has shown that patient engagement in the medical course is higher and more effective when physician and patient achieve a shared understanding on issues such as the patient's emotional elaboration of the disease, his/her expected role in decision-making, his/her level of health knowledge and the ability to manage treatment plans. Our evidence indicates that health professionals often have a poor understanding of their patients' perspectives with respect to patients' general level of engagement in their care, desire for information, perceived health status, level of health literacy, and emotional states. Because perceptions of patients can influence health professionals' communication and decision-making and because they often have limited awareness of their patients' perspectives, medical trainings devoted to increase health practitioners' understanding and help them improving communication practices devoted to foster effective patient engagement and patient engagement-sensitive decision making practices are needed. To address this gap, thanks to a research collaboration and partnership between the author of this dissertation and the Institute for Professionalism & Ethical Practice (Harvard Medical School) - which developed the PERCS model aimed at training health professionals in communication and relational skills within difficult conversations -, we propose a complementary educational protocol – namely, the "Patient Engagement Training Program" - to train clinicians in managing challenging conversations with adult cardiac patients at different level of the patient engagement process and in assessing the patients' beliefs about the cause, nature, meaning, and skills for managing his/her health condition as well as the patient's preference for a partnership with the doctor.

Keywords. Patient engagement; patient-doctor relation; medical education; medical communication; patient engagement training program; institute for professionalism & ethical practice

1. INTRODUCTION

1.1 WHY TRAINING HEALTH PROFESSIONALS IN PATIENT ENGAGEMENT STRATEGIES?

In line with the recognition of the importance of patient engagement and of the crucial role of patient-clinician relationship in fostering it – as well demonstrated by the empirical evidences outlined in chapter 4 -, the training needs of health professionals who have to support patient in effectively engaging in health and disease management also need to be considered as a public health priority. As described elsewhere in this dissertation, patients' encounters with health care professionals are both sporadic and ongoing, vary in intensity, and increasingly involve an array of specialist and generalist practitioners (Weiner, Cole et al., 2004; Weiner et al., 2005). Whilst the vast majority of chronic disease management – and among them notable is the case of the cardiovascular care as stated in chapter 4 - is usually conducted by the patient as part of their everyday lives, consultations between patients and healthcare professionals constitutes the pinnacle for the exchange of information and decision making and are the main lever for promoting effective patient's engagement in healthcare (Sears et al., 2014). The extent to which professionals are able to participate in effective communication is likely to make a difference to encouraging and supporting decisions and self-care actions which may enable patients to optimally engage in their healthcare and effectively manage their condition outside of health service settings (Vanderford et al., 2002). Whilst there is a considerable body of theories and evidence regarding medical education to teach techniques to elicit behavioral change in patients (i.e. smoking and alcohol-related problems) (Bandura, 1977; Janz and Becker, 1984; Rollnick et al., 1993; Prochaska and Velicer, 1997), there is as yet very little knowledge in how to train health professionals in ways to enable their patients to become actively engaged in their care; moreover, a lack of specific trainings can be observed in the cardiological field thus requiring the development of

targeted interventions in this clinical area. Health professionals must be given the opportunity to develop their competencies in patient centered care — particularly their communication and relational skills in order to better manage the relational and emotional dynamics occurring in the encounters (Larson & Yao, 2005). Clinicians must also be given the resources needed to work collaboratively with their patients, to help them access and understand health information, to offer support in making choices to those who need it, and, more in general to support their gradual engagement in the medical course according to their unique emotional, cognitive and behavioral mindset featuring the phase of engagement they are attending.

In addition to the potential benefit of improved patient outcomes, a care approach devoted to enhance patient engagement also may be beneficial for the health professional (Drenkard, 2014; Laurance et al., 2014; Grande et al., 2014), thus reinforcing the need to train them with this aim. A cause of clinician's frustration and burnout is recognized to be the patient's non-adherence to treatment or recommended lifestyle change, element which is much more emphasized in the case of chronic disease such as heart failure. Goals established collaboratively and aligned with the patient engagement status are more likely to be realistic and attainable, potentially leading to reduced clinician's frustration (Frank et al., 2014). Furthermore, better-quality clinician-patient relationships are known to reduce the likelihood of malpractice suits.

Certainly there are some real and perceived barriers to implementing patient engagement within chronic care pathways (Manias et al., 2014). Time pressures, insufficient communication and relational skills, and clinicians' perceptions about their role are among these (Polinski et al., 2014). Yet it behooves physicians to recognize that their direct effect on patient outcomes is usually limited and adjust their interactions with patients accordingly. The more effective approach is to adopt a collaborative style that can meaningfully help patients determine how they can best manage their healthcare. This is not surprisingly defined by

health practitioner as a challenging task often leading to perceive conversations with chronic cardiac patients as difficult (Jaarsma et al., 2009; Barclay & Maher, 2010).

1.2 COMMUNICATION SKILLS TRAININGS IN CHRONIC CARE

In medical practice, effective patient-health provider communication and relationship have been recognized as a central clinical skill to be taught (Maguire et al., 2006; Chant et al., 2002; Ammentorp et al., 2006; Brown et al., 2008) . This applies especially in the field of chronic care where successful interaction between health practitioners and patients is of great importance in maintaining an acceptable quality of life and achieving positive long-term health outcomes (Stewart, 1995; Levinson et a., 2007; Maguire & Pitceathly, 2002; Griffin et al., 2004; Butow et al., 2008). Also in the specific area of cardiovascular care it is well acknowledged (Naylor et al., 2004; Dickson & Riegel, 2009). Stewart focused attention on the beneficial effect of improved communication on the emotional health of the patient, symptom resolution, functional and physiologic status, pain control and engagement in healthcare.

However, effective communication is not something that develops automatically over time and with experience (Butow et al., 2008). Otherwise, health professionals can be trained in communication skills (Maguire & Pitceathly, 2002). The usefulness of training courses to improve communication skills for health professionals working in chronic care is now recognized (Lee et al., 2002) though the content and form in which these should be delivered still needs further investigation.

Communication skills training (CST) has become one vehicle to build skills that optimally advance the clinical agenda, alongside promoting professionalism and excellence of care (Von Fragstein et al., 2008).

Recently, mostly in the United States and in less occasions in Europe, increased attention has been given to the training and assessment of health professionals in communication skills. Beginning in 1998, international medical graduates, both in US and in Europe, were required to have their communication skills assessed before beginning postgraduate training.

Participation in CST programs is not limited to trainees, because a growing body of licensed physicians around the world are contributing as participants in, and developers of, such programs. This focus on CST is founded on three basic premises. First, effective communication skills in consultations are linked to important patient and physician outcomes. Second, communication skills are not always optimal; thus, these patient and physician outcomes can be improved. Third, communication skills can be taught. Pretest/posttest methodologies are commonly employed to evaluate the success of training (Merckaert et al., 2002). In 2002, Cegala (2002) published a systematic review of 26 intervention studies of CST for practicing physicians and trainees in graduate medical education commencing in 1990. The authors conducted a study to systematically review completed international research studies exploring CST in provider populations. They conclude there is good evidence that CST is effective in improving the communication skills of physicians (Cegala et al., 2002).

Communication skills training has been found to improve doctor-patient communication. However, the improved behaviors may lapse over time (Rao et al., 2007). It is therefore important to practice new skills, with regular feedback on the acquired behavior. Some have said that medical education should go beyond skills training to encourage physicians' responsiveness to the patients' unique experience (Cegala et al., 2002).

1.2.1 Effective teaching methods

Literature suggests a set of effective methods tested in international communication skill trainings (Berkhof et al., 2011).

Basic knowledge

The majority of trainings for developing the health professional's attitude towards patient centered communication, recognize as a central aim to provide significant and up-to-date knowledge about the values and concrete teqniques to manage conversations with patient which are really patient centered (Wilkinson et al., 1998; Kurtz et al., 2007; . For instance, detailed handouts or short lectures, or both, might provide evidence of current deficiencies in communication with patients, reasons for these deficiencies, and the adverse consequences for patients and clinicians (Aspegren, 1999; Nehls et al., 2014). Participants should be told about the communication skills and changes in attitude that remedy deficiencies and be given evidence of their usefulness in clinical practice (Kurtz et al., 2007).

Modelling

A second teaching method which has been demonstrated to be effective when training doctors in communication skills, is to provide an educational context where trainers could demonstrate their key communication and relational skills in action— with audiotapes or videotapes of real consultations. The participants should discuss the impact of these skills on the patient and health professionals (Butow et al., 2008; Nehls et al., 2014).

Alternatively, an interactive demonstration can be used. A facilitator conducts a consultation as he or she does in real life but using a simulated patient (Dosser & Smith, 2014). The interviewer asks the group to suggest strategies that he or she should use to begin the consultation. Competing strategies are tried out for a few minutes then the interviewer asks

for people's views and feelings about the strategies used (Shen, 2014). They are asked to predict the impact on the patient. Unlike audio-taped or videotaped feedback of real consultations, the "patient" can also give feedback (Lane et al., 2007). This confirms or refutes the group's suggestions. This process is repeated to work through a consultation so that the group learns about the utility of key skills.

Practicing key skills

If doctors are to acquire skills and relinquish ineffective communicational behavior that block their patient engagement, they should have an opportunity to practice and to receive feedback about their relational performance. However, the risk of distressing and deskilling the doctor must be minimized (Maguire & Pitceathly, 2002).

Practicing with simulated patients or trained actors has the advantage that the nature and complexity of the task can be controlled. "Time out" moments can be called when the health professional gets stuck. The group can then suggest how the interviewer might best proceed (Nestel et al., 2014). This helps to minimize deskilling. In contrast, asking the doctor to perform a complete interview may cause the doctor to lose confidence because "errors" are repeated. Asking doctors to simulate patients they have known well and portray their predicament also makes the simulation realistic. It gives doctors insights into how patients are affected by different communication strategies. In this sense, simulation-based teaching is a satisfactory basis for acquiring interpersonal skills (Liaw et al., 2014; Liu et al., 2015).

The objective in creating any simulation experience is to achieve a high degree of fidelity, implying a close replication of the real-life, human situation. Fidelity to the real clinical situation helps students to react as they would in a real-life scenario. Using simulation to enhance the fidelity or authenticity of the learning experience has been indicated as extremely valuable when patient-centeredness is at stake.

1.3 THE PROGRAM TO ENHANCE RELATIONAL AND COMMUNICATION SKILLS (PERCS): A LEARNING ENVIRONMENT FOR DEVELOPING HEALTH PROFESSIONALS' PATIENT ENGAGEMENT STRATEGIES

Training health professionals in interpersonal communication is the cornerstone of medical education as patient-clinician communication is the primary tool for sharing relevant health information and to make chronic patient engaged in effective self-management (Ammentorp et al., 2007; Dickson & Riegel, 2009). It is imperative for health care providers to use their communication skills to elicit clear reports of symptoms to accurately diagnose health problems and to assess the patient engagement level according to the model described in chapter 4 (i.e. understanding patients' self-management competencies, information baggage and their emotional status), for consumers to share their personal health experiences and ways of coping with the disease with those caring for them, and for consumers and providers to exchange relevant health information throughout the course of health care treatment (Cegala et al., 2000). Yet, the strategic use of interpersonal communication in health care delivery is most complex, multifaceted, and often problematic, necessitating a careful study of the communication process with patients at different level of the engagement process (see Chapter 4 and 5) to increase understanding and help improve health practitioners' communication practices devoted to foster effective patient engagement in the area of cardiac care.

1.3.1 Description of PERCS's pedagogy

Among the current programs delivered in the US to train doctor in effective communication and relational skills, it is notable the Program to Enhance Relational and Communication Skills (PERCS), a project of the Institute for Professionalism & Ethical Practice at Children's Hospital Boston (Browning et al., 2007; Meyer et al., 2009) – Harvard Medical School. The

workshop is interdisciplinary in its structure, involve health practitioners with different levels of professional experience, employs trained actors to portray patients and family members, and involves learners in improvised case scenarios. The program responds to several developments in contemporary health care: medical education reform, changing definitions of professional competence, and calls for greater attention to qualities of compassion, trust, and respect in practitioners' relationships with patients and families. The program's pedagogy responds to these developments by creating a safe climate for relational learning, by enacting emotionally challenging and ethically salient case scenarios, and by integrating patient and family perspectives in novel and substantive ways (See appendix 1 for an example of case scenario). By creating a curriculum and learning environment that explicitly embraces the experience of learners, the program's aims at highlighting the patient and family perspectives and to ground the learning process in the everyday relationships of clinical practice (Lamiani et al., 2012).

The PERCS educational approach, called relational learning (Browning et al., 2007), is based on the conviction that the learning that matters most in the professional development of health care professionals occurs in the context of relationships established among practitioners, patients, and family members. The strength of the PERCS educational approach, developed initially to explore end-of-life conversations in the pediatric context, has expanded its application to a wider range of difficult conversations in the pediatric field as well as adult medicine, including discussion of organ donation, disclosure of medical error, and assisting family members during the invasive medical procedures of loved ones (Curley et al., 2012). However, up to now, PERCS hasn't still focused specifically on issues related to chronic patient engagement in healthcare. From here, the idea to develop a training primarily devoted to address this educational gap and foster the healthcare professionals' ability to engage their patient in the whole process of care.

2. THE "PATIENT ENGAGEMENT TRAINING PROGRAM"

Aligned with the PERCS learning principles and pedagogy and according to the premises about the need to foster health professionals' skills in patient engagement, we developed an educational protocol aimed at increasing health professionals communication and relational strategies for patient engagement. This protocol was built upon the research results and the patient engagement model described in this dissertation (see Chapter 4) and its strength is linked to the fact that it was designed in line with the empirically investigated patient's experiences and expectation of care.

2.1 GOALS OF THE PROGRAM

The "Patient Engagement Training Program" is designed to help health professionals in managing challenging conversations with chronic patients at different levels of engagement in order to enact effective strategies to assist them in becoming effective self-managers of their healthcare. Particularly, health professionals attending this training are expected to acquire knowledge and skills for a deeper understanding of their patients, allowing support to be more effectively tailored to a person's underlying engagement level.

Particularly, health professionals attending the training are expected to gain the following learning outcomes:

- increase in understanding of the nature of patient engagement in healthcare;
- improvement in communications skills devoted to engage patients;
- improvement in confidence in managing chronic patients;
- improvement in the ability to assess the patient's engagement level;
- improvement in the ability to tailor support according to the patient engagement level;

- learning how to deal with patients at different levels of engagement;
- development of more effective patient-health professionals interactions fine-tuned with the patients' role expectations;
- learning specific strategies to improve patient engagement;
- having the opportunity to reflect on personal attitudes and relational behaviors.

2.2 PARTICIPANTS AND SETTINGS

Participating providers would be whoever in the clinical settings involved in providing every day care to adult chronic patients (i.e. physicians, nurses, physiotherapist, occupational therapists, psychologists…). This training is designed for inter-professional treatment teams according to the multiple care needs featuring patients with chronic diseases. It was general and not for specific disease: for this reasons, participants are not belonging to a specific medical specialization, but the only requirement is that they are involved in chronic care delivery. For these reasons, the training program is thought to be implementing in different indication fields and across healthcare settings.

2.3 STRUCTURE AND FORMAT

The intervention is designed based on the PERCS model (Browining et al. 2007) with refinements for health professionals based on adult learning theory (Merriam, 2001; McLean & Vermeylen, 2014) and studies of continuing medical education (CME) (Cantillon & Jones, 2009;. Mann, 2002; Mazmanian & Davis, 2002), to the authors at the time of study initiation) to promote experiential learning and immediate clinical application.

Using a combination of web-based seminar, face-to-face workshop, and virtual reality based skills maintenance, health professionals will be provided with an up to date knowledge and skills about patient-centered communication and patient engagement theory useful for

managing conversations with adult chronic patient with different levels of engagement in healthcare (see Figure 1.6).

FIGURE 1.6 FLOWCHART OF HEALTH PROVIDER LEARNING'S MODULES

LEVEL OF LEARNING NEEDS' COMPLEXITY

MODULE 3

ADVANCED

SKILLS' MAINTENANCE
BY USING VIRTUAL REALITY

MODULE 2

INTERMEDIATE

THE PATIENT ENGAGEMENT MODEL IN PRACTICE:
FACE-TO-FACE WORSHOP WITH SIMULATED CASE
SCENARIOS

MODULE 1

BEGINNING

WEBINAR ON THE THEORY OF
PATIENT ENGAGEMENT MODEL

THEORETICAL UNDERPINNINGS

BIOPSYCHOSOCIAL MODEL
CHRONIC CARE MODEL
PATIENT & FAMILY CENTRED CARE
PATIENT ENGAGEMENT MODEL

Data collection

Pre-survey

Training attendance

Post-survey

2.4 DESCRIPTION OF THE EDUCATIONAL INTERVENTION

The "patient engagement training program", based on the fruitful encounter between the PERCS approach and the patient engagement model developed in this research project (see chapter 4) consists of 3 core modules each of them devoted to address learning needs with different levels of complexities (beginning, intermediate and advanced). Following the detailed description of each module.

2.4.1 Module 1: "BEGINNING"

The first module in step 1 of the educational training is aimed at imparting healthcare professionals the theoretical framework, key competencies and effects of the patient engagement model described in Chapter 4. The main objective here is to work through the patient engagement model step-by-step. This module is also the theoretical base for module 2 where healthcare professionals will be asked to face with simulated case scenarios.

More in details the training session will consists in a one 120-min webinar with interactive small group learning session delivered remotely but in real time to 8-15 participants each. It will be delivered using power-point supported interactive presentations and scientific and conference call (via Web-Ex), as well as discussion guidance from webinar facilitators. Webinar format will feature: introduction of the new knowledge content, participant activities to practice the skill and wrap-up. All these didactical methods will be applied with the aim of offering the theoretical underpinnings to effectively implement patient engagement knowledge, skills and attitudes in the whole chronic care process.

The sequence of the topic will be: 1: introduction to the patient/family centered and the chronic care models; 2: patient-centered communication skills and techniques; 3: the theory of the patient engagement model (see chapter 4).

2.4.2 Module 2: "INTERMEDIATE"

This second module is designed as a one day-long face-t-face workshop which brings together practitioners of different professional disciplines with varying levels of experience. Particularly, this face-to-face training session will be developed according to the standard PERCS model, and will include 10 –15 interdisciplinary participants, and two faculty facilitators representing medical, and psychosocial perspectives.

Faculty facilitators will cultivate an atmosphere of acceptance, humility, and curiosity that encourages participants to feel comfortable and to reflect on their own clinical practice

The curriculum will incorporate brief didactic presentations summarizing established approaches for sharing difficult news with patients and the evidence base for improving communication and relational skills

At the center of the program will be 4 adult chronic care case scenarios enacted with professional actors that unfolded clinically over several conversations with the "patient" and/or "family," followed by debriefing and videotape review. Each case scenario will be developed according to the different phases of the PHE model (each case will be featured by a patient in a specific phase of the model itself – blackout, arousal, adhesion, eudaimonic project). Participants will have the opportunity to engage in realistically enacted conversations, to review video clips and receive feedback, to observe others, and to participate in experiential collaborative learning with interdisciplinary colleagues. The core learning occurs through live enactments of difficult conversations with actors portraying

patients and family members, followed by guided debriefings that support individual and group reflection. By taking part in these facilitated discussions, participants enhance their communication skills; more importantly, they explore the ethical dimensions of these high-stakes conversations. They reflect on how to connect to patients and families in stressful circumstances and how to share with families the moral burden of the challenging and sometimes excruciating decisions they face. Participants are concretely reminded that patients and families need understanding and kindness at these difficult times, a need which speaks directly to the personhood of clinicians.

2.4.3 Module 3: "ADVANCED"

This module is conceived as a "supplemental booster sessions" a that will be delivered by providing a virtual reality training featuring advanced simulated case scenarios of patient-doctor interaction aimed at consolidating the communication and relational strategies acquired in the previous modules and at reinforcing effective strategies for patient engagement.

Technological advances have made available to health-care professionals a wide set of innovative training tools. Among these, virtual reality seems to have a great potential to enhance the learning process (Mantovani et al., 2003).

The possibilities provided by the use Virtual Environments, such as 3D immersion, multiple perspectives and multisensory cues offer a number of potential benefits to health-care education and training. This modules features the use of virtual reality as it has been successfully used to simulate person-to-person interactions for training in psychiatry and the social sciences in a variety of circumstances by using real-time simulations of personal interactions. This indicates that VR could be useful not only to support the acquisition of

technical skills, but also to enhance a complex set of skills including the personal aspects of patient care which are in line with the core objective of this educational protocol.

2.4.4 Course evaluation and outcome measures

All participants will be asked to complete questionnaires before and immediately after the each module. Participants will rate their sense of preparation, communication and relational skills, confidence, and anxiety. Open-ended questions asked participants about lessons learned, aspects of the training they found most helpful, and suggestions to improve the training. Three-month follow-up questionnaires will be conducted by e-mail and standard mail

2. 5 DISCUSSION AND CONCLUSIONS

By attending the "patient engagement training program", participants will deepen their understanding of patient and family perspectives, learned and practiced a range of communication and relational skills, recognized valuable existing competencies, and strengthened their commitment to patient engagement. We maintain that the experiential nature and realistic enactments of the program will be vital to its success, engaging participants emotionally and providing opportunities for practice.

Relational learning opportunities can help practitioners bring their very best selves to these difficult encounters with confidence, clarity, and a sense of purpose.

This training concept still needs to be implemented and tested and, as just underlined, it was developed basing on the insights emerged from our research in the cardiovascular field, and thus, it should be tested and adapted in other clinical areas. Moreover, it is based on research

results developed in the Italian context: for this reason it is required to be tested in other countries in order to explore its generalization and/or hypothesis of adaptation.

Finally, we maintain that it is essential that some form of programme evaluation – in terms of patients' satisfaction towards their health professionals who attended the training – should be included in order to insure quality and modify the curriculum as necessary.

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APPENDIX 1. EXAMPLE OF CASE SCENARIO (Browing et al., 2007)

Billy O'Brien.

Billy is a five-year old boy from an Irish American family. He arrives by helicopter from a nearby community hospital. He was playing on the beach with his family when he disappeared. Mr. O'Brien had been in the water with Billy, and went back to his blanket for a flotation device. After a 5- to 10- minute search, Billy was found submerged in shallow water, initially pulseless. CPR was performed at the scene by his mother; he was transported by EMS to the nearest hospital. On arrival he was unresponsive with GCS of 3 but with normal sinus rhythm, hemodynamically stable, on moderate ventilator settings. CT of head was normal, C-spine films normal, cervical collar in place. Exam on arrival: pupils 4 mm bilaterally and poorly responsive, no spontaneous movements, no response to deep pain. Blood work sent and pending.

Conversation 1 (Sunday morning)

The parents (Bill Senior and Lisa) have just arrived by car and are in the waiting room. The physician and nurse go to meet them. On the basis of the presentation, the clinicians know that the most likely outcome is death. If the child survives, he will probably be in a persistent vegetative state, or pvs (i.e., permanent unconsciousness). There is a small chance that he may regain some features of consciousness, but almost certainly he will never regain relational capacity.

Conversation 2 (Monday afternoon, eight days after accident)

Billy's parents have been at his bedside since Sunday. Billy received standard medical management for increased ICP and had remained hemodynamically stable, on moderate ventilatory settings, with no spontaneous respiratory effort. CT showed diffuse cerebral edema. Neuro exam otherwise unchanged, without any detectable neurological function. An examination for brain death was performed on Wednesday morning after rounds, but during the apnea test Billy started to make some respiratory efforts, so he was placed back on the ventilator. The results of the test were explained to the family. Billy is not brain dead at this point, but other than this respiratory effort, he has no evidence of neurological function. His prognosis continues to be dismal, most likely either death or pvs. The chances for a better outcome are extremely slim.

Billy still shows no spontaneous motor activity, and he shows posturing in response to deep pain. When attempts are made to wean the ventilator, he makes occasional respiratory efforts, but he is still definitely ventilator dependent. If the ventilator were withdrawn at this time, Billy would likely die within minutes to hours (although one can never be sure). Otherwise, he will require a tracheostomy and g-tube with transfer to a rehabilitation hospital or nursing home. He may eventually wean from the ventilator, but is likely to remain in a vegetative or near-vegetative state.

The physician and nurse meet with the family to discuss options. Legally and ethically acceptable options cover a wide range. At one end of the spectrum, the family could opt to do everything possible to keep Billy alive, including tracheostomy, g-tube, and chronic ventilation. At the other end of the spectrum, the family could opt for comfort care only. This would involve removing the ventilator and providing only those treatments that contribute to patient comfort, including the administration of sedation and analgesia, titrated to any signs of pain or suffering. As noted above, this would probably (but not definitely) lead to Billy's death in a matter of minutes to hours.

Although these decisions do not need to be made emergently, this point represents an important "fork in the road," and the clinicians need to guide the family in choosing the path that is most consistent with their beliefs and values. The physician and nurse stop by the bedside.

Conversation 3 (Next day)

This is a continuation and completion of the conversation from the previous day.

AFTERWORD: CONCLUSIONS AND FUTURE RESEARCH DIRECTIONS

This dissertation started from the assumption that health systems throughout Europe and the world are searching for innovative and cost-effective ways to make their services more responsive to patients and in line with the principles and values at the base of a participatory healthcare environment. On the other hand, if we assume a marketing perspective, we can ascertain that there is a perceived and unavoidable need to respond to consumer pressure and to make health care more like other consumer experiences. But the call for increasing patient engagement in healthcare – where patients are encouraged to take an active role as a key player in protecting their health, choosing appropriate treatments for managing chronic disease – is often ignored and there is still scarce agreement about how to define and promote it, starting from the feature of the patient-health provider relationship which can hinder or foster its realization. It also has impeded the design and implementation of educational trainings specifically devoted to teach clinicians how to manage the relationship with patients featured by different levels of engagement in their care pathway. Finally, due to this scarce reflection upon the meaning of patient engagement and upon the shapes it might assume in the medical practice, also a lack of awareness about what it means for the professionalism of the 21st century clinicians is notable.

In line with these premises, we have emphasized the need for conducting an integrated approach to the study of patient engagement throughout this dissertation. In chapter 1, we presented the epistemological and historical premises of the participatory medicine movement which is the "cradle" of the concept of patient engagement – subject of this thesis. In chapters

2 and 3 we summarized and discussed the literature about participatory medicine by providing a conceptual anatomy of the main concepts currently used to describe the active role of patient in healthcare (i.e. patient empowerment; patient participation; patient involvement; patient activation; patient engagement) - see chapter 2; and by offering an in-depth examination of the literature specifically focused on the patient engagement concept – see chapter 3. These introductory chapters were generally aimed to outline the breadth and depth of the contributions in this dissertation, and to invite exploration between perspectives and settings of application. Chapter 4 summarizes the results of a two-year long in-depth grounded theory study on patient engagement which made reference to the expressed view and perspectives of individuals affected by heart failure – a prototypical disease in the chronic care field. This work was conducted in order to elucidate particular feature of patient engagement and provide an interpretive rendering of this phenomenon by focusing on meaning and process at the subjective and relational levels. This qualitative in-depth research developed a theoretical model of the psycho-social process at the base of patient engagement and highlighted the key components of the patient-doctor relationship which can facilitate of hinder the process itself. This work allowed to foster more detailed and empirically grounded research on this topic. In following on from the findings – both theoretical and empirical-, the last section of this dissertation is conceived as a showcase to illustrate and discuss possible avenue for future applications of the results presented along the previous chapters and in particular in chapter 4. Particularly, chapter 5 was devoted to offer an innovative vision about the process of clinical decision making by suggesting the opportunity for adopting an engagement-sensitive decision making style which advocate the importance of preparing patients for a shared decision making clinical encounter, partly by changing attitudes towards engagement, partly recognizing the not always appropriateness of this decisional style. Finally, chapter 6 presents the structure proposal of an educational intervention aimed at

teaching communication and relational skills to health professionals specifically devoted to foster chronic patient engagement in their healthcare pathways. These final chapters tried to integrate empirical evidences for promoting translation of the theory into practice of patient engagement.

What is patient engagement?

The global architecture of this dissertation was thought to provide an indicative framework and some answers to the questions that laid the ground to the research conducted in the author's doctoral path: "What is patient engagement?"; "What are the feature of the patient-health professional relationship that could foster or hinder its realization?"; "How participatory medicine might impact on a renewed professionalization of the medical profession?". The studies presented convey on the one hand the variety of definitions currently available in the academic literature of the concept of patient engagement; on the other hand, tried to "solve the puzzle" by developing an evidence-based definition of patient engagement based on the patient lived experience and perspective. This thesis tried to bring these definitions into dialogue with each other. A broadest and dynamic view of patient engagement, stated explicitly in chapter 4 and echoed in the following chapters, suggests that it is not possible to avoid considering the relational dynamics occurring between patients and doctors to understand the development of this process. Considering the medical consultation, engagement can be seen to be dependent on the contributions of all parties concerned (patients, doctors and also other caregivers).

Within this framework, the author suggest that distinctions should be made between desired and achieved level of patient engagement; and that, because not all patients want to be

engaged at all times, patient engagement cannot be understood in global terms as an "on-off status", but only within specific settings and basing on the stage of the patient's illness course. Indeed, preliminary evidences suggested that patient engagement should be considered as a processual phenomenon which changes its features along the care process and depends not only on the patient's health literacy but also, on the emotional elaboration and level of adjustment to his/her health status. Recognizing the role of psychodynamic mechanism in promoting or hindering the patients' ability to engage in their healthcare is a results of this work and can be useful to promote fine-tuned and effective patient-doctor relationship.

Particularly, if effectively engaged, patients can play a distinct role in their health care by:

- ✓ understanding the causes of disease and the factors that influence health;
- ✓ self-diagnosing and treating minor self-limiting conditions;
- ✓ selecting the most appropriate treatment for acute conditions, in partnership with health professionals;
- ✓ managing treatments and taking medications appropriately;
- ✓ monitoring symptoms and the effects of treatment;
- ✓ being aware of safety issues and reporting them;
- ✓ learning to manage the symptoms of chronic disease;
- ✓ adopting healthy behavior, to prevent the occurrence or recurrence of disease.

The author of this dissertation maintains that recognizing the patient's role and seeking to strengthen it is fundamental to securing a more participatory approach to health care delivery. It also provides the essential underpinning for strategies that aim to reduce health inequalities

and improve health for all, in line with the well-known programming goal of the World Health Organization (WHO).

Considering these premises, interesting insights emerged also for developing effective trainings for health professionals – still missing in the current medical curricula - devoted to give them knowledge and skills to promote the engagement of their patients. Fostering a culture of partnership between health professionals and patients requires professionals to develop a specific set of skills and attributes.

In our vision, clinicians will require some fundamental knowledge and skills:

- ✓ a deeper understanding of the patient's perspective both in terms of unmet needs and role expectation in the patient-doctor relationship;

- ✓ the ability to make patients able to appropriately navigate sources of information on health and health care;

- ✓ the ability to educate them about protecting their health and preventing the occurrence or recurrence of disease;

- ✓ the ability to elicit and take into account a patient's preferences;

- ✓ the ability to share treatment decisions when appropriate;

- ✓ the ability to provide support for self-care and self-management;

- ✓ the ability to work in multidisciplinary teams;

- ✓ the ability to use new technology to assist patients in becoming more engaged in their health.

In this sense, we maintain that both patient and health professional's education needs to become an integral part of health policy strategies to really implement the principles and the values featuring a participatory healthcare environment.

Final remarks and recommendation

To sum up, this dissertation outlines what the research evidence tells us about the patient's experience of being engaged in their care and its impact for their overall quality of life. Patient engagement is a much more complex concept that is generally understood and certainly more so than current health policies that promote it would suggest. Research results highlighted that engagement is not a status but has a processual nature which may potentially sustain an actual innovation of healthcare paradigms in research and intervention, by providing a wider vision of patients' experiences and preferences when navigating their healthcare journey. The contribution of this thesis provides multiple entry points for seeing what patient engagement looks like in practice and how our understanding of it can be developed through further focused and nuanced research – both qualitative and quantitative.

This thesis allow us to consider patient engagement from different viewpoint: in ideal form, through the eyes of researcher and policy makers who state definitions "a priori"; and in terms of how it is actually enacted and experienced by patients in their medical course. Moreover, possible lines of interventions that could be implemented to improve patient engagement are discussed. To be effective, this areas of interventions should adopt a broader and more systemic conceptualization of patient engagement that would lead to a more genuine consideration of patients as persons, who have histories, desires, needs, preferences and projects for their present and future lives: projects that – at least at the emotional level – should not become inconsequential because of chronic conditions, but – at most – be reconfigured and reoriented, in the eudemonic development of a new self-representation. To

have a sense of control over one's own disease a treatments - not only at the behavioral level, but primarily at the cognitive and emotional levels - appears to be crucial for guaranteeing a true engagement of people towards their health and care. In other words, this may call for a rewording of the term "patient engagement" to "personal health engagement", in order to underline the importance to help patients become aware, accept and incorporate their disease (and its treatment) in a new, achievable and positive planning of one's own health and wellbeing. Engaging patients in their care remains a crucial issue in the treatment and management of chronic patients, particularly for high-risk patients. In as much as chronic disease management requires long-term adherence to complex regimens, the attitudes and the subjective experience of patients are of primary importance and must be taken into consideration.

Further research should aim to gain a better understanding of the role of the contextual influences in facilitating patient engagement for effective disease management. Within this element, a number of different structural conditions – such as the nature of the health problem and the organizational settings of care provision.

We thus advocate for future research projects able to guarantee a deep understanding of the subjective patient engagement experience in order to sustain the shift from a "patient centered" to an actual "people oriented" approach to medicine. Therefore, we suggest to move from the consideration of individuals as merely "patients" to "persons" able to plan for their present and future life trajectories on the bases of their subjective experience of health engagement. "Persons" who want to "speak laud their voices" for orienting healthcare system approaches and priorities. "Persons" who need to be heard, understood, and considered for the innovation of healthcare systems as participants in their wellbeing achievement and eudaimonic expression of self-potentialities.

Moreover, from our perspective, there is a growing need for research approaches that are able to give voice to the intimate view of problems and needs for each patient. This would really promote care practices that are fine-tuned with the subjective experience of patient engagement and priorities. In this arena, qualitative research can contribute substantially to the revision of healthcare practices in the aim of fostering better patient activation in their own health management. As our results suggested, focusing on the subjective experiences concerning the patients' illness journey, and their own individual ways of engaging in health management, have to be acknowledged an indispensable component of healthcare research, and it may illuminate which models are most effective, thus fostering innovative interventions that can make the healthcare system more responsive to patient needs.

Finally, beyond the rhetorical call for increasing patients engagement, we recognize the urgency to have an evidence-based measure of it and capture its impact when planning and implementing initiatives aimed at sustaining the engagement of consumers in their health. In this aim, the results of the research presented in this dissertation have contributed to the development of an assessment tool - the Patient Health Engagement Scale (PHE-scale) - whose process of validation is still ongoing[7].

These insights into the meaning of patient engagement should be considered only a first step but also a precious input to facilitate the identification of the linkages and contributions that can be made, across different research and disciplinary approach, in the study of patient engagement. It also might enable identification of gaps that potentially need to be filled. It aimed at offering future pathways of research and reflection to enable patients and their

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[7] See: Graffigna, G., **Barello, S**., Bonanomi, A., Lozza, E. (2015) Measuring patient engagement: Development and psychometric proprieties of the patient health engagement (PHE) scale. Submitted to: *Frontiers in Psychology in Clinical Settings*.

organizations, healthcare practitioners and policy-makers to advance their understanding of taken-for-granted, yet opaque, concept that is high on the health policy and governmental agenda. Undoubtedly, much remains to be understood in this highly topical and important field of inquiry. Our theorization allowed to reach down to fundamentals of patient engagement, up to abstraction and probes into experience; but also poses new questions about this phenomenon. Questions that are always fruitful and desirable when planning new lines of research. We hope that the preliminary insights we have constructed in this work will facilitate future developments in practice, teaching and research.