Guendalina Graffigna, Serena Barello, Stefano Triberti (Eds.)

Patient Engagement

A Consumer-Centered Model to Innovate Healthcare

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Introduction

Western Societies are facing several challenges at the economic, social, and environmental levels. The demand for healthcare is increasing and changing its focus due to the ageing of populations and the rise of chronic conditions. Technological and scientific advancements in the healthcare sector have gradually improved the life expectancy of people. Less people are dying from infectious diseases and more people are living longer. As the population ages, more people are at risk of contracting chronic diseases, with a consequent escalation in demands for healthcare. The extended life expectancy and the expectation of an improved quality of life is putting pressure on Western healthcare systems, which need to improve their management approaches and their services delivery in order to become better attuned to the evolving demand of their clients. Precisely, in a period of limited resources, healthcare systems are forced to achieve a better balance in "doing more with less". Consequently, health systems are now searching for new and effective ways to make their services more sustainable at the economic level and more responsive to their patients' needs and expectations.

In this framework, encouraging people to engage in health care management, by supporting them in the decision-making process and in enacting healthy behaviors, is crucial for achieving such goals. The concept of patient engagement – borrowed from the marketing conceptualization of consumer engagement – is the assumption that making patients/clients co-producers of their health might enhance their satisfaction with the healthcare system, as well as their responsibility, by improving positive clinical outcomes and reducing health delivery costs. Precisely, the experience of engagement is a key qualifier of the exchange between the demand (i.e. citizens/patients) and the supply of healthcare services: understanding the strategic levers that sustain patient engagement is a key priority to innovating healthcare systems and to improve their sustainability.

Why a New Book on Patient Engagement?

Across the world, policy makers, health professionals, and scholars agree about the urgency of engaging patients in the process of their care, but concrete guidelines for practices do not exist yet. The issue of patient engagement has been dealt with in a poorly systematic way so far: only in sporadic peer reviewed articles and managerial position papers. Thus, handbooks able to offer a more comprehensive and applicative vision of this complex phenomenon are urgently needed.

By assuming a Consumer Psychology perspective, this book offers a comprehensive theoretical vision on patient engagement by suggesting concrete tools and insight for promoting it. Precisely, after introducing the *Patient Health Engagement Model* (PHE model), and its value to orient healthcare practices, this book discusses how new technologies are crucial resources to enable innovative interventions aimed at promoting patient engagement. The book concludes by suggesting possible fields of application for patient engagement interventions in different healthcare settings and situations.

The First Section of the Book: Towards the *PHE Model*

The first section of this book aims at setting the ground for introducing the key role of patient engagement in the process of healthcare innovation. The first Chapter discusses the main global challenges that are impacting on Western healthcare systems. These issues are forcing the healthcare system to revise its way of delivering services in order to make them more sustainable and better able to satisfy patients' demand for care and cure. In this light, the Chapter introduces the value of patient engagement in innovating healthcare and to guaranteeing a renovated partnership with its different stakeholders.

Chapter 2 is conceived as a 'glossary' aimed at defining the main concepts used to define the active role of patients in their care. This growing plethora of terms risks being confounded for healthcare professionals, policy makers, and scholars, and my hinder a real commitment to practice. This Chapter, by defining the key concepts recurrent in the field of participatory medicine (such as patient participation, patient involvement, patient empowerment, patient activation...), helps to clarify the innovative applicative potentialities of patient engagement.

Finally, Chapter 3 introduces a concrete theoretical framework aimed at defining and modeling patient engagement. More specifically, by assuming a Consumer Psychology perspective, this Chapter introduces the *Patient Health Engagement Model* (PHE model) and describes the features of its four experiential phases (i.e. *blackout, arousal, adhesion, eudaimonic project*). Furthermore, it highlights the main factors that sustain patients' evolution throughout their engagement journey. The PHE model introduced in this Chapter will be the main *fil rouge* within the following two sections of the book, which describe concrete strategies and tools to promote patient engagement in different healthcare settings.

The Second Section of the Book: the Value of Positive Technology to Promote Patient Engagement

The second section of the book focuses on new technologies. We will show how the goal of patient engagement can be achieved thanks to the smart use of technological tools, to the point that the new affordances that comes from the technological revolution can be considered as the main instruments for intervention aimed at fostering the well-being of patients. Indeed, these types of technologies are labeled "positive technologies” (Chapter 4), since they are designed with the aim of improving the wellness and health of individuals, groups, and organizations. We will explore the scientific paradigm of *Positive Technologies* in order to understand (1) how a technology can be used to foster patient engagement, and (2) what types of technologically enhanced experiences are preferred in the light of a patient engagement framework.

Chapter 5 presents general insights along with an operational model in order to explain how positive technologies for health engagement have to be *designed*. Considering patients’ needs and priorities as the foundation of design, the User-Centered Design (UCD) approach appears to be more desirable in the context of the creation of technologies for patient engagement purposes. In addition to this, the Chapter offers an innovative view of the User Centered approach thanks to a new model (the *Perfect Interaction Model*, PIM) which is also presented here; also, the prescriptions of the model are adapted to the field of patient engagement thanks to the association between the PIM and the PHE models.

Finally, the last Chapter of the section (Chapter 6) presents an example of a technology-based intervention, which will be evaluated from the joint viewpoints of user experience and patient engagement. This functions as an example of how the two important concepts can be implemented in the real-life context of an intervention for health.

The Third Section of the Book: the PHE Model in Practice

Modern health care is complex, and many patients struggle to obtain, process, communicate, and understand, even basic health information and services. Many patients lack health literacy, or a true understanding of their medical conditions. Many practitioners fail to provide the information that patients need to make the best decisions about their own care and treatment, and even when patients do receive detailed information, they can be overwhelmed or lack confidence in their own choices. In other words: *“How can patients be engaged in practice and how we can support this process?” “Isn’t there concrete guidelines for health professionals to make decisions which are in line with patients’ desires and expectations? “To what extend should clinicians engage family caregivers in the care process in such a way that they become a resource for healthcare?*

The third section of this book offers possible answers to these questions through the lens of the PHE model. These concrete ‘tips’ for orienting actions may be useful for all decision makers in the healthcare arena – physicians, nurses, and other clinical providers, but also public health and hospital administrators – who are committed to promoting patient engagement in their healthcare organization.

In Chapter 7 potential solutions for delivering consumer-oriented decision making are discussed; specifically, concrete tips for talking with patients are provided, taking into account their level of health engagement and attitudes toward their involvement in care decisions.

Chapter 8 and 9 discuss the value and the challenges of engaging family caregivers in the patients' care. These Chapters offer insights related to effectively collaborating with families to improve patients' quality of care. Chapter 8 will discuss the case of parents' engagement in NICU care environment, which is a paradigmatic case that testifies the relevance of collaborating with the family of a young patient. On the other side, Chapter 9 deals with the crucial role of informal caregivers in the care of chronically ill elderly patients.

Finally, Chapter 10 offers an insightful picture about how hospitals should respond to the call of patient engagement by enabling a number of participative initiatives able to innovate present care delivering models.

It is our hope that these reflections may sustain our readers in identifying the processes and systems that may support effective patient engagement in treatment decisions; in ensuring staff training aligned with the call of patient engagement; in monitoring their patients' progresses towards engagement and in intervening to overcome the obstacles that may emerge.

Guendalina Graffigna, Serena Barello

Innovating Healthcare in the Era of Patient Engagement: Challenges, Opportunities & New Trends

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

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

1 Introduction

In this chapter, we offer an overview of ongoing societal and global tendencies that are deeply reframing healthcare. The citizens' demand and expectations toward health and care, precisely, is continuously evolving, resulting in setbacks of consolidated knowledge and practices related to the traditional management of healthcare organizations and services (Barello et al., 2012; Glaser et al., 2014). The incertitude provoked by this evolving and fluid scenario is putting pressure on healthcare professionals, managers, policymakers, and technological engineers and designers, who are in a desperate search for new insight and advice to innovate healthcare and make it more sustainable and effective (Plsek & Greenhalgh, 2001; Pruitt & Epping-Jordan, 2005).

Moving from this frame, we outline how the concept of patient engagement may be a valuable option to make sense of the evolving scenario in which healthcare systems need to act and to orient changes and actions. Patient engagement, conceivable as a qualifier of the exchange between the “demand” and “supply” of healthcare, has, so far, raised the interest of experts across the world, both inside and outside academia. Several empirical studies have also demonstrated the positive outcomes of patient engagement at the clinical, psychosocial, and economic levels (Graffigna et al., 2014).

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

Let’s start this promising patient engagement journey together!

2 The Main Challenges of the 21st Century

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

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

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

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

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

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

3 When the “Demand” for Healthcare Changes: Directions of Innovation

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

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

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

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

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

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

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

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

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

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

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

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

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

Overall, the concept of engagement attempts to offer understanding in the complex and mutable context of healthcare delivery and organization that we described in the previous paragraphs. Its final aim is that of giving (back) a leading role to patients and taking them on board for a more efficient and effective process of care delivery. Furthermore, patient engagement can be—from our perspective—the key to systematically reading and making sense of the different organizational, relational, and psychological components in play in the dynamic exchange between the “demand” and “supply” of health and care (Graffigna et al., 2014).

In our vision, the concept of patient engagement qualifies the relation that the patient ("the demand") established—or may establish—with his/her reference healthcare system ("the supply of healthcare") in the different phases of the care process. The objective is favouring the autonomy of the patient toward the conscious management of his/her health and illness, following the idea that a good partnership between patients and healthcare providers may lead to several positive outcomes. As we shall discuss in the next chapters, new technologies, if developed according to a true patient engagement perspective, may be an important set of tools and strategies to accomplishing this ambitious revolution in healthcare.

5 The Advantages of Engaging Patients in Their Care

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

- ***Patient engagement allows the improvement of clinical outcomes and of patients' satisfaction towards the care process.*** Patient engagement is related to a better quality of care and patient/health provider relationship, thus improving a patient's clinical indicators and compliance to recommended therapeutic regimens (Green & Hibbard, 2012). Making people aware of their health service options by supporting them in the decision-making process and engaging them in preventive health behaviours is vital to achieving successful health outcomes (Bellardita et al., 2012). Favouring a good psychological and emotional tenure will foster a self-image as active and engaged and may improve an internal locus of control over disease. These components appear crucial to guaranteeing a better quality of life and more positive health experience. Patients engagement is essential to obtaining quality goals and improved outcomes in terms of disease prevention (e.g., cancer screenings) and healthy behaviours (e.g., weight control, not smoking) (Hibbard, 2008). Patient engagement in the therapeutic process is a crucial element to making the patient feel a part of the treatment plan itself and, thus, to adhere better to the prescribed therapy with a decrease in relapse. Finally, engaging people in health is vital to social inclusion and the maintenance of an active role in society. More engaged and motivated people are active and protagonistic in their communities. Thus, they will be better able to maintain social linkage and strengthen their roles and contributions within society in general.
- ***Patient engagement allows cuts in healthcare delivery costs.*** From this perspective, patient engagement seems a possible answer as it increases individual responsibility and awareness about one's health and the risk of unhealthy behaviours. Patient engagement also seems to contribute to fostering sustainable lifestyles and avoiding unsafe conduct (Jordan et al., 2008; Reid et al., 2010; Cosgrove et al., 2013). Furthermore, patient engagement in the therapeutic process

is a crucial element to make him/her feel like a partner in the intervention itself, which will led to better adherence to the prescribed therapy and a decrease in relapses. An improved efficacy of therapeutic intervention, thus, would increase organizational and managerial sustainability of healthcare by diminishing the "doctor/service shopping" phenomenon and inappropriate access to healthcare structures and doctors. Patient engagement, in terms of better patient sensitization, knowledge, and empowerment in his/her process of care and cure, thus, seems to be crucial to gaining an efficient balance between the increase of health demand and the reduction in economic resources for the healthcare system in all mature societies today. Furthermore, patient engagement may not only contribute to the reduction of direct costs for the healthcare system, but it also can concur with the (re)orientation of economic resources in the management of healthcare systems to reduce wasting finances (Fisher et al., 2011; Hibbard et al., 2013).

6 Engaging Patients "from Theory Into Practice": Agenda Setting

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

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

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

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Giving (Back) a Role to Patients in the Delivery of Healthcare Services: Theoretical Roots of Patient Engagement

Abstract: As the concept of patient engagement is increasingly accepted and valued by both academics and policy makers, the number of terms and definitions used to describe the active role of patients across various healthcare settings and health disciplines has increased, often leading to semantic confusion among healthcare professionals, managers, and policy makers. This chapter examines the literature on the concept of patient engagement and related concepts, including definitions and theoretical perspectives. The chapter is conceived as a "glossary" of conceptualizations related to the active role of patients in their healthcare journey. Based on this theoretical review, it will be easier to understand the value and the applicability of the patient engagement concept. More specifically, patient engagement may be viewed as an umbrella term that qualifies the systemic relation that occurs between the "supply" and the "demand" of healthcare – at different levels and in different situations. Considering this meaning, patient engagement is a broad term which incorporates the other terms, such as patient adherence, patient compliance, self-management, patient involvement, patient participation, shared decision-making, patient activation, and patient's technology engagement, which are more traditionally used to denote the active role of patients in their care, as discussed in this chapter.

Keywords: Patient engagement; Patient Adherence, Patient Compliance, Self-Management, Patient Involvement, Patient Participation, Shared Decision Making, Patient Activation, Patient's Technology Engagement

1 Introduction

This chapter is a "glossary" of the main recurrent concepts related to patients' participative role in health and care management.

Since the epochal turning point promoted by the patient centered approach to medicine (Stewart, 2001), many theories about how the patients can be involved in the clinical process have been developed. Furthermore, several concepts and terms are often used synonymously to indicate the active role of patients in the healthcare process.

In our opinion, to concretely innovate healthcare in the direction of patient engagement, it is fundamental to clarify the existing conceptualizations and define what may be the overlaps and differences between the concept of patient engagement and other related concepts.

This chapter, after introducing the Participatory Medicine paradigm and its pivotal role in enhancing healthcare professionals and managers' sensibility towards the importance of modifying healthcare practices based on patients' perspectives, will offer a deep discussion of the most important (and recurrent) concepts related to the patients' role in the healthcare process. In particular, the chapter will deal with the concepts of: *patient adherence, patient compliance, self-management, patient involvement, patient participation, shared decision-making, patient activation, and patients' technological engagement*. In particular, this chapter will provide a review of the most up-to-date definitions of each of those concepts and discuss their relations and overlaps with the more recent concept of patient engagement.

The chapter will end by synthesizing the conceptual "boarders" of the patient engagement concept, its aspects of innovativeness and its potential for medical practice.

2 Historical Milestones in the Development of the Concept of Patient Engagement: The Tradition of Participatory Healthcare

We are currently in the midst of one of the most rapid and profound shifts in the history of medicine. When many of today's physicians were still in school, most patients had little or no access to detailed information about their health conditions. The internet was not available and medical libraries were off limits. Over the span of a few years, patients gained access to more medical information, easily accessible through portable smart phone devices, than the late-20th-century Surgeons General had direct access to. The balance of power is shifting, and the amount of health data is exploding. Change is afoot. Participatory medicine is a movement in which networked patients shift from being mere consumers to being responsible drivers of their health and in which providers encourage and value them as full partners (Dyson, 2009; Kabat-Zinn, 2000; Weitzel, et al., 2009).

In the framework of Participatory Medicine, many conceptualizations of the potential active role of patients do exist. Let's see them in detail.

3 Distinguishing the Concept of Engagement from Other Closely Related Concepts

It is fundamental to understand the innovative value of the concept of patient engagement and its relationships with other concepts existing in the medical and psychological literature. Indeed, the term patient engagement evokes other terms, which are closely linked to it, such as patient compliance, patient adherence, patient empowerment, patient activation, patient involvement, patient participation (Menichetti et al. 2015), shared decision-making, and patient's technological engagement (Barello et al., 2014).

In the next section, we will offer a definition of each of these concepts and will discuss their conceptual relationships with the concept of patient engagement.

3.1 Involvement, Participation, and Shared Decision-Making

In the last decade, the ability to involve the patient in his/her care process and collaborate with the health professionals (the physician in particular) in the process of medical consultation has been recognized as one of the primary objectives of improving the quality of health services (Entwistle and Watt, 2006).

The scientific literature on the topic offers a wide variety of terms to describe this objective. The main terms are involvement, participation, and shared decision-making. However, there is not a unified vision, nor are there shared guidelines to apply the concept to the real contexts. Moreover, the "involvement" and "participation" terms seem to be used interchangeably in the scientific debate (Gallant et al., 2002; Thompson, 2007).

Considering semantic opacity, the two concepts of involvement and participation appear to be used only when referring to the precise moment of the negotiation of clinical decisions, that is, when a dyadic communication takes place between the patient and the clinician. Indeed, the literature conceives and measures the patient's involvement/participation considering the medical consultation between an "expert" actor (usually the physician) and a "non-expert" one (the patient).

Despite this, it is possible to note that two main theoretical conceptions still dominate the debate. The main difference between the two is related to the level to which the concepts are analyzed (Entwistle and Watt, 2006). The first one, which is psychological, focuses on the subjective dimensions of the patient involved in the medical consultation. Moreover, it is interested in identifying emotional and cognitive factors that can foster the active participation of the patient in clinical decision-making. These factors are often related to the concept of "health literacy" (Marteau and Dormandy, 2001; O'Connor, 2003).

The second theoretical tradition, the medical one, focuses on the clinical and relational competences of the physician, which are needed to involve the patient in the clinical decisions. In this sense, communicative and interpersonal abilities are conceived as the main factors fostering or preventing shared decision-making in the care process (Charles, Gafni, and Whelan 1997; 1999).

The link among the concepts of "involvement", "participation", and "shared decision making" engagement is evident, since much of the literature is interested in understanding the active role of the patient in the care process. At the same time, it is clear that these terms represent different levels of the analysis of the communication between the supply and the demand for health services.

As mentioned previously, the concepts of “involvement” and “participation” are fundamentally related to the dyadic communication between the clinician and the patient. Moreover, they come out of a compensatory effort to modify the implicit asymmetry of the medical decision-making process. Indeed, the “expert” clinician often appears to take a paternalistic approach to the clinical decision-making, and he/she is usually recognized as the sole holder of the better therapeutic choice. The authors who study the concepts of “involvement” and “participations” sustain that a greater democratization of the decision-making process is needed. In this sense, the clinicians should consider the personal needs and expectations of the client/patient while providing health services.

The concept of “engagement” refers to a wider communicational context. Accordingly, the medical consultation constitutes only one of the possible levels of the analysis of the supply and demand for health services. In other words, an “engaged” patient is not only a patient able to actively participate in the clinical decision making, but also a patient able to activate the global healthcare system; to utilize the care and disease management offered by the conventional organizational contexts present in the territory; to promote new forms of assistance (being themselves supported by new technologies or not); and to generate them from a non-expert context of care. Doing this, the engaged patient is able to virtuously interface with the expert system that provides health services. An interesting example in this direction are the patients who decide to promote their own health rights at social/political levels or the patients who fund associations in order to help other people with similar health conditions and their caregivers.

3.2 Compliance and Adherence

The literature that studies the modalities to which the patients manage medical prescriptions and their relationship with the system that provides them often use the terms “compliance” and “adherence”. In general, they refer to the patients’ adaptive behaviors when they follow the medical prescriptions.

Despite this, the two concepts seem to have different meanings in the scientific debate. Precisely, the term “compliance” comes from the Latin *cumplere,* which means “to adapt one’s behavior to another’s desire, rule, or need” (Oxford English Dictionary, 2010), and it is used to describe a conduct of the patient that responds to a coercion by the “expert” figure (usually the physician) (Haynes & Sackett, 1979; Fletcher, 1989). This concept is based on a paradigm that comes from a disease-centered medicine. In this sense, the physician is considered the only expert of the pathology. For this reason, he/she is also in a dominant position of power in the healing relationship. It is easy to see that this concept implies the impossibility of a real exchange between the patient and the system that provides the health services. The relationship with the physician is relentlessly unidirectional.

The physician not only shows a paternalistic approach towards the patient while managing the pathology and providing prescriptions to be strictly followed, but also has the task of judging the behavior of the patient as either correct or incorrect (Playle & Keeley, 1998). Indeed, the "compliance" is characterized by the patient's attitude towards doing what he/she has to do, adapting his/her own life to the physician's indications. Consequently, the compliant patient is characterized by a passive/dependent attitude, that is, he/she is completely subservient to the health professional (Evangelista, 1999).

The "adherence" term comes from the Latin *adherere*, which means to be "attached, near" (Pianigiani, 1988) and is more related to a patient centered paradigm. In this case, the main objective to be pursued is a care system in which the patient is a fundamental actor and partner of the health professionals in the construction of adequate responses to his/her demand for care (Anderson, 2002; Stewart, 2001). With this paradigm in mind, those who provide health services need to support autonomy in the patients, which is a key factor in improving the system, in terms of both the quality of life and reduction of costs (DiMatteo, 2004; Thorpe, 2005). The main difference between the terms "compliance" and "adherence" is that the second is more open to an active involvement of the patient in the communication exchange with the physician in order to make decisions about the care plans. In this sense, the active participation of the patient should be promoted. Moreover, he/she is seen as a fundamental actor in the management of his/her own health and in the communicational relationship with the medic.

Indeed, the concepts of "compliance" and "adherence" reveal a vision of the client/patient to healthcare system relationship, which is still limited to the dyadic communication with the physician. Moreover, a passive approach to care still shines through these two concepts, since both of them imply a relational hierarchy in which the expert physician provides life rules for the non-expert patient, in which the competence of the patient regarding negation is poorly considered. Indeed, discussing the terms "adherence" or "compliance" means referring to a value judgment of the physician regarding a patient, who can be more or less "good" in their responses to the physician's judgments and prescriptions.

The patient engagement concept goes beyond the mere evaluation of the patient's behaviors and attitudes in accepting or disregarding the physician's prescriptions, although it may be adopted in order to foster adherence/compliance. Moreover, the concept of patient engagement moves toward a more democratic vision of the exchange process between the physician and the patient and/or between the supply and demand for health services. In this context, the diverse actors, with their own diverse competences and subjectivities, are considered in the system in order to promote virtuous forms of dialogue and fruition of the health system in its complexity.

3.3 Self-management

The verb “to manage” comes from the Latin *manus* (hand), which means using an instrument with one’s own hands. In the medical lexicon, “self-management” means the ability of a patient to manage the symptoms, the treatments, as well as 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 based on individuals’ personal needs and expectations.

This state is recognized as the outcome of a process of acquisition regarding information about a disease and its implications. Thanks to this, the patient becomes autonomous in the treatment 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, self-management becomes one possible positive outcome of a patient engagement process. Moreover, it appears to be one of the prototypical contexts in which a high engagement level manifests itself, similar to a high adherence to treatments and a profound partnership between the patient and the physician in the decision-making process about care treatments.

3.4 Patient Empowerment

Those ones who are familiar with a psychological literature may understand the term “empowerment”. It refers to a psychological state in which the patient achieves control and power over his/her own health/disease state and possible treatments (Ajoulat et al., 2006; Feste, 1995). This state is generated within an educational process, and it is the outcome of an exchange of knowledge between the expert clinician and the patient, the latter being conceived as a passive receptor of information.

In this sense, the objective is to promote a re-acquisition of agency and self-efficacy for the patient over his/her own health. Progressively, this allows one to recover his/her autonomy after the experience of the disease onset (Anderson and Funnell, 2005).

Although this approach is related to a person-centered vision, the creators of this concept often have a solipsistic idea of the patient, as if he/she was taken out of the social context. They consider the dyadic relationship with the clinician only.

Therefore, while the concept of “empowerment” focuses on the individual in the relationship, the concept of engagement focuses on the relationship itself. Indeed, it explores the demand for care of the patient as situated into a systemic vision. Moreover, while “empowerment” is conceived as the outcome of a cognitive boosting process of the patient and of his/her health literacy level, “engagement” sustains not only the knowledge aspects of the patient’s health experience, but also the emotional aspects related to the personal acceptance of the health condition and the behavioral skills to manage it.

In the light of these considerations, the concept of "empowerment" and the concept of "engagement" seem to be strongly connected in a reciprocal and virtuous relationship. It is possible to hypothesize that "empowerment" mediates the engagement process as an intervening factor that modulates the relationship modalities between the patient and the healthcare system.

3.5 Patient Activation

Considering 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. In the context of the scientific debate about the participation of patients in the process of care, the term "patient activation" refers to the level of knowledge, ability, and confidence in the patients' capacity to manage his/her own health and interact with the healthcare system (Green et al., 2012; Hibbard et al., 2005). A possible increase in the activation of patients is positively associated with the augmentation of healthy behaviors (e.g., physical exercise, diet…), adherence to the medical prescriptions, and behaviors related to information seeking for prevention purposes (Hibbard, Stockard, Mahoney, & Tusler, 2004).

In 2004, Hibbard defined the concept of patient activation as composed of four phases. Moreover, she developed a scale to measure patient activation, 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 their health management. 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 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 are able to maintain their new lifestyle behaviors in the long-term, even in the context of stressful conditions.

The concept of activation features numerous elements that resemble the characteristics of the patient engagement process. Indeed, the two terms are often used synonymously in the scientific debate (Hibbard, who is the founder of the research tradition on patient activation, also uses the word "engagement" as a keyword for her works). However, according to a more careful analysis, we may see how the two concepts differ. The concept of "activation", as it is evident from the name itself, focuses mainly on the conative dimension of the behavior of the patient, and assumes that the main driver of activation is the level of knowledge of the patient about the disease and its management (health literacy). Moreover, there is a strong focus on the disease experience and on the management of it in the institutional context of the care (i.e., the medical consultation, the adherence to treatments, the fruition of services inside the hospital). Less attention is devoted to the "external" of the institutional hospital context and to the role of caregivers, peer network, and social context. In the end, the authors focus on the behavior of patients as a reactive response to the healthcare system and to its organizational practices. As such, the concept of patient activation is still quite passivizing (Graffigna et al., 2014; Graffigna et al., 2015).

Differently, the concept of "engagement" tries to explore the dialogue between the supply and demand of health services, considering a more inclusive spectrum of the non-institutional contexts that are important for the individual. The aspect of the everyday life of the patient, of his/her routine activities, and of the need to help them positively include the experience of disease in the wider experiential domain of his/her own life "outside the hospital", is the main driver of the patient engagement conceptualization. Indeed, the fully engaged patient becomes able to recognize him/herself as an individual who perceives the disease as only one of the possible experiences. In virtue of this ability to adapt to the situation and to project a more sustainable lifestyle, the patient becomes able to virtuously interface with the healthcare system. Moreover, he/she becomes a real "apostle" of good engagement practices in the context of his/her own community.

To reach this level of personal maturity, the process of engagement requires an elaboration of the subjective perception of the position as a "patient", considering diverse experiential dimensions. Indeed, it is not possible to reduce these dimensions only to the cognitive and behavioral factors (which are typical of the construct of activation), but also to the emotional dimension, that is the ability of the patient to make sense of his/her own clinical condition, which is equally fundamental (as we shall discuss in the following chapter).

3.6 Technology Engagement

To avoid confusion, it is useful to differentiate patient engagement from another important concept. As we will argue in the next chapters, patient engagement can be easily achieved thanks to the implementation of interventions based on new technologies. In this sense, technological tools help guide a patient through a process of development that allows him/her to become fully engaged in his/her own disease and illness management. To reach this objective, patients who benefit from new technologies certainly have to be "engaged" in the use of such technologies.

However, engaging a patient in a technology use does not coincide with engaging him/her in the process of care. Technology engagement (Sharafi et al., 2006) means that one is motivated to use the technological tool, that is, he/she is genuinely curious about the tool, and he/she is able to maintain a continuous use over time. Moreover, technology engagement is often conceived as a phenomenon related to the concept of "flow" (see Chapter 4).

When a technological tool is used in the context of a patient engagement intervention, technology engagement would become an important aspect of ensuring that the technology-based intervention will have the expected effects. It should also be noted that the "direction" of a patient engagement intervention is always related to the process of care, regardless of whether a technology is present in the intervention.

4 Towards a Definition of Patient Engagement: Its Relationship with Related Constructs

To sum up, as introduced in Chapter 1, patient engagement may be considered an umbrella term that qualifies the systemic relation between the demand and the supply of healthcare at different levels and in different situations (Menichetti et al. 2015). If considered according to this meaning, patient engagement overarches the other terms that are traditionally used to denote the active role of patients in their care, such as *patient adherence*, *patient compliance*, *self-management*, *patient involvement*, *patient participation*, *shared decision making*, *and patient activation* (see Table 1 and Figure 1).

Discussing the connections between these traditional terms and patient engagement, the concept of "activation" has a degree of overlap with engagement, but it differs according to the breath of its consideration of the healthcare relation. The concept of "activation" is mainly limited to the attitude of patients within the institutional context of care (i.e., the Hospital, the medical consultation…) and is particularly anchored to the prototypical situation of a doctor-patient consultation.

Other concepts are strongly anchored to different prototypical situations of patient's disease management. On the one hand, "self-management", which includes the concepts of adherence and compliance, specifically refers to the behaviours that the individual is called to undertake in order for the effective application of therapeutic prescriptions to occur. These constructs (i.e., "self-management", "adherence", "compliance") come from a hierarchical vision of the healthcare relationship, where the healthcare provider (i.e., the expert) prescribes to the patient (i.e., the lay actor) the rules to better manage his/her disease. Due to this view of the relationship, these concepts bring a little attention to the theme of therapy negotiation. "Self-management", "adherence", and "compliance" imply that the physician is in a position of evaluation, determining whether the patient has performed well or badly, as well as whether they are able to respond adequately to the expert's requirements (Vlasnik, Aliotta, and DeLor, 2005; Haynes and Sackett, 1979).

In contrast to these traditional terms, the concept of "engagement" underlines a strong democratization of the exchange between physician and patient; thus,

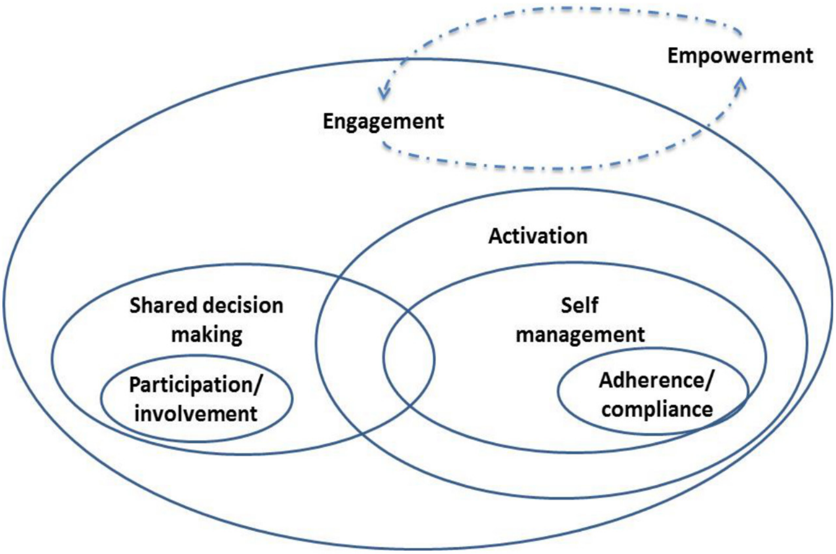

Figure 1: Patient engagement: An umbrella concept to innovate healthcare.

between the demand and supply of health services. From this perspective, different actors convey their subjectivities and their different skills to promote virtuous forms of dialogue and the better use of health services and structures.

On the other hand, “shared decision making”, which includes the concepts of “involvement” and “participation”, refers instead to the dyadic context of the medical consultation and the cognitive/emotional attitude of the patient in the negotiation of clinical decision-making.

The conceptual link between the concepts of “involvement”, “participation”, “shared decision-making”, and the concept of “engagement” is evident because they suggest the active role of patients in the process of care negotiation. Nevertheless, it is clear how these terms focus on a different level of the exchange between demand and supply of healthcare services (Murray and Gafni, 2006; Thompson, 2007).

As mentioned earlier, the concepts of “involvement”, “participation”, and “shared decision making” are mostly limited to the dyadic context of the exchange between doctor and patient; the concept of “engagement”, instead, involves a broader and systemic context between demand and supply of health services, where medical consultation is only one of the possible levels of the analysis. An engaged patient is able to become not only an aware consumer of the traditional form of health services, but also a good promoter of best practices of health promotion in his/her social context (for example, sharing care practices in online forums and communities by advocating for patients’ rights at the institutional level or by becoming founding member of a patients association).

In this framework, an exception is the concept of “empowerment”, with which the concept of engagement entertains an associative relationship of mutual influence.

Table 1: Definitions of the different concepts related to the active role of patients in healthcare

Concept	Authors	Definition	Relation with engagement
Empowerment	*Feste, 1995* *Ajoulat et al., 2006*	Empowerment suggests a position of re-acquisition of agency for patients, indicating a subjective sense of control over their disease. An empowerment-oriented approach views patients as being responsible for their choices and the consequences of their choices.	Empowerment entertains an associative relationship of mutual influence with the concept of engagement. It is a prerequisite for the process of engagement, but in turn is fed by the positive experiences that the patient makes in his journey of engagement
Activation	*Hibbard et al., 2005*	The term patient activation indicates the level of knowledge, skills, and confidence, implicated in the patient managing their own health and interactions with the system of care.	The concept of activation presents different degrees of overlap with engagement, in activation, however, the relation context is limited to the institutional and dyadic care relation between the doctor and the patient
Self-management	*Nakagawa-kogan et al., 1988* *Clark et al., 1991*	Treatment that combines biological, psychological, and social intervention techniques with a goal of maximising the functioning of regulatory processes, basing on the patients' own beliefs and expectations. The term also refers to day to day tasks an individual must undertake to control or reduce the effect of disease on physical health status with the collaboration or the guidance of a health provider. These behaviors also require sufficient knowledge of the condition and its treatments.	Engagement defines the exchange between patient and health care system, not only in terms of the transfer of knowledge and skills focused on purely managerial aspects of the care. Moreover, it does not reduce the exchange to the context of the dyadic relationship between doctor-patient and it mainly refer to an individual context of care
Adherence	*Vlasnik et al., 2005* *Robinson, 2008*	The term adherence refers to the patient's ability to follow treatment recommendations. It is considered a key factor in improving the patient's quality of life and reducing costs.	Adherence describes a more democratic version of the process of exchange between doctor and patient. It too, refers to an individual context of care
Compliance	*Haynes, 1979* *-Fletcher, 1989*	The extent to which a person's behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice. In other words, it refers to patients doing what the health professionals want them to do.	Engagement goes beyond the specific assessment of the behavior and attitude of the patient towards the requirements of the clinician. Compliance thus refers to a more narrowed individual context of care

continued **Table 1:** Definitions of the different concepts related to the active role of patients in healthcare

Concept	Authors	Definition	Relation with engagement
Shared decision making	*Murray et al., 2006.*	Doctors might encourage patients to seek and read information from other sources and to discuss this at subsequent encounters. Doctors may also need to help patients to interpret information obtained from other sources.	These terms describe a more negotiating role of the patient in care management, but the concept of engagement involves a broader and systemic context between demand and supply of health services, where medical consultation is only one of the possible levels of analysis. Involvement and participation mainly refer to a dyadic context of care
Involvement and participation	*Entwistle and Watt, 2006* *Thompson, 2007*	Involvement and participation are used as interchangeable terms and describe the relationship between patient (lay) and health provider (expert) in the process of clinical decision-making.	

The concept of empowerment connotes a position of agency for patients. It is made possible through re-acquisition of the subjective sense of control over their disease (Aujoulat, d'Hoore, and Deccache, 2007). It is a prerequisite for the process of engagement fed by the positive experiences that the patient gains on his/her journey of exchange between the demand and supply within the healthcare system.

5 Conclusions

In this chapter, we discussed various terms and concepts that are populating current debates about patients' active role in healthcare. Our aim was offering a preliminary glossary of the different concepts in order to lay groundwork and forward from the confusion that this plethora of terms might provoke. Only by agreeing on a shared conceptualization and definition of different concepts will be possible to realistically set healthcare innovation goals and build concrete guidelines to achieve them.

Furthermore, this analysis of the different concepts related to patients' active role in healthcare offers us the possibility to better shape the margins of the engagement concept by also highlighting its traits of innovativeness and, on the contrary, its continuities with other more classical conceptualizations used in the healthcare domain.

Based on these premises, the following chapter will propose a concrete framework to make sense of the potentialities of the engagement process and its applicability to innovate health and care.

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Guendalina Graffigna, Serena Barello

Modelling Patient Engagement in Healthcare: Insight for Research and Practice

Abstract: Living with an illness is an ongoing, continually shifting process in which people experience a complex dialectic between themselves and their healthcare context. Patient engagement in their care is a dynamic, evolutionary process that involves moving from a disease-centric model, to the maximization of individual potentialities—even with the disease—and the recovery of some form of life project. In this chapter, the authors outline a theoretical model (PHE model) that explains the subjective experience patients go through to become engaged in their health management process and the factors that may enact the transition from one phase to the next in the process itself. This view of the patient engagement process suggests that a fully engaged patient status is the final outcome of a series of emotional, cognitive, and behavioural reframing of one's health condition, and the success of the patient at each phase of the process depends on the success of the previous phase. The last phase of the engagement process culminates in a patient who has gained a positive approach to health management and has recaptured an active role in society by re-establishing plans for wellbeing. Such a patient has succeeded in incorporating disease management into their life. The model described is also a useful course of action to innovate healthcare services and practices in a more engaging way.

Keywords: Patient engagement; PHE model; healthcare innovation; healthcare management; patient centred medicine; consumer psychology; consumer health

1 Introduction

In the previous chapter, we discussed the value of engaging patients to make the delivery of healthcare services more sustainable and better able to face challenges of the 21th century. However, so far, the idea of engaging patients in health and care sounds more like a fashionable claim, rather than a real commitment to practice. Indeed, concrete guidelines for practice that are truly able to orient the planning and assessment of healthcare interventions to improve patient engagement are yet to come. To set the grounds for a real innovation of healthcare in the direction of an enhanced partnership with clients, we propose a consumer psychology conceptualization of the patient engagement process. It is our conviction that only by grounding healthcare interventions in a deeper understanding of patients' experiences, priorities, and expectations, can they become truly effective in engaging patients. The *Patient Health Engagement Model* (*PHE model)* that we describe in the following section offers important cues for research and practices with the aim of achieving a new partnership between the "demand" and "supply" of healthcare.

In this chapter, after discussing the value of engagement though a consumer psychology perspective of patients, we describe the experiential characteristics and phases of the *PHE process* by grounding it in real patient cases. We then highlight the experiential factor that, based on our *PHE model*, result in allowing patients to pass from one *PHE position* to the following. Finally, we summarize key applicative advantages of the proposed *PHE model* for different healthcare practices.

2 Modelling Patient Engagement: How a Consumer Psychology Perspective May Help

As mentioned in Chapter 1, it is curious to note that, despite the growing "buzz" about patient engagement and the different attempts to define how this is achieved, patients' voices about this process has been fairly neglected so far. At present, scarce attention has been paid to patients' perspectives about what engagement in healthcare is, how desirable it may be, and situations and drivers that may sustain it. Indeed, there are still very few evidence based studies that have aimed to give a voice to patients, to their experiences, and to their will to engage in health and care (Barry & Edgman-Levitan 2012; Barello et al., 2014).

From our perspective, this lack of "ecological foundation" for the concept of engagement puts it at risk of becoming a missed opportunity for really innovating and improving healthcare service sustainability. In other words, we believe it key to "*see engagement from patients' eyes*" to really gain insight into orienting healthcare actions and addressing priority policies.

The discipline of consumer psychology (Foxall et al., 1998; Haugtvedt et al., 2012) is defined as the study of processes that individuals, groups, or organizations enact to select, secure, use, and dispose of products, services, experiences, or ideas, in order to satisfy their needs and to fulfil their goals and values. This field can offer interesting cues to move forward in the modelling of the subjective experiences of patient engagement. Unveiling consumers/patients' processes of decision making about their health-related conduct, desires, and un-met needs regarding care services and wellbeing support, may cast some interesting light on the conditions that hinder or facilitate patient engagement.

Consumer psychology, thanks to its methodological approaches and theoretical stances, may help us uncover:

- **How patients think, feel, reason, and select, among different alternatives** (e.g., healthcare organizations, care services, treatment options).
- **How patients' health management is influenced by the environment** (e.g., culture, family, peer networks, media).

- **The phases of Patients' decision making** and how limitations in patient knowledge or information processing abilities, rather the attributes of the different options, influence final decisions.
- **How patients' motivations and behaviors, related to health management, change across time, cultural context, and situations,** and the reason why some conduct appears so irrational, even though it is preferred by patients.

The analysis of these drivers of patients' experiences enables a process-like conceptualization of the engagement experience that potentially leads to a real innovation of healthcare paradigms in research and intervention. Furthermore, it opens to a wider and more systemic vision of patient engagement, while emphasizing the behavioral activation component (Hibbard, 2004) risks to be a "reactive" and "compensatory answer to the still "passivizing" approach of medical care (Graffigna et al., 2014).

In this framework, we believe that a deep psychological understanding of the patient engagement experience may sustain the shift from "*patient centered*" to "*people oriented*" medicine. We advocate for a substantial move from considering individuals as merely "disease carriers" to people who makes (realistic) decisions for their present and future life trajectories based on their sense-making processes. People who want to speak up to orient healthcare systems approaches and priorities. People who need to be listened to, understood, and considered, in order to innovate healthcare systems and make them useful supports for their well-being and eudaimonic expression of self-potentialities.

3 The PHE Model: Phases and Features

Through combining a consumer psychology perspective with more than 10 years of research and practice dedicated to the in-depth understanding of patients' perspectives about their illness journeys, we developed a conceptual model (*Patient Health Engagement Model – PHE model*, see Figure 2) that may be particularly useful to understand patient engagement and how it develops. In this model, we define *patient health engagement* as a multi-dimensional psychosocial process resulting from the conjoint cognitive, emotional, and behavioral enactment of individuals toward their health conditions and their health management (Graffigna et al., 2014).

Patient health engagement is a dynamic and evolutionary process that involves the recovery of life trajectory—even with the disease. The patient engagement process features four experiential positions: blackout, arousal, adhesion, and eudaimonic project.

This view of the patient engagement process suggests that a fully engaged patient results from a series of emotional, cognitive, and behavioral reframing of his/her health condition, and the success of the patient in advancing along this process depends on how he/she succeeded in previous phases. The last position of the engagement process (i.e., eudaimonic project) culminates in a patient that has gained a positive approach to health management and has recaptured an active role in society by re-establishing plans for wellness. Such a patient has succeeded in incorporating disease management into his/her life. This process also features peculiar ways of interacting and engaging in decisional negotiation between the patient and the healthcare provider that depends strongly on the phase of the process through which the patient is passing. In the following paragraphs, we discuss the specific features of each phase of the engagement process by offering some clinical vignettes to make our model description more understandable in practice.

3.1 Blackout

The occurrence of a critical episode (e.g., a new diagnosis, the worsening of a disease condition, a disease relapse, etc.) leaves patients in a state of emotional, behavioral, and cognitive *blackout*. Patients feel the critical event is out of their control. They feel "in suspension", a deep state of anxiety, and they need to obtain support from someone in order to cope with their new healthcare situations (see for an example "*Patient case 1: Maria*").

In this stage of the engagement journey, the disease onset and its management are experienced by patients as distressing and unacceptable; they have not yet acquired effective coping strategies to manage their new health conditions, and they are not yet aware of what is happening in their bodies. Patients in this stage still have understanding of their health conditions, and they cannot easily comphrehend the information they receive about their respective diseases (*cognitive blindness*). Moreover, patients feel blocked and unable to orientate their behavioral conduct to enable self-management of their diseases (*behavioral freezing*). Patients in this stage appear completely focused and overwhelmed by their illness experience, and they tend to "put aside" other interests or needs.

These patients are passive toward their healthcare system; namely, they expect to be recipients of care, and they seek a "paternalist approach" to receiving this care. In other words, patients have a top-down vision of their healthcare interventions, where their role is limited and passive. To overcome the experience of this "*blackout*" connected to the disrupting health event, patients need to develop trusted relationships with their healthcare providers. Healthcare professionals are asked to support patients and offer empathic responses to educate them about their health. If patients fail to build solid relations with their healthcare providers, their emotional, cognitive, and behavioral responses may become dysfunctional, which often leads to patient dropout.

Patient case 1-Blackout phase: Maria, Type 2 diabetes, 68-years-old, follows oral therapy
I felt very tired, fatigued. So, I went to the doctor, and then attended the examinations. When the doctor saw the tests, I was diagnosed with diabetes. The diagnosis came to me like a heartbreak: I felt strong discouragement, and I cried. I thought, "What will be my life now??" I always felt good in my life, and I have always done everything I wanted, I said "I am a rock", like I was invincible or something. The fact is that then when something happens to you, your entire world collapses. I have to admit that it's still hard for me to accept this diagnosis. Diabetes scares me, I remember when I was a child of an old aunt who had diabetes, and then came the diabetic foot, and many other complications. I cannot think of ending like her. You do feel like a slave of the disease and of the therapy. It's hard to accept that you will have to live with them forever. Now, I regularly follow the therapy, but I admit that, sometimes, I forget to take the pill… when you go out with friends, you feel a little ashamed 'to take the pills,' you feel ill. I don't like to tell about my illness friends and colleagues, as it seems to me that they then treat me as a sick person. I prefer to pretend nothing happened; only my relatives know about it. I want everything around me to remain the same. I know I have to follow a diet and move more, but the doctor was a bit vague on this: I try every day; for example, to go to the shop and walk. But, I do not follow a strict diet, nor do I have time to go to the gym. With my doctor, I have a quite good relationship, but I am a bit ashamed to ask him so many questions. You feel a bit stupid when you don't understand a lot of things, when you have so many doubts. I prefer to just trust what he says. I try to follow what he tells me, although sometimes I do not strictly follow the rules about eating. When the children return home, or you have guests for dinner…some violation of the rules is inevitable! My personal experience of medical consultations is filled with a lot of anxiety (in my heart I'd rather not have them) because I'm always terrified that something is going wrong, that my disease will worsen. Unfortunately, with this disease, you cannot stay quiet and you have no hope of healing. Now, I have something like a "mark" on my own life.

3.2 Arousal

In the position of "arousal", patients are hyper-attentive to every signal in their bodies (*emotional alert*). Symptoms are perceived as an alarm that worries the patient and may cause overwhelming emotional reactions. Compared to the state of "blackout", patients are better informed about their health condition, although their health knowledge is still superficial and fragmented (*superficial knowledge*). Moreover, they are behaviorally unable to self-manage their diseases and treatment prescriptions (*behavioral disorganization*). In this position, patients perceive healthcare professionals as an important point of reference who can help them manage their illnesses and treatment experiences (with which they have difficulty coping). Considering that there was good initial relationships with healthcare providers, patients begin to learn and test self-management patterns and cope with their health statuses more effectively. Patients start to become aware of the treatment options available, and they have matured in their decision making about first choice criteria for healthcare services.

Patient case 2-Phase of arousal: Fausto, heart failure, 57 years, follows beta-blocker therapy
On Easter Sunday, late afternoon, I began to have a pain in my chest, I did not associated it with anything in particular, then I found myself on the ground, and I remember my wife telling me, "what are you doing there?", she called the ambulance, and they arrived very fast. They brought me here immediately, they had been already warned, they took me in pneumodynamics, they put the stent, everything was in my mind, but not just in my mind, very quick. Sure, there have been times when I was ill, among other things. I was almost always conscious; from the moment I opened my eyes, there was an immediate sense of physical well-being. Then, a week passed , of course with some thoughts and worries because I had never had anything like that, and I wondered why it had happened to me. If I compare today with 10 years ago, I get tired a lot more frequently. I also have to sleep more, and be more careful in general, even with work. I also feel physical fatigue a lot more than 10 years ago. I do not like this thing here though. Compared to the state of my health, I always feel a bit alarmed. Obviously, I would like to have certainties or confirmations that everything is fine...or about what I can do so this does not happen again. Since this happened, I sleep a lot less, I do not know why, maybe because of drugs, I do not know. In general, I feel more upset, a little more anxious. The main fear is that it may happen again. For example: I'm about to take a shower and my wife says, "Do not close the door!" or "take away the key from the door, because if it happens to you again... " ... or other thoughts of mine, such as "now I start a trip, so I take a plane... what can I do about putting the heavy bag on it?" And then any little pain, even if we all have some pain sometimes, if I have it now, the thought are a bit different, because I'm anxious. You always feel a sword of Damocles over your head. Then, I'm following many therapies, but I would like to understand better, how long will it take? Six months? A year? In short, there are many questions about my illness and my treatment that I would ask all the time, and even though you can always call your doctor, if you do then you feel a little shame. The internet is useful, however, if you leave the banality of information that is all the same. Each of us is an individual case and needs specific answers, which you will never find on a computer. I mean, you feel a bit lonely and confused.

3.3 Adhesion

In a more advanced stage of their engagement journey, patients acquire a broader spectrum of health literacy (*cognitive adhesion*) and behavioral skills (*formal adherence*) to comply with medical prescriptions and feel confident in their own emotional strength to cope with their illness. Furthermore, patients have accepted their health conditions and have come to terms with the negative emotions connected with the critical health events (*acceptance*). However, patients are still not completely autonomous in managing their health conditions and related treatment rules (e.g., healthy lifestyle and correct medication regimen). Particularly, patients experience difficulties in dealing with those prescribed rules and life style regimes every time their life context changes (e.g., going to holiday, travelling for work). This is because patients have not fully understood and elaborated the rationale behind medical prescriptions (e.g., the final "whys" of rules and treatments), but merely passively comply with it (e.g., they are "good executors" at this stage). Consequently, patients experience the need to hang on the healthcare professionals' authority and prescriptions passively, and they perceive the healthcare professional as an anchor: The absence or impossibility of relying on their healthcare professionals' counseling may be disruptive for patients at this stage of the engagement journey.

In other words, although patients at this stage still prefer to attribute the responsibility of disease management to the healthcare professional, they start to perceive the importance of their role as collaborative members of the care team. This understanding sets the scene for a positive mechanism of exchange between the demand and supply of healthcare services and patients become closely related to the experienced quality of the healthcare system; a healthcare system that should be truly attuned to their care expectations.

Patient case 3-Phase of adhesion: Cesare, aortic stenosis, 64 years old, follows anticoagulant and beta-blockers therapy

Ageing, I have always tried to be more careful at least with basic health conditions, such as cardiac function, blood tests, prostate, usual controls, you know. I raised the level of attention about myself. Despite this, this incident happened to me. The disease is called acute dissection, and it is a laceration in the interior of the aorta, the blood slips off, dissected, it can occlude blood vessels, especially the two carotid arteries, in fact, I was told that the right one was already occluded, so I felt terrified of something that was absolutely new to me. Luckily, it happened at home, and we were alarmed and alerted immediately; within half an hour of feeling sick, the ambulance arrived and then everything went well, the usual things, I felt very bad, so they administered morphine, and they brought me here to the clinic. So, now I have to be very very very careful, maybe too much; for example, the pressure measurement every single day, without fail because the doctors told me, "The only danger for you, the only important signal you have to consider is the raising of the pressure." Then what do you do? You control it always, even in the early days at home, I controlled it 3–4 times a day. However, I am very grateful to the doctors and to all the staff of the clinic; they were very attentive and very empathetic to me. To me they are still important today. I try to be autonomous in controlling the state of my health and managing my therapy; that is, I do not call the doctor every 10 minutes. I call for the important things. I must say, though, that the disease has changed my life and my personality a lot. Before I felt like a lion, now I feel much more fragile. I am much more attentive of my health. I cannot do all the activities of the past, although I'm much better. It's a little bit of a psychological issue, even if I feel good and if the doctors have reassured me; however, I always feel somewhat sick.

3.4 Eudaimonic Project

In the "eudaimonic project" position, patients have fully accepted their condition; furthermore, they have understood and elaborated that the "identity of patient" is only one possible identity. They are able to better incorporate the disease into their life projects, and they are no longer overwhelmed (such as in the blackout phase) by their health conditions; rather, they are able to integrate their condition with other spheres of their lives (*elaboration*). To achieve this emotional elaboration, they use internal resources to project satisfactory life plans for their futures. Patients gradually become co-producers of their health, and they are capable of enacting more effective health management. Furthermore, they become more satisfied with their quality of life.

In this process, patients become more active in effectively searching for information about their disease conditions and management. This allows them to attribute full meaning to their healthcare experience (*sense making*) and in due time enact self-management behaviors, even when life contexts change (*situated practices*). In this position, patients also develop a more mature and psychologically sustainable perspective about their diseases, which can now be better integrated into their life.

In this phase, healthcare professionals are akin to "trusted allies", patients rely on them for advice and situated counselling to tailor care according to their evolving needs and expectations. Only in this engagement position do patients become managers of their health and care, and become able to enact true partnerships with the healthcare system. Patients are no longer passive; rather, they have learned how to mobilize the healthcare system proactively to best manage their condition. Furthermore, patients at this stage become active "ambassadors" of their communities' needs and expectations, by raising other patients' concerns to policymakers, helping others navigate the healthcare system, and collaborating with the healthcare system to improve its quality and equity. Furthermore, patients in this phase offer experienced testimonials of good self-management practice and are able to assist other patients who have similar experiences.

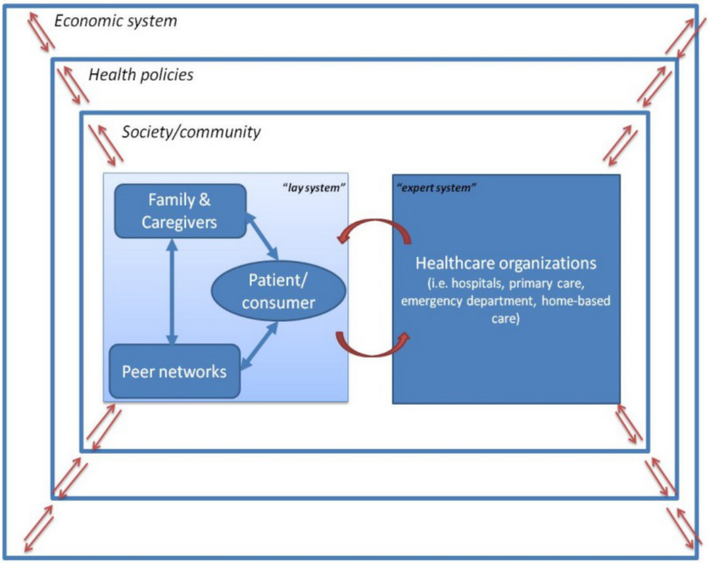


Figure 1: The process of patient engagement: A qualifier of the exchange between demand and supply.

Patient case 4-Phase of eudaimonic project: Lucia, breast cancer, 76 years old, follows oral therapy

I was diagnosed with breast cancer eight years ago. I had felt breast lumps in the shower and, in my heart, I knew that it was a bad thing. I went immediately to the doctor, did the controls, and then there was the diagnosis. When the doctor told me those words, "breast cancer", I collapsed. In a moment, it was like my children, my husband, all the good years gone by, passed in front of my eyes… honestly I felt was already dead. We immediately decided to proceed with the operation, while I was in a state of shock. Then, the devastation of chemotherapy. But luckily, those years have passed. Today, I am following an oral therapy that is much less devastating. It gives me new hope. I've learned to enjoy the little everyday moments, to project myself less in the future. So, once I always looked forward to the future, with this… with all the things I had to do, family, children, work. I did not really enjoy this! Today, however, I can enjoy the little joys of daily living. For me, the most important thing is not to feel myself as a concern for my family. I re-started working a little. I also try to manage the house; of course, I have to get help on the heavy work, but I can still do some things on my own. I also have hobbies, and I hang out with friends. I have always been an optimistic type, and I think it is important to see things from the good side, even with a serious medical condition. For example, last year I went skiing, I met three other older people like me, but they were not sick, and we had some lovely walks; we didn't ski, but we did the nice little things that gave us some peace. So, that is important as well. In short, I am very careful in checking my health, listening to the signs of my body.

Also, I am very accurate in the assumption of my therapy. But, I'm determined not to let the disease take over my life and my relationships, I know that I may not have many more years to live, and for this reason, I want to enjoy them more than ever!

4 Moving Along the PHE Model Journey: Experiential Levers and Key Actions

As described above, disease medical condition greatly affects the patient's psychological functioning and life experiences. To move along the process of engagement and make patients better able to interact with the healthcare system and be more satisfied, it is important to sustain them in their elaboration and reframing of their health experiences. In particular, at each position of the PHE model journey, some key actions are important to improving the experiential synergy among the three experiential dimensions—think (cognitive level), feel (emotional level), and act (behavioral level)—that are at the basis of the engagement experience (see Figure 2; cfr. Graffigna et al. 2014).

4.1 From the Blackout to the Arousal Position

At first, the patient has to come to terms with the critical health event that disrupted and de-organized their life and accept their new health condition by compiling knowledge about the disease and its treatment. In particular, to pass from the position of blackout to arousal—and start engaging in an exchange with the healthcare system—individuals have to accept that they are now also patients. In other words, patients need to reframe their identities to that of a patient by understanding the nature of the changes in their bodies and the associated symptoms. To enable this change, the healthcare system needs to educate patients and improve their understanding of their health and related conditions. In this educative process, the quality of the patient-healthcare provider relationship is fundamental because it functions as a positive catalyzer of the care process. Moreover, the healthcare system needs to sustain caregivers in coping with their patients' reactions to their illness experiences.

4.2 From the Arousal to the Adhesion Position

As we have seen before, in this phase, patients are emotionally distressed; they feel anxious and alerted. They experience loss of control over their bodies and emotional reactions, and they feel ineffective in managing their health status. They also feel unable to autonomously manage their diseases and their daily life activities. To

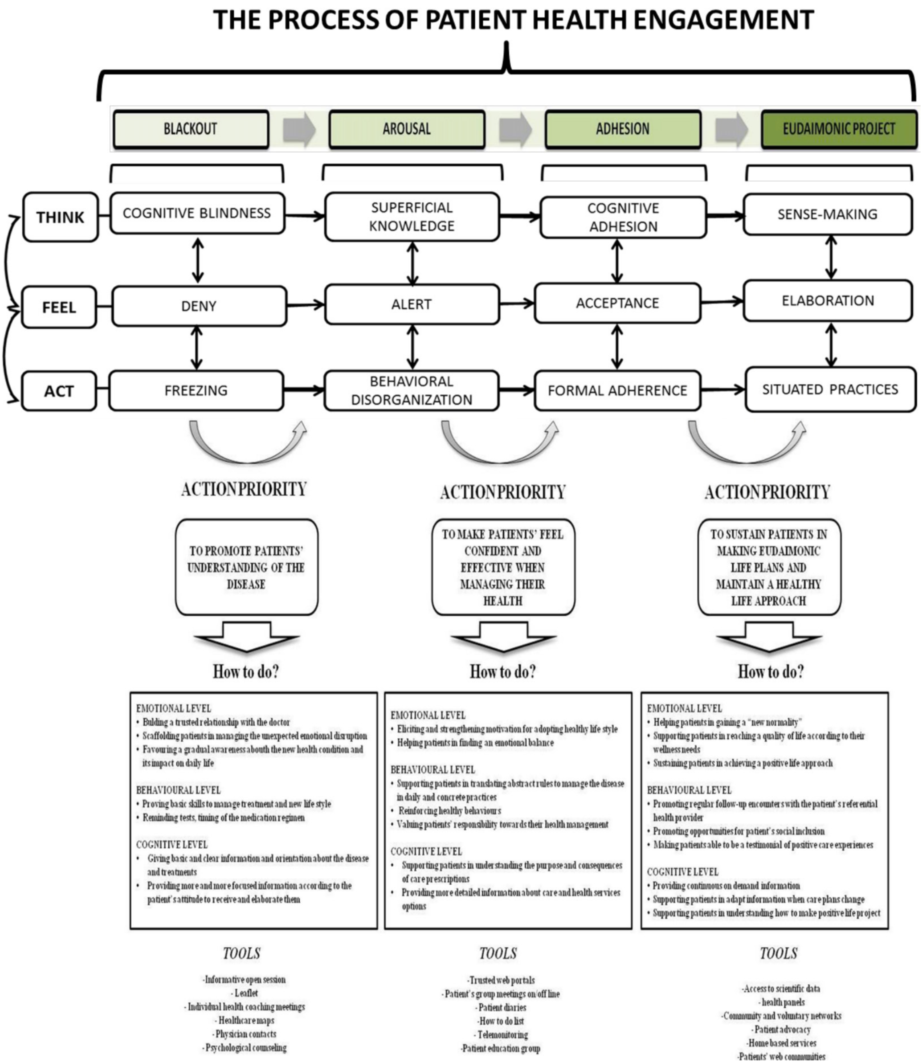


Figure 2: Positions of patient engagement and corresponding action priorities to sustain it (Adapted from Graffigna et al, 2014).

sustain patients in moving forward along their engagement journeys into the adhesion phase, the healthcare system needs to provide patients with occasions to improve their sense of self-efficacy and confidence towards health management. Furthermore, patients need to be motivated to manage their health and care autonomously, and they need to receive approval on the small goals they achieve through the course of their treatment. To be successful in this process, patients need to be educated, and their healthcare professionals should help them learn to prioritize their goals, identify obstacles, and build trustworthy relational care networks.

4.3 From the Adhesion to the Eudaimonic Project Position

Patients moving from the adhesion to the eudaimonic project position should overcome the narrowing of their life horizons produced by the traumatic experience of the medical condition. In other words, at the beginning of their engagement path they only focus on their “patient identity” by reducing their daily life spheres and interests. This is due to the emotional reaction to the traumatic health experiences and the disruptive effect of the disease on quality of life. To evolve along their engagement journeys and to mature into a positive approach to health management, it is important to sustain patients in maintaining active social roles in their communities. Furthermore, patients need help making life plans that consider disease management as part of their lives. In other words, patients need to be sustained in re-achieving some form of life projects, even if confined compared to their earlier life.

Furthermore, the patients need help incorporating their new identity as a patient into the broader domain of their lives. Patients have to maintain focus on more satisfactory and positive spheres of their private lives to reframe the disease on their existence. In other words, they need to feel like protagonists of their lives. This delicate psychological process has to be legitimized by the healthcare system and sustained by society, which needs to reframe its vision of the patient not only as a disease carrier, but also as a person with different meaningful life experiences that include illness management.

4.4 The Potential Role of New Technology

As highlighted in this chapter, engaging patients calls for healthcare organizations to revise their care models. This also requires innovative actions to favor the exchanges between the health consumers and their healthcare providers effectively. In this framework, eHealth tools might become a valuable option to innovate healthcare systems and service delivery (Riva et al., 2012). Generally speaking, eHealth technologies can enable patients to access health information easily (e.g., Google, Wikipedia, eBooks, Twitter, library web portals), receive support from peers (e.g., Facebook, Google+, Twitter, patientslikeme.com), and to interact with clinicians (e.g., phone, Mobile phone, SMS, e-mail). Moreover, such technologies may be useful tools to share patient information within the healthcare system itself, between healthcare professionals and (sometimes) patients/lay people (e.g., EHR or PHR), or even to support remote health monitoring (e.g., telemedicine).

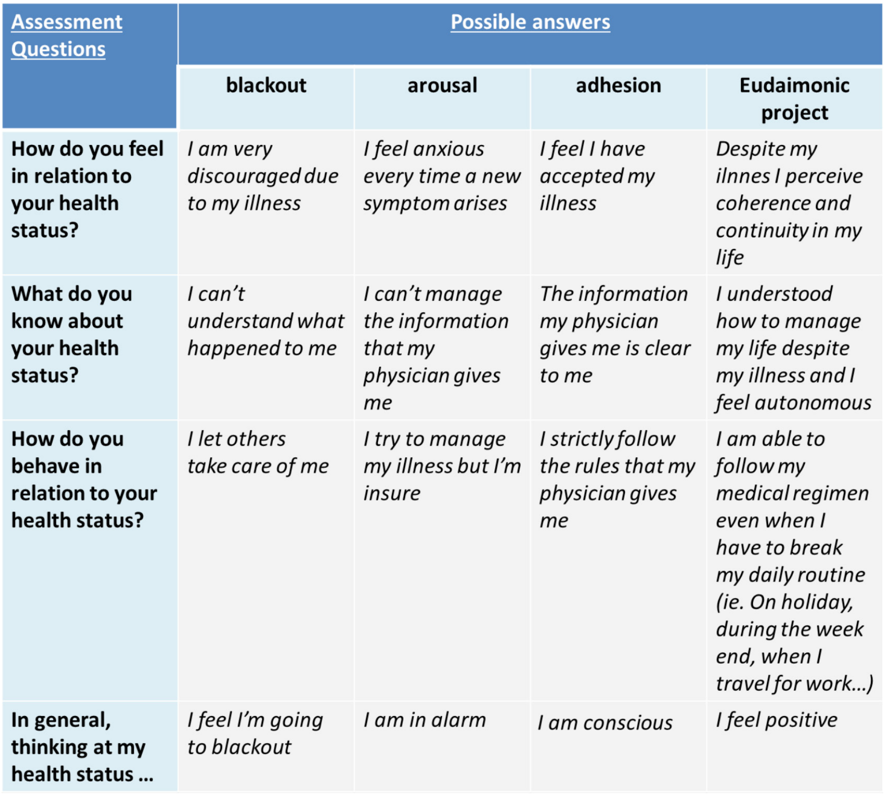
In this framework, eHealth is not confined to a single technology; more precisely, it is a process featured by a system of relationships (Eysenbach, 2001). At the first level of analysis, eHealth implies the relationship between the healthcare provider and the patient. However, at deeper levels of complexity, this implies the relationship between clinicians, providers of technological devices, and end users. In particular, at least the first and the third of these relationships are strongly connected to the act of engaging patients in the process of care, or promoting effective behavioral, emotional, and cognitive changes, within patients' complex lives and within their attitude to exchanges with the healthcare system (Graffigna et al., 2014). In this sense, implementing eHealth interventions means choosing, monitoring, and managing an integrated system of technological resources based on the specific conditions of the patient and their specific care needs.

Thus, to develop eHealth tools that are truly able to promote healthcare innovation in the direction of engaging patients in the co-construction of their health management, it is crucial to consider the specific unmet needs that patients might experience in different phases of the patient engagement process (Graffigna et al., 2013). According to this vision, not only disease condition and the necessities of the associated treatment, but also the patients' illness experiences, quality of life expectations, and willingness to be involved in the healthcare management process should be the guiding principles in eHealth tool design and implementation. Specifically, the discipline of "Positive Technology" (see Chapter 4)—the scientific and applied approach to the use of technology to improve the quality of our personal experience through its structuring, augmentation, or replacement—may orientate the development of eHealth devices that are able to boost patient engagement. More specifically, a positive technology can enhance patients' motivations toward illness prevention and the self-care process, as it can foster patients' autonomy by structuring them in the passage from one engagement position to the other by shaping the power dynamics that regulate the exchange between demand and supply of healthcare according to patients' specific needs and conditions.

5 The PHE Model in Practice: Opportunities for Innovating Healthcare

As we have seen in the previous paragraphs, the *PHE model* allows one to understand the experiential and psychosocial characteristics of patient engagement. The evolution from one phase to the next may vary in time, depending on the characteristics of the patient and the context in which he or she is embedded. Furthermore, this process is not always linear. Patients may become stuck for longer periods in a position or even revert to a previous phase of engagement in the case of additional traumatic events.

The *PHE model*, however, offers important support for healthcare professionals and managers to comprehend the stage at which their patients are at, which will help them plan more patient-centered interventions that are able to improve patient autonomy and competence in health management. The *PHE model* is conceived such as a compass to orientate the assessment of patient engagement in clinical consultations, to unveil patients' healthcare service expectations and unmet needs to plan new ser-



Assessment Questions	Possible answers			
	blackout	**arousal**	**adhesion**	**Eudaimonic project**
How do you feel in relation to your health status?	*I am very discouraged due to my illness*	*I feel anxious every time a new symptom arises*	*I feel I have accepted my illness*	*Despite my ilnnes I perceive coherence and continuity in my life*
What do you know about your health status?	*I can't understand what happened to me*	*I can't manage the information that my physician gives me*	*The information my physician gives me is clear to me*	*I understood how to manage my life despite my illness and I feel autonomous*
How do you behave in relation to your health status?	*I let others take care of me*	*I try to manage my illness but I'm insure*	*I strictly follow the rules that my physician gives me*	*I am able to follow my medical regimen even when I have to break my daily routine (ie. On holiday, during the week end, when I travel for work…)*
In general, thinking at my health status …	*I feel I'm going to blackout*	*I am in alarm*	*I am conscious*	*I feel positive*

Figure 3: Four patient engagement assessment questions and relative answers

vices, and to assess the engagement goals achieved by specific interventions. We will now discuss these implementations in more detail.

– ***PHE model such as an assessment tool.*** The process of patient engagement, as explained above, appears to be a function of the synergic evolution of patients' cognitive, emotional, and behavioral attitudes toward their health and care management. Thus, based on the model, it is possible to briefly assess the clinical position of a patient by simply asking four straight forward questions that assess the patient's psychological attitudes toward his or her health condition (see Figure 3). This set of questions—and the answers which will determine the patients' stage in the model—may orientate clinicians, managers, and other professionals in dealing with interventions aimed to sustain patients' self-care abilities in assessing primary psychological needs and care expectations. The *PHE model* questions the health literacy of the patient (ability to think about the disease and its management); the state of emotional elaboration about the diagnosis and the health condition (their way of feeling when reflecting on health status); and the consequent behavioral competences related to the self-management of his/her own care (their attitude of acting toward the disease). Moreover, it may offer clinicians a general picture of patients' global perceptions when describing attitudes toward health conditions and their management. The *PHE model* may be also used to measure the level of engagement achieved by such interventions (see Chapter 6 for an example of use of the *PHE model* to assess a technology-based rehabilitation intervention). In other words, the *PHE model* may be also used as a post intervention assessment tool to test the achieved goals and to optimize or re-orientate interventions. Measuring the level of patient engagement after an educational session, after a medical consultation, or even after service delivery reorganization, may be an important asset to account for the changes and achieved goals. Figure 3 describes the four main questions that healthcare professionals can ask patients to assess their engagement attitudes toward health and care management, together with the expected answers that patients at the different positions of the *PHE process* may respond. "Furthermore, based on the PHE model, te PHE Scale may help healthcare professionals and patients' to measure their level of engagement in care management (Graffigna et al. 2015).

- ***PHE model as a framework to innovate the healthcare system.*** As discussed before, it is our conviction that, to truly promote patient engagement and innovate healthcare services, it is important to deeply understand patients' psychosocial experiences toward health management. Only by understanding the experiences and interpretations of patients in relation to their diseases and their treatment is it possible to orientate interventions that are able to answer their needs and expectations. In other words, patients' perspectives about their engagement experiences should be metaphorically conceived such as the "cell" of the whole process of health engagement. However, we are aware that several other levels are implied in the redesigning of healthcare service delivery when aimed at improving patient engagement. When planning interventions aimed to promote and sustain patients' engagement, it is important to consider the different organizational layers and actors involved in the process. In other words, not only should patients' subjectivities be considered and managed, but also those of their caregivers and peers together with their healthcare professionals. Furthermore, not only should the situation of the clinical consultation be regarded as crucial to influencing patients' abilities to engage in their health management, but all "lay", not only institutional, exchanges about the disease and its management should be considered. The influence of organizational aspects that rule the healthcare system (such as process, procedures, roles, organizational cultures) should be considered in regard to the health engagement path of patients. Policy making also plays a fundamental role in sustaining the process of patient engagement and in making possible the revision of healthcare service planning and delivery to be more engaging. From our perspective, the *PHE model* offers important cues to innovating and improving healthcare practices at different levels by guaranteeing that eventual revisions in the systems are grounded in the ecological understanding of patients' needs and expectations and are, thus patient centered. In the second section of this book, you will find examples of how the *PHE model* may be used to orientate interventions at the clinical consultation level (Chapter 7), for supporting caregivers (Chapter 8–9), and to orientate organizational changes (Chapter 10).

6 In Conclusion: The Advantages of Adopting the PHE Model

In this chapter, we tried to answer a question which many healthcare professionals, managers, and policies, struggle to answer, "*How does patient engagement develop?*" To provide a concrete and useful answer and to move a step forward from the vague and abstract conceptualizations that, to date, have populated the Internet and managerial journals, we proposed adopting the theories and empirical research approaches that belong to consumer psychology. Consumer Psychology is a well-established discipline that seeks to unveil the basic subjective processes that rule individuals' decision-making processes and choice behaviours in different domains of daily life. Consumer Psychology theories, over time, have shown their effectiveness, not only in diagnosing purchasing behaviours, but also in orienting managerial practices aimed to improve exchanges between "demand" and "offers" for products and services. Consumer Psychology, applied to healthcare, may offer important clues to unveiling the roots of patient care preferences, the way patients make decisions among treatment options, and the reasons why they act or do not act concerning specific health management regimes. In other words, consumer psychology may help in understanding the "*reasons*" behind individuals' ways of reasoning, behaving, and feeling in relation to health and care.

In this light, the *PHE model* constitutes a simple and concrete conceptualization of how patients may "*think*", "*feel*", and "*act*", in relation to their health conditions and, thus, how patient engagement may (or may not) be possible. In particular, the four experiential phases of engagement featured by the *PHE model* cast light on the subjective complexity of the health engagement experience and offer insight to support healthcare interventions and practices at their different levels of complexity (i.e., from the dyadic situation of the medical consultation, to the organizational level, to the level of health policy making). In other words, patient engagement cannot simply be conceived as an "on-off" status; how the *PHE model* highlights, patient engagement is a process like experience that may (or may not) evolve over time. Patient engagement is a complex psychological development that takes time and needs to be specifically sustained during the different phases of its development. To achieve this goal, only grounding healthcare delivery in the ecological understanding of patients' experiences, preferences, and needs, may be the answer to innovating healthcare in the direction of a patient engagement approach.

The *PHE model* also underlines the different subjective components that play a role in the engagement process, and advises against simple conceptualizations of such experiences that only emphasize behavioural components. According to the *PHE model*, health management behaviours enacted by patients are the outcomes of a complex intertwining of cognitive and emotional elaboration processes. Finally, in the chapter, we discussed the value of the *PHE model* in orientating healthcare practices. The model may be used both to assess the level of engagement of a target population of patients and as a theoretical compass to orientate the planning and delivery of healthcare actions aimed to sustain health engagement. Moving from this general framework to further substantiate this point, the following sections of this book offer some example applications of the *PHE model* to assess and plan educational or care interventions at different levels of organizational complexity.

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Positive Technology for Enhancing the Patient Engagement Experiences

Abstract: New technologies are fundamental resources to fostering patient engagement in clinical and organizational settings. Not only can they allow clinicians to provide care services and support the diagnosis process, but they can also be used to understand patients' care experience and to promote patients' engagement in their own care management. In this sense, the Positive Technology paradigm constitutes a scientific and applied approach to the use of new technologies to structure, augment, or replace personal experience. Indeed, using new technologies allows; (1) the generation / promotion of positive emotions (Hedonic Technologies); (2) support in the achieving of positive and self-actualizing experiences (Eudaimonic Technologies); and (3) the promotion of connectedness and social integration, as a dynamic and controllable aspect of well-being (Social/Interpersonal Technologies). This chapter provides examples of how positive technologies can be used in healthcare settings to improve patients' engagement in their healthcare.

Keywords: Positive technologies; Patient Engagement; Positive Emotions; Flow; Social Presence; PHE model.

1 Introduction

As the previous chapters highlighted, increasing evidence demonstrates that patients who are more actively engaged in their healthcare experience have better health outcomes and incur lower costs to the healthcare system. In this sense, patient engagement is a crucial objective to be pursued by healthcare interventions.

But how is it possible to achieve it? Here we focus on a particular group of resources, namely the *technological* ones. It is known that the use of new technologies presents extraordinary strengths in engaging individuals and also patients. Indeed, technology modifies our experience of everyday tasks and activities; it makes it possible for us to perform actions which would not be possible basing on our biological resources alone; it give us sensations and emotions beyond our natural perception. In general, it is possible to say that technologies improve the quality of our experience. However, the impact of new media and new technologies on our well-being is still a controversial topic, and also the application of new technologies to complex fields such as the patients' experience is still variable and potentially confounded. In the healthcare context, new technologies are currently used both in "micro" and "macro" applications.

"Micro" applications refer to the implementation of technologies to support single patients in the quality of their experience. Indeed, some technological applications in healthcare are not focused on mere disease treatment. On the contrary, they encompass the objective of helping patients to manage the personal and emotional discomfort associated with the illness experience (Triberti & Liberati, 2014). For example, virtual reality and videogames are currently used for rehabilitation purposes. Currently, virtual rehabilitation is adopted for the treatment of several types of disabilities, such as disabilities following strokes (Laver, George, Thomas, Deutsch, & Crotty, 2011; Saposnik & Levin, 2011; Subramanian et al., 2007), musculo-skeletal and orthopedic disabilities (Burdea, Popescu, Hentz, & Colbert, 2000; Girone, Burdea, Bouzit, Popescu, & Deutsch, 2000), and cognitive or psychological impairments (Riva, Mantovani, & Gaggioli, 2004). In this context, the patient is provided with a virtual simulation that moves him/her to test and improve the residual (or even currently lacking) abilities in a secure environment monitored by professionals. In this way, a technological resource is designed to allow patients to regain the highest possible level of autonomy and quality of life.

Diversely, "macro" applications refer to the use of new technologies at an organizational level. Indeed, health organizations can use internet-related technologies to improve not only the administration of care plans to their patients, but also the consideration of patients' personal needs and issues. For example, EHR (Electronic Health Records) designed to include information about patients' values, health goals, and action plans, proved to be particularly efficient in fostering positive behavioral change in the patients (Chunchu, Mauksch, Charles, Ross, & Pauwels, 2012). Similar interventions can be used to share medical information with the patients, thereby promoting mindful self-care planning in them (Grant et al., 2006).

These two examples show how the use of new technologies in the healthcare context can be complex and varied. Current literature in this area often misses a common vision and also shared, practical guidelines to explain exactly what the positive effects of technology implementation are, and how is actually possible to achieve desirable goals. In the present chapter, we will propose an emergent framework that is able to constitute a general strategy for the successful use of technologies for the purpose of health and well-being.

2 Introducing the Positive Technology Paradigm

According to recent studies in the field of Human Computer Interaction, the goal for technology design is no longer simply to respond to users' basic needs and objectives, but to take into consideration their higher-level desires too. An example of this trend comes from usability studies, where the ease of use of technologies is now considered only a first step towards the creation of artefacts able to guarantee engaging and positive *User Experiences*.

This evolution is in accordance with important achievements in social sciences. At the start of the 21st century modern psychology was criticized for its almost exclusive focus on the study of human pathologies, limits and illnesses (Seligman & Csikszentmihalyi, 2000). Based on this criticism, the authors identified a growing need for a "science of happiness" that would be able to study the features of pleasant experiences and to design and resources to promote them in individuals, groups, and organizations.

With these aims in mind, they founded the discipline of "Positive Psychology", a scientific approach to the manipulation of the quality of experiences with the goal of increasing wellness and generating strengths. Martin Seligman (2002) later identified three types of "happy life" that highlight the possible sources of subjective well-being:

- **The pleasant life**, achieved through pleasant emotions;
- **The engaged life**, achieved through engagement in satisfying activities and utilization of one's strengths and talents;
- **The meaningful life**, achieved through serving a purpose larger than oneself.

Moreover, Keyes and Lopez (2002) identified three pillars of well-being and positive functioning: a) positive emotions, b) high psychological functioning, and c) high social well-being.

In the context of healthcare, Seligman (2002) highlighted that human strengths can act as buffers against illness, suggesting that such strengths can be important resources for both prevention and therapy: courage, future-mindedness, optimism, interpersonal skill, faith, work ethic, hope, honesty, perseverance, the capacity for flow experiences, and insight are important examples.

In general, it is possible to say that the research conducted by Seligman and colleagues highlighted the sources of positive experiences. Recent research showed that new technologies in particular can intervene in modifying/fostering all of these dimensions. This gave rise to the emergent paradigm of Positive Technology (Riva, Baños, Botella, Wiederhold, & Gaggioli, 2012). According to this new paradigm, the quality of experience should become the main guiding principle for the design and the implementation of new technologies. Elaborating on the main concepts of Positive Psychology, the emergent paradigm identified three domains for the positive technological applications:

- **Hedonic Technologies**
- **Eudaimonic Technologies**
- **Social/Interpersonal Technologies**

Focusing on technologies, which are instruments easy to design, learn, and implement, the Positive Technology paradigm provides precise guidelines to positively work on the experience of people. In this sense, this conception may generate crucial guidelines for managing patient engagement. Indeed, it is possible to associate the PHE phases with the possibilities and opportunities highlighted by positive technologies, providing examples of useful tools and insights for the engagement of patients in healthcare plans. We will now elaborate on the three domains of positive technologies in order to associate them with the diverse elements of patient engagement experience.

The first domain is related to the generation and support of positive emotions in the technology users. According to the Broaden-and-Build Theory (Fredrickson, Danner, & Snowdon, 2003; Fredrickson, 2001) positive emotions (such as joy, interest, commitment, gratitude, etc.) broaden an individual's momentary mindset, allowing the generation of personal resources. In a broader sense, positive emotions are related to longer and healthier living (Fredrickson, 2000).

Research in the field of Hedonic Technologies has demonstrated that interactive-simulation technologies are particularly suitable for fostering positive emotional states. For example, Virtual Reality obtained remarkable results in fostering and manipulating joy and relaxation (Baños et al., 2012; Grassi, Gaggioli, & Riva, 2009; Riva et al., 2007). These results were consistently related to the possibility for participants to actively interact within the virtual environment and within the meaningful content of the virtual realities. According to Serino and colleagues (2013) the main features of VR technology able to induce positive moods are:

- Interactivity (that motivate the participants to be engaged in the activity)
- Manipulability (that allows the tailoring of any virtual experience to the intentions and the needs of a given user)

In this sense, videogames and serious games (a term which identities videogames designed for educational purposes) proved to be useful technological tools to inducing positive emotional states (Argenton, Triberti, Serino, Muzio, & Riva, 2014). According to Frome (2007), this is due to four factors: narrative (roleplaying and feeling the emotions of fictional characters), gameplay (frustration-satisfaction cycle related to loosing and winning), simulation (experiencing new and engaging activities simulated by the game), and aesthetics (fruition of the game design as a piece of art).

In general, interaction and interface features of new technologies can be designed with the goal of generating pleasurable experiences, according to a "Hedonomics" approach (Hancock, Pepe, & Murphy, 2005; Hsee, Hastie, & Chen, 2008). However, positive emotions and pleasure are not the only sources of well-being. As we have previously said, people may achieve positive experiences via personal growth and fulfillment too. Indeed, human beings are not passive receptors of emotional stimuli, rather they are able to flourish by exercising their capacities on a cognitive, affective, and social level (Argenton et al., 2014). When this happens, an individual can be engaged in a state of *flow*, namely a feeling of fluidity and concentration, characterized by absorption and intrinsic enjoyment (Csikszentmihalyi, 2002; Csikszentmihalyi, 1988; Nakamura & Csikszentmihalyi, 2002). A state of flow is typically triggered by a dynamic equilibrium the individual perceives between high environmental action opportunities (challenges) and high personal resources to manage them (skills). The state, also labeled "optimal experience", is characterized by the ongoing task having clear rules and providing unambiguous feedbacks. The individual in flow experiences a loss of reflective self-consciousness and is fully concentrated on his/her own actions within the environment, moved by intrinsic motivation; also alterations in the experience of time/duration are expected to happen.

These self-actualizing experiences are typical of the interventions in the field of Eudaimonic Technologies. Indeed, another interesting aspect of flow is that it can be used by individuals to actually improve their own resources. More specifically, individuals can exploit an optimal experience to discover and use new and unexpected psychological resources to promote personal involvement in a process labeled "transformation of flow" (Massimini & Delle Fave, 2000), which has also been considered for rehabilitation purposes (Riva, Castelnuovo, & Mantovani, 2006a).

To achieve a state of flow the individual should be involved in a task, so Eudaimonic Technologies are predominantly interactive technologies. Numerous researches have demonstrated that flow can be reached in the context of diverse technologies, usually characterized by increasingly demanding challenges that motivate the users to fully activate their own skills in order to achieve clear goal settings. In this sense, numerous technological activities have been found able to promote flow and engagement in their users, such as e-learning (Davis & Wong, 2007), computer hacking (Voiskounsky & Smyslova, 2003), virtual reality (Riva, Castelnuovo, & Mantovani, 2006b; Riva & Gaggioli, 2009), web browsing (Skadberg & Kimmel, 2004), and playing videogames (Argenton et al., 2014; Kaye & Bryce, 2012; Triberti & Argenton, 2013).

The final level of positive technology is related to the use of technologies to promote connectedness, sociality, and collaboration among individuals, groups, and organizations. The challenge for Social/Interpersonal Technologies is to understand how it is possible to generate a mutual sense of awareness between the individuals involved in a communicative interaction, especially when they interact at a distance.

Of course, new communication technologies such as web-chats allow the users to communicate, but the information and sensations they can vehicle about mutual awareness are low. What it is important to foster in individuals is the highest possible level of social presence, which could be defined as the sensation of being with other selves in a real or virtual environment, a result of the ability to recognize the intentions of others (Davide, Triberti, & Collovà, 2014; Riva, 2008). Biocca and Harms (2002) have identified some elements that help to create a sense of social presence, valid for both real environments (face-to-face relations) and virtually mediated ones.

For example, the sensory perception of body shapes (or their digital representations), the psychological involvement with another intelligence, and behavioral engagement in the context of interaction and synchronization, are particularly important factors in order to promote this sensation. In general, the level of social presence in a mediated environment is strongly influenced by the "media richness", that is, the properties of interface that permit verbal and nonverbal communication, recognizable actions in the environment, and naturalistic representations in terms of appearance and behavior (Biocca, Harms, & Burgoon, 2003; Joyce & Brown, 2009). Social presence appears to be a fundamental factor in the functioning of online shared experiences: recent research highlighted that high levels of social presence are identifiable in successful collaborative environments and media-driven decision making (Mennecke, Triplett, Hassall, Conde, & Heer, 2011). These high levels of social presence/mutual awareness can be associated with the phenomenon of networked flow (Gaggioli, Milani, Mazzoni, & Riva, 2011), a peak creative state that is achieved by the members of a team. It is a process, which begins with the co-construction of a shared frame and culminates with the creation of a novel artifact or concept.

This paragraph briefly introduced the areas of interest in the Positive Technologies approach. We highlighted fundamental concepts and examples of how technologies can be used to foster well-being. In the next paragraph, the Positive Technologies approach will be discussed in the context of patient engagement.

3 Positive Technologies and Patient Engagement

From an applied viewpoint, Positive Technologies can be used to (Graffigna, Barello, Wiederhold, Bosio, & Riva, 2013; Riva et al., 2012):

- *Structure* the experience, for example providing a goal, rules, and a feedback system. The goal is useful in helping subjects to experience a sense of purpose, so that they focus their attention and resources on it. The rules, that limit the ways of getting to the goal, push the individuals to see the experience from a different viewpoint. The feedback system tells players how close they are to completing the task and this fosters their motivation to try to achieve it.
- *Augment* the experience in sensorial, informational, and emotional terms. This not only enriches the pleasure of the experience, but also enhances interaction possibilities and sense of control over the activity.
- *Replace* physical experiences with synthetic ones. For example, virtual reality and video games can simulate a physical presence in a synthetic world that reacts to the action of the user as if he/she was really there. Also, communication technologies allow the users to generate and maintain social relationships across spatial and temporal limitations. In general, “replacement” technologies allow the users to experience activities that would not be possible or easily accessible in the physical reality.

In the coming paragraphs, we will explain how these main applications of positive technologies can be useful to engage patients in their own care experience. More specifically, we will elaborate on the position expressed in Graffigna and colleagues (2013).

As the previous chapters highlighted, patient engagement is a process composed of four incremental and evolutionary phases. To be fully engaged, the patient has to move beyond the first stages to achieve a personal well-being and fulfillment even in the context of his/her pathological condition.

Firstly, the patient falls into an initial state of emotional, behavioral, and cognitive blackout determined by the critical event of the diagnosis: it appears unexpected, dramatic, and out of personal control (phase 1: *blackout*). Then, the patient is prey to his/her emotions. The symptoms feel from their body are constant triggers for anxiety, stress, and dysregulated emotional reactions (phase 2: *arousal*). As a third step, the patient starts to develop knowledge and behavioral skills to effectively adhere to medical prescriptions and feels sufficiently confident in his/her health condition management (phase 3: *adhesion*). Finally, the patient's experience features acceptation of the pathological condition, and the patient is able to recognize his/her personal resources not only to manage the condition, but also to recapture a positive life planning oriented to the future (phase 4: *eudaimonic project*).

Positive Technologies methods can be easily applied to help patients in moving through the engagement phases and reaching a positive state in the context of their health condition. According to Graffigna, Barello, and Riva (2013a, 2013b), positive technologies are particularly suitable for *experience structuring* in the first two phases, by using goal setting and feedback systems techniques; diversely, *experience augmenting* is the main objective for technological implementation at the last two phases level. Here we elaborate on this, explaining what exactly these technologies can do to help patients at the diverse stages of the engagement process (see Figure 1).

Positive technologies for the blackout phase should help patients to manage the dramatic experience of the disease onset. In this phase, the patient can be overwhelmed by his/her own feelings and it is possible that he/she would not be able to immediately follow medical prescription and/or modifying his/her own everyday plans. The patient often tries to deny the situation and to not think about it. In this phase, technology can be used to manipulate the emotional state of patients and help them in recovering control over their own experience. Numerous examples in the literature show how new immersive/interactive technologies can provide mood induction, and also significantly reduce the experience of stress (Cipresso et al., 2012; Grassi et al., 2009; Serino et al., 2013), anxiety (Repetto & Riva, 2011), and even physical pain (Mahrer & Gold, 2009; Malloy & Milling, 2010; Triberti, Repetto, & Riva, 2014).

Emotional control should also be maintained in patients in the second phase, namely the arousal phase. However, the goal for this phase is to drive patients towards the active understanding and application of medical prescriptions. In this scenario, positive technologies help patients in achieving *knowledge* and *organization*. For example, online portals and/or smart-phone apps can be designed to provide the patients with organizational structure; these type of technologies may become a rich tool for " health lifestyle education", assisted living, medical education, and public health surveillance (Boulos, Wheeler, Tavares, & Jones, 2011). The apps in healthcare have three characteristics (van Velsen, Beaujean, & van Gemert-Pijnen, 2013): first,

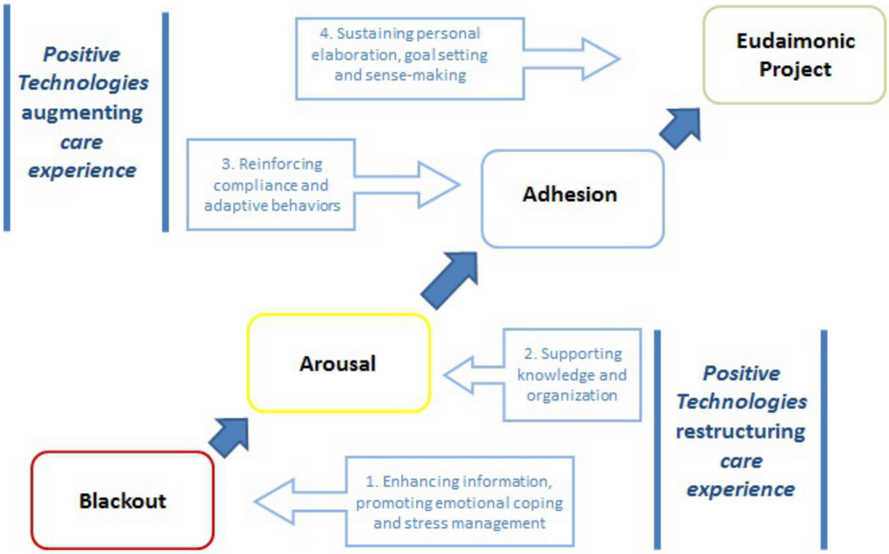

Figure 1: A scheme highlighting the cross-phases technology implementation for the patient engagement process.

usually thanks to open source politics, they can work as a gateway to medical information; second, they tend to standardize content to be readable and understandable by different types of stakeholders; and third, they are able to customize content and functions according to the individual's characteristics and context.

From the adhesion to the eudaimonic project phase, the individual is characterized by a personal experience of the disease which is (at least in part) already bound to a positive activation. In this sense should be sustained through augmentation of the positive features of their situation. Social/Interpersonal Technologies allow the patients to initiate and maintain contact with people who are important figures for their engagement development.

The patient's ability to make and pursue life projects should also be promoted and enriched. In this context, patients benefit from confrontation and collaboration within communities of other patients and healthcare providers. This is possible through implementing the care process in 3D avatar-mediated Virtual Worlds, within the context of an innovative eHealth service that provides personalized immersive therapy (pHealth). The interaction between real and 3-D virtual worlds may convey greater feelings of "being there", facilitate the clinical communication process, promote positive group processes and cohesiveness in group-based therapies, and help patients in achieving interpersonal trust towards their doctors, peers, and caregivers (Gorini, Gaggioli, Vigna, & Riva, 2008).

The implementation of positive technologies in medical interventions and policies is related to the establishment of a virtuous "positive cycle" for healthcare (Figure 2).

Figure 2: The positive cycle of positive technologies in healthcare, from Graffigna and colleagues (2013).

In this chapter, we introduced the Positive Technology paradigm and briefly elaborated on its suitableness for patient engagement interventions. However, the field of Positive Technology is still partially unexplored and open to the possibility of technological projects for well-being in the future. For this reason, in many fields of intervention, positive technologies are still to be designed and produced. The question is, how can effective positive technologies be designed and tested?

According to Graffigna and colleagues (2013), in order to technological advances being able to play a crucial role in sustaining people’s health management in everyday life, they have to be “ecologically” designed and well-attuned to people’s health needs and expectations.

In Chapter 5, we will provide insights to guide a patient/user centered design of positive technologies.

4 Conclusion

The present chapter introduced theoretical resources and instruments to achieve patient engagement in healthcare settings. Positive technologies, which are technologies designed to elicit positive emotions (hedonic technologies), support self-actualizing experiences and flow (eudaimonic technologies), or improve connectedness between individuals, groups, and organization (social-interpersonal technologies) constitute an essential resource to help patients in their path through activation and engagement in their own healthcare. According to Graffigna, Barello, and Riva (2013b), in order to be effective, positive technologies for health engagement have to be tailored to the patients' needs and personal situation. The PHE model explains the current experience of the patient who is developing his/her own personal engagement in the process of care. With these stages in mind, positive technologies can be used to structure the experience of the patient, for example modifying his/her emotional responses when he/she is overwhelmed by the shock of the diagnosis (blackout phase) or supporting knowledge management when he/she starts to manage the pathological condition (arousal phase). Moreover, positive technologies may be used to *augment* the patients' experience in terms of treatment adherence and adaptive behaviors (adhesion phase) and even complex goal-setting so that the patient would be able to achieve a positive attitude despite the pathological condition (eudaimonic project phase).

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Engaging Users to Design Positive Technologies for Patient Engagement: the Perfect Interaction Model

Abstract: This chapter elaborates on the design of positive pechnologies for patient engagement. According to literature, new technologies for patient engagement should be “ecologically” designed, taking into account the personal situation and needs of the patients. This could be done by adopting a User-Centered design approach, which is based on the involvement of the end-users of the technology from the very first stages in the design process. In order to achieve this objective, this chapter will propose a User-Centered approach to the *design* of new technologies applied to the healthcare context. A new operational model labelled PIM (Perfect Interaction Model) which is able to analyze the intentions, the feelings, and the real-life context of the patients in the technologies’ design process is also described. Moreover, the PIM is then associated with the PHE Model, highlighting the important aspects of patient engagement that should be be considered in the design process.

Keywords: Positive Technologies; User Experience; User-Centered Design; PHE model; Perfect Interaction Model.

1 Introduction

In the previous chapters, we have shown how new technologies can be used to promote the patient engagement process; different types of technologies may be implemented to structure, augment or substitute the experience of patients, accompanying them through the four-phases process of engagement in their own care plan (see Chapter 5). Moreover, we explained that positive technologies should be “ecologically” designed and well-attuned to peoples’ health needs and expectations (Graffigna, Barello, Wiederhold, Bosio, & Riva, 2013). But, how is it possible to do this?

Patients deserve to be taken into consideration in the context of the design of the technologies; it is not acceptable to design and implement new instruments for patient engagement without a deep look at what the patients want, need, are interested in, and are actually able to do. In this sense, fundamental insights come from the field of User Experience (UX) and User-Centered Design (UCD). In the present chapter, these concepts will be explained. Then, we will introduce a new model which shows how the intentions of the technology users have to be taken into consideration, especially in the context of their relationship with the technology features. In the end, the model for UCD will be associated with the characteristics of patients, from the point of view of their care engagement process.

2 User Engagement for the Positive Technology Design

As in medicine, a person-centered approach is also developing in the field of technological design: it is increasingly acknowledged that design must be centered on the person, namely the *user*. Indeed, the study of human-technology interactions evolved from the application of theories regarding internal cognitive processes to approaches more focused on the contextually-situated activities of the individuals (Kuutti, 1995).

User-Centered Design (UCD) is an approach to design and development of technologies that considers users' needs as the primary guides for technological implementation. In this section, we will elaborate theoretically on the concept of UCD, and introduce a new general model to sustain patient/user consideration when designing positive technologies for healthcare.

UCD (Garrett, 2010; Lowdermilk, 2013; Miller, 2005) is considered by many the gold standard approach to achieve a satisfactory user experience. The goal of this type of design consists of ensuring that no aspects of the user experience take place in the interaction outside of the designer's knowledge. The only way to achieve this is to *actively involve the user* in all the steps of the design of the product, rather than only in the evaluation phase, as in the ergonomics/usability approaches that were popular in the last few decades. In this sense, UCD is a broad term which refers to any design process where the end-users deeply influence how the design takes place (Abras, Maloney-Krichmar, & Preece, 2004).

The first step of a UCD is the identification of the different *stakeholders* who are involved in the technology (Sharp, Finkelstein, & Galal, 1999). Indeed, "users" are not simply those who directly interact with the technology's interface. According to Eason (1987), primary users are in direct contact with the application; secondary users are occasional users of the technology, benefit from its effects, outcomes, and/or products and/or use it via an intermediary; tertiary users are someway affected by the introduction of the technology, and may be those who decide to purchase/implement it for the other types of users. Considering these important distinctions, Table 1 shows an example of *who* should be taken into account when designing a positive technology for healthcare and engagement.

In UCD, all these types of users may become active contributors in every step of the design process. These steps can be described according to what Garrett (2010) considers the five elements constituting the product to be designed:

- *The Surface*, which is the interface of the product, namely the set of physical devices with which the user interacts to activate the functions;
- *The Skeleton*, which is the positioning of the interface devices according to a logic of efficiency: it defines where the devices are in relation to each other;
- *The Structure*, which is the basic concept of the skeleton. It defines the categories in which the functions of the system must stay, to express them in the positioning of the skeleton;

Table 1: The different types of users UCD has to take into account.

Primary users	**Secondary users**	**Tertiary users**
(those who directly interact with the technology)	*(those who someway benefit from the technology; use it via an intermediary; may have an influence about the primary users using/not using it)*	*(those who are affected by the technology use and decide its purchase/implementation)*
Patients, clinicians	Caregivers, designers, developers, technicians	Healthcare organizations, companies that provide funds for the technology
Example: A diabetes patient uses a smart-phone app everyday to remind of insulin injection and to register glucose values; the doctor also uses the app to monitor the patient at a distance	Example: Designers and developers use the app to test it and improve its functions; the caregivers help the patient to have the access to the device necessary to its use	Example: A pharmaceutical company funds the smart-phone app development; the hospital presents it to the patients and encourages its use

- *The Scope*, which is the set of objectives and sub-objectives of the system. It defines what functions the system must have in order to allow their inclusion in the categories of the structure;
- *The Strategy,* which is users' action-plan with which they approach the system. It must be consistent with the idea of the designer.

Garrett's *Five Planes Model* is useful to understand how it is possible to fine-tune technologies to harmonize them with users' needs, attitudes, and intentions.

This concept highlights the main features of a technology, which is not only a physical instrument. It is a basic idea/project, which needs to exist not only in the designer's mind but also in the intentions of the users (the strategy); it encompasses a careful understanding of the set of actions users will play out to achieve their objectives, and of the contents it has to show to adequately respond to them (the scope, the structure, and the skeleton); and, on the basis of the previous elements, it considers the analysis of the users' behavior directly using the technology's interface (the surface).

To sum up, UCD of positive technologies is based on the consideration of individuals' personal needs, concerns, and issues to orientate technology creation and application. Research methods can be used to understand users' characteristics and use this information as the basis for design.

In the first stages of a UCD of a positive technology, **qualitative unstructured interviews** (Wood, 1997) can be used to understand the important needs of the different types of users. Moreover, from the point of view of the patient engagement according to the PHE model, qualitative interviews are particularly suitable to identify the patient's positioning through the engagement phases (*blackout, arousal, adhesion, eudaimonic project*) (see Chapter 2). In this sense, interviews orientate the co-construction of the basic strategy of the technology; the concept of what is created for, pursuing a situation of total correspondence between designer and user's representations.

When a product/technology is designed at least in its fundamental functions and properties, it needs to be proved in relation to the context in which it is expected to be used (1) and in relation to what functions the users will primarily consider and interact with (2). **Contextual inquiry** (Dekker, Nyce, & Hoffman, 2003; Viitanen, 2011), a semi-structured interview with the users that the designer conducts *within* the context of the technology's use, allows the understanding of the physical/environmental challenges and opportunities for its adoption. Then, different versions of the application (also with simplistic/preliminary interfaces) can be prototyped and tested, without creating physical versions of the technology. This can be made thanks to **paper prototyping** (Snyder, 2003) (sheets of paper representing the application are moved in front of the user, according to the actions he/she declares to do) and **virtual prototyping** (Bordegoni, Ferrise, & Lizaranzu, 2011; Wang, 2002) (using virtual representations of possible interfaces, allowing limited interaction possibilities).

Usability tests based on quantitative measures (Garrett, 2010) (e.g: time of task completion, opinion questionnaires, psychophysiological measures…) may be used only at a later stage of the design process, to evaluate interfaces which are expected to be closer to the final version.

These are research and evaluation methods generally useful to provide UCD for technological applications. But, what aspects have to be taken into account when a research-based design or a User Experience project is evaluated? In the next section, we will briefly introduce a new model to guide User Experience studies.

3 Intentions and User Experience: Introducing the Perfect Interaction Model

The model is labeled "Perfect Interaction" because it actually represents the interaction in which every level functions as it should. That is, intentionality of the user successfully interfaces with the right level of the technology in use, and adequate feedback is received in the context of action. But, what exactly does this mean? Firstly, it is important to understand what an intention is, and why it is possible to conceive it as something constituted by a complexity of levels.

Consider my actions when writing this chapter as an example. I have just written the letter "x", writing the word "example". This small action is related to my consciousness and volition thanks to a precise intention. But what is an intention? If

I think about my own intention, I see that something very complex explains my action. I'm writing a letter to write a word, and I'm writing this word (and many others) to write a chapter about positive technologies and patient engagement. Moreover, I'm writing this chapter to provide useful insights for the achievement of patient engagement in healthcare, and I'm doing so (and not doing something else) because, at the moment, I think this is a good thing to do in order to be a good researcher in my field.

This example shows that a complexity of inner experiences is related to a physical action. According to this phenomenon, Pacherie (2006; 2008) argued that three types of hierarchically-distributed intentions exist. *Future-directed intentions* (or distal intentions) are the outcome of practical reasoning about means and plans. They can last for years and are not situation-dependent (my intention to be a good researcher is not directly influenced by the opportunities and constraints of the situation in which I am at the moment); *Present-directed intentions* (or proximal intentions) have motivational and control functions upon what I want to do *now* in order to advance in the achievement of future-directed intentions, so they are temporally and contextually constrained (my intention to write this chapter needs to be negotiated with contextual factors such as the time I have, my physical and psychological state at the moment, the functioning of the computer I use, and so on); finally, *Motor intentions* represent and guide the fine-grained aspects of action implementation, namely the motor ones. They develop at a time scale of a neurological micro-present, which only partially overlaps the conscious present. My intention to write the "x" letter (and many other letters) is essentially unconscious, since I do not consciously decide that I'm about to write "x". Nonetheless, my "moving the fingers in a precise way to write x" is totally consistent with the superior intentions (present-directed: writing the chapter; future directed: being a good researcher) and the entire hierarchy of my intentions is necessary to fully understand and explain the generation of my action.

The Perfect Interaction Model (see Figure 1) is based on the assumption that a *natural isomorphism* exists between the intentional hierarchy of the user and the characteristics of the technology. That is, when the user meets the technology, a *dovetailing process* begins, in which every step of the intentions of the user interlocks with a precise level of the technology. In Figure 3, three arrows symbolize these steps of interaction.

- Arrow 1: the distal intention of the user dovetails with the goal of the application, which is the scope for which it has been created. That is, the user wants to achieve something ("X") and the technology represents an opportunity to generally-extend the user's action in order to reach that purpose.
- Arrow 2: the proximal intention of the user transforms the distal intention, which is the general objective to be pursued, in one or more actions to be performed now ("Y"). The proximal intention dovetails with the structure of the technology, which is the set of functions that it allows. The structure is composed of temporal and spatial constrains that imply an order and an organization for the action.

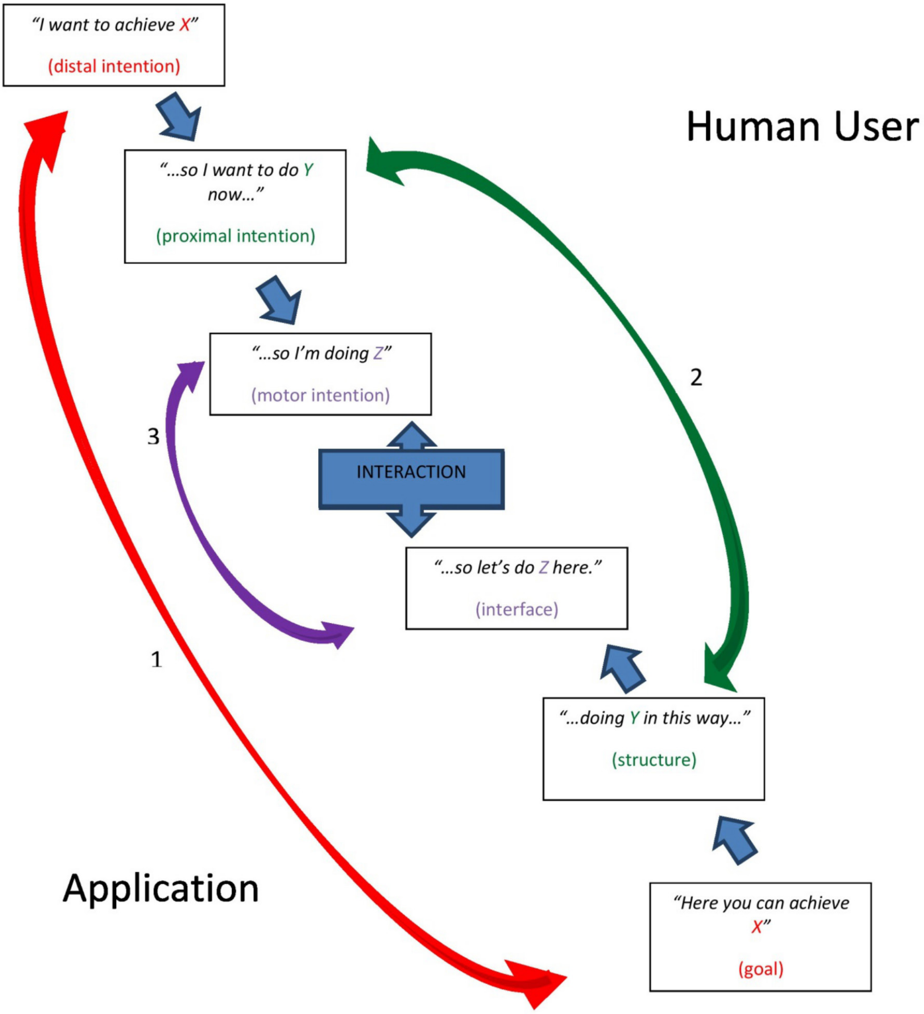

Figure 1: The Perfect Interaction Model.

- Arrow 3: the motor intention describes the fine-grained aspects of the action (e.g.: you have to move your fingers in *this* way, "Z"). It dovetails with the interface of the technology, which is the physical representation of the structure and is composed of a number of interactive devices to make the technology work

The PIM is useful to orientate both user experience evaluation and UCD. Indeed, representing the perfect interaction, it helps in identifying what may not work in an actual interaction that has to be analysed or evaluated. More specifically, it allows six types of malfunctions that could possibly happen in a complex interaction to be recognised. Table 2 shows these types of malfunctions, which are located at the six

Table 2: Possible interaction malfunctions according to the PIM.

	User	**Application**
1) Distal Intention and Goal	The user doesn't know what he/she wants	The application does not have a clear scope
2) Proximal Intention and Structure	The user doesn't know how to act to obtain what he/she wants	The functions are not adequately expressed in the structure
3) Motor Intention and Interface	The user isn't able to move	The Interface is not usable

steps of the interaction. They are comprised of three malfunctions related to the application (goal, structure, interface) and three malfunctions related to the user (distal intention, proximal intention, motor intention).

The possible interaction malfunctions deserve to be recognized by the evaluator to guarantee redesign orientation, and also by the designer *in advance* to provide a final technological tool that properly responds to the user's needs and expectations.

In the next section, we will elaborate on the PIM model used to orientate the design/evaluation of positive technologies for patient engagement. In order to do this, examples of every possible interaction malfunction will be provided and analysed.

4 Perfect Interaction for Patient Engagement Technologies on the Basis of the PHE Model

Considering the field of positive technologies for patient engagement, we now provide some examples of types of malfunction, to help designers and evaluators in correctly identifying them.

- **Arrow 1, user:** "The user doesn't know what he/she wants". According to the PHE Model, a patient who is in the blackout phase is overwhelmed by the emotional shock of the diagnosis he/she received. The patient may deny what it is happening and so, independently from the application correctly working, he/she probably does not yet have a clear intention to confront the disease and to start managing it. This can result in a random use of the technology, with no intrinsic motivation and high probability of dropping out.
  Mandatory intervention: if no UCD was provided (i.e., based on the personal situation of the patient), the patient should be guided in the understanding of his/her condition and in the formation of a positive intention plan

- **Arrow 1, application:** "The application has not a clear scope". This happens when communicational problems affect the application and/or the related healthcare plan. For example, a patient in eudaimonic project phase has a clear intention to manage his/her medical prescriptions, but the medical app he/she wants to use has multiple and confounding functions.
  Mandatory intervention: the app should be tailored on the patient's needs and context. It is possible that no redesign is required. The doctor and/or the caregivers may help the user to understand what functions of the app are useful to his/her healthcare plan, and what functions can be ignored/eliminated
- **Arrow 2, user:** "The user doesn't know how to act to obtain what he/she wants". A patient in the adhesion phase has a clear distal intention to manage his/her pathological condition, but he/she may still adhere in an automatic manner. The patient is still trying to understand what he/she has to do to achieve the general objective. Say, a patient is invited to join a virtual world in order to get in contact with other patients and learn from their personal experience with the disease. The objective is clear and also the application is entertaining and usable, but many virtual places and affordances for socialization are available, so he doesn't know where to go and what exactly to do in order to start the positive experience.
  Mandatory intervention: the user should be actively assisted in the technology use.
- **Arrow 2, application:** "The functions are not adequately expressed in a structure". Imagine a patient who approaches a serious game to learn how to cope with her stress. The application proposes and supports some relaxation exercises and, at the end of each session, a sheet appears with some numerical indexes of her performances. Unfortunately, the user doesn't understand what exactly they mean. Are they high or low scores? Are they positive or negative? What should she do to improve her relaxation skills? This is a typical structure problem.
  Mandatory intervention: the functioning of the application should be tailored to the user's knowledge and abilities. Partial redesign is probably required.
- **Arrow 3, user:** "The user isn't able to move". This problem can be particularly important when designing technologies for patients. Because of a disease condition, a user can be limited in his/her motor or perceptual capacities. For example, when designing an app for Parkinson patients, interaction devices should be designed taking into account the possible motor impairments. If interaction problems emerge related to the user's physical limitation, the *Mandatory intervention* is partial or total redesign.
- **Arrow 4, application:** usability and ergonomics problems make the interface difficult or impossible to use, or even unsecure.
  Mandatory intervention: partial or total redesign.

In these ways, the PIM can be used to orientate design decisions in the field of positive technologies and in the light of the PHE model.

5 Conclusion

The present chapter introduced theoretical resources and to achieve positive user experience for patient engagement in healthcare settings, thanks to the use of user-centered designed positive technologies. Indeed, new technologies constitute resource to helping patients in their PHE path through the four phases of their engagement experience (i.e. *blackout; arousal, adhesion, eudaimonic project*- see Chapter 5). According to Graffigna, Barello, and Riva (2013b), in order to be effective, positive technologies for health engagement have to be tailored the patients' needs and personal situation. This could be made thanks to UCD methods, taking into account the hierarchical structure of users' intentions and their applicability to the design of the technological application. The PIM constitutes a useful toolkit in this sense, for both design and evaluation. Furthermore, we provided examples of PIM-based analysis of possible problems affecting new technologies designed to foster patient engagement in its different phases of development (PHE model), highlighting the mandatory interventions to improve their ability in fostering patient engagement.

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Stefano Triberti, Serena Barello, Guendalina Graffigna, Giuseppe Riva, Antonio Candelieri, Francesco Archetti

Evaluating Patient Engagement and User Experience of a Positive Technology Intervention: The H-CIM Case

Abstract: The present chapter will provide an example of an intervention evaluation from the joint viewpoints of patient engagement and user experience. The authors evaluated H-CIM, a technological platform for the intelligent monitoring of physiological data of elderly patients performing physiotherapy exercises. Descriptive quantitative measures, behavioral observation, and qualitative interviews are integrated to evaluate H-CIM ability in (1) guaranteeing a positive experience to its users and (2) supporting them in advancing through a patient engagement development. This contribution would constitute a practical example of how these fundamental factors should be considered and evaluated when implementing positive technology for healthcare.

Keywords: Rehabilitation; Positive Technologies; User Experience; Patient Engagement; Intelligent Monitoring.

1 Technologies for Patient Engagement: a Roadmap of Methodologies to Develop Effective e-Health Interventions

In this chapter the authors will discuss how the PHE model could be useful to orientate the evaluation of a technology designed to augment the patient's clinical experience and health outcomes. The discipline of user experience and the patient engagement theoretical perspective may be insightful paradigms to be integrated. The authors shall discuss how these perspectives may be jointly useful to developing methodological guidelines in order to design and evaluate technologies for health which are in line with the patient's care needs. As described in Chapters 1 and 4:

- Patient engagement is a crucial objective to be pursued in the context of healthcare interventions, above all where patients are asked to face long term care interventions;
- New technologies, according to the positive technologies paradigm, constitute a fundamental resource to achieving patient engagement as they may improve the effect of clinical interventions by fostering patient adherence to treatments and

ease the transfer of medical prescriptions from the hospital settings to the home and the everyday life.

In order to demonstrate the value of integrating the patient engagement and user experience perspectives for developing effective technology-mediated care plans, we will provide an illustrative case based on a technology designed for rehabilitative interventions.

2 The Intervention Field: New Technologies for the Physical Rehabilitation of the Elderly

Considering the societal challenges described in Chapter 1, healthcare services aimed at providing care to chronic elderly populations are devoting themselves to the search for new ways to ensure effective and efficient treatment programs to augment health outcomes in the long term by actively engaging health consumers (Laver, Ratcliffe, George, Burgess, & Crotty, 2011;Barello, Graffigna, & Vegni, 2012; Gruman et al., 2010; Graffigna et al., 2014). In particular, the physiotherapy rehabilitation field constitutes a relevant setting to exemplify the relevance of developing health technologies aimed at sustaining patient engagement in the care process.

Rehabilitation, on the one hand, assists patients who have sustained damage to the motor system as a result of acute clinical events, for example strokes (Jette et al., 2005); also, it allows the patient to improve damaged motor skills (even in cases of severe disability) related to the physiological aging process (Persad, Cook, & Giordani, 2010). In both cases, the engagement of patients is essential to reducing the disability resulting from the disease and to support the recovery of an active role in the society. Many of the new methods concerning the use of positive technologies that are currently being investigated are already demonstrating encouraging results in supporting the process of treatment and rehabilitation (Graffigna, Barello, Wiederhold, Bosio, & Riva, 2013; Riva, Baños, Botella, Wiederhold, & Gaggioli, 2012; Rizzo & Kim, 2005). Regarding physical rehabilitation and physiotherapy, the following technologies are widely used:

- Video games (usually based on analogical devices such as the Nintendo Wii) or virtual reality (Laver et al., 2011; Maggiorini, Ripamonti, & Zanon, 2012; Smith & Schoene, 2012)
- Robotics to support movement (assistive exoskeletons) (Forlizzi, DiSalvo, & Gemperle, 2004; Kousidou, Tsagarakis, Caldwell, & Smith, 2006; Lund, 2009)
- Tele-rehabilitation, or multimedia communication between patients and therapists (Tousignant et al., 2011)

As suggested by the aforementioned studies, these profoundly heterogeneous technologies share some potential to support the rehabilitation process:

- When compared with “traditional” rehabilitation methods (not supported by technology) rehabilitation involving technological aspects is equally effective with respect to the goals of rehabilitation (Scherer, 2002), ensuring the automation of the exercises and the autonomy of the patient (Huete, Victores, Martinez, Gimenez, & Balaguer, 2012) and consequently reducing the care costs (Fuhrer, 2007).
- Moreover, patients evaluate them as interesting, fun, and engaging, and their positive attitude is often linked to the overall success of the care experience (Kintsch & DePaula, 2002)

New technologies are characterized by the ability to structure, augment, or replace the patient’s experience, promoting strengthening of capacity, but above all a positive and self-fulfilling experience (Riva et al., 2012).

However, the outcome of the rehabilitation process does not directly emerge from the use of a health technology. Indeed, it is not sufficient that the technology “works well” from a technical viewpoint. Moreover, the patient must be able to use it and feel actively engaged in the experience of the intervention.

3 Developing Health Technologies for Patient Engagement: a Methodological Road Map Based on the PHE Model

As health technologies are becoming more affordable and acceptable, this is an opportune time to widely adopt them to better engage patients in the self-management of chronic diseases. Thus, adopting the right technology should be a priority for healthcare systems devoted to sustaining long term engagement of health consumers. To this aim, there is the need to make use of methodologies aimed at designing and evaluating technologies in order to really promote patient engagement and demonstrate its effectiveness at the clinical level.

As just discussed in Chapter 2, the PHE model demonstrates how patient engagement gradually develops along the medical course. Moreover, each phase of the engagement process features specific care needs and priorities. In order to promote effective technology-mediated care plans, it is fundamental to map the patient engagement experience and to align the care interventions to it.

So often, the development of health technologies risks leaving the human element and context of use behind. However, we can only generate progress towards the crucial goal of patient engagement for health if we focus on peoples’ care experience. People are emotional and individuals are networked, whereas today’s healthcare systems are stuck on transaction-based models that don't meet people where they are, this way not being capable of anticipating their future care needs.

In the light of the PHE model, health technologies built by analyzing the user experience may sustain engagement by truly understanding the individuals' care expectations. The in-depth analysis of the user experience allows the understanding of patients' behaviour, motivations, and goals, and to use these to craft desirable experiences that enhance their interaction with health technologies and amplify their effect on clinical outcomes.

Patient engagement interventions need to begin with clearly understanding the specific human qualities of the patients we aim to serve. Technologies which are in line with these principles may be more effective than others not taking into account the patients' mindset concerning their health status.

To analyse the user experience in the case of healthcare, means to understand the patients' experience of interaction with technologies designed to sustain their clinical process. This experience features multifaceted dynamics and subjective reactions that may hinder or foster the effectiveness of the technologies themselves in promoting patient engagement.

Due to the variegated nuances of the patient care experience, multiple inquiry tools may be used to understand its different aspects. In depth interviews, questionnaires/self-reports, and observations of patients during or after the interaction with the technology, may constitute a useful toolbox to enable the development and evaluation of user-centered technologies really attuned with the engagement phase the patient is passing through. These methods, if combined, may produce a detailed picture of fundamental aspects of the patients' care process – i.e. illness experience, care expectations, wellness plans, and meanings associated with health technologies – which are all useful to designing technological instruments for patient engagement (see Figure 1) .

These tools may be useful to:

- Evaluate the user experience with the technology
- Evaluate the technology's abilities in promoting and sustaining patient engagement

4 Sustaining Patient Engagement in Rehabilitation Activities: a Case Study of the H-CIM Platform

Let us now see how these research methods for understanding user experience may be used to analyze the effectiveness of a technological platform designed to promote patient engagement in rehabilitation activities. This case could be informative for technology developers and clinicians when developing and applying technologies in the care process and to ensure that they are able to sustain patient engagement in the care process.

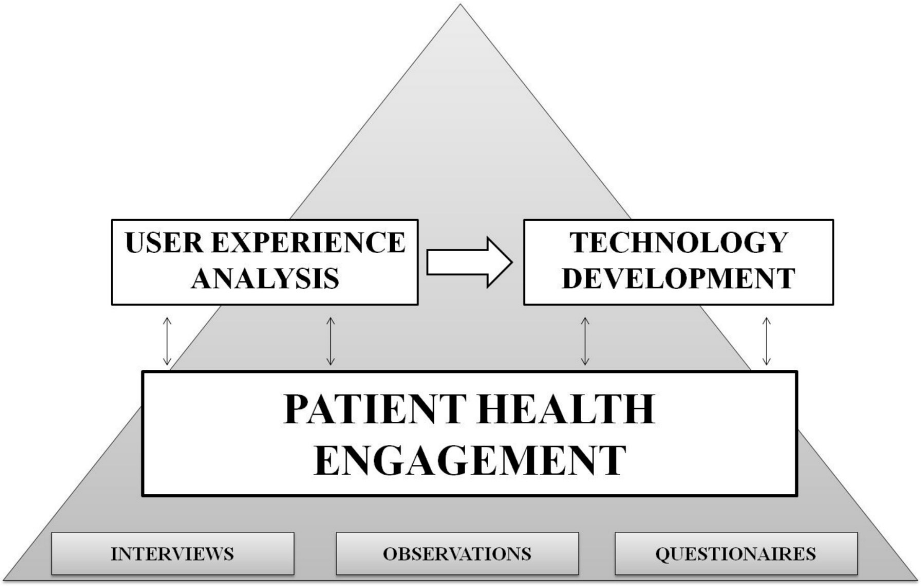


Figure 1: User experience analysis of e-Health technologies for patient engagement: a methodological framework.

H-CIM (Health-Care Intelligent Monitoring) is a platform that detects physiological signals regarding the state of health and activity of an elderly patient at home, acting in his/her daily living environment. The “home processor”, this way labelled because it is a personal computer placed in the house of the patient, records by three sources of data:

- Environment (network of ambient sensors). These are related to environmental parameters and to the presence of subjects within the frame of reference;
- Movement (wearable). These data are acquired through a set of devices worn by the monitored subject (accelerations of the dominant upper limb, trunk, and lower limb with respect to the three axes);
- Bio-signals (wearable). These data are acquired through a device worn by the patient and refer to the parameters of medical-clinical interest (e.g., heart rate) to be monitored during the various activities conducted by the patient.

This technology has been used to monitor the patients when they were performing rehabilitation exercises: the elderly patient should be able to perform the exercises autonomously, enabling the recording of the signals, and thus giving immediate information about his/her current process to the physician. This allows the physician to monitor the status of the patient in his/her daily life (1) and in the context of exercises that are a part of his/her rehabilitation (2).

The authors observed the test sessions of the technology which involved three elderly patients. The patients performed rehabilitation exercises shown by the phys-

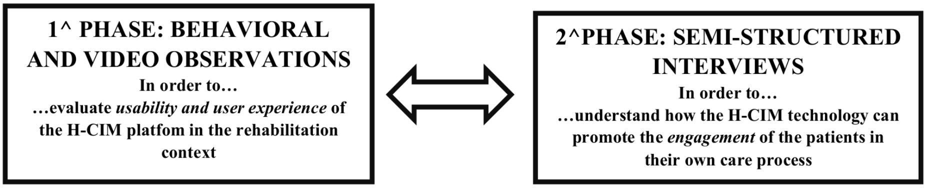


Figure 2: Main of the user experience analysis.

iotherapist in a video, while wearable and environmental sensors registered their physiological parameters.

4.1 User Experience Evaluation

This case study (three prototypical subjects, mean age 72 years, stable clinical condition) has provided two research modules covering respectively the first and second aims (see Figure 2). In the first phase, behavioural observations were designed to track the “in-vivo” interaction modalities between the patient and the technology when they were asked to complete physiotherapy exercises. Semi-structured interviews were then administered to the subjects, with the aim of understanding the experience of interacting with technology in order to comprehend how it can facilitate their engagement in the care process. We assessed the patients’ engagement position by asking four questions (see Chapter 2 for more details about the instrument), which evaluate the patients’ psychological attitude toward their health condition management. This set of questions – and the corresponding responses that the model interprets– allowed us to also assess the patients’ disposition toward interacting with technologies for self-care. We assessed the state of health literacy of the patient (his/her ability to think about the disease and its management by using the e-health technology); the state of emotional elaboration about the diagnosis and the health condition (his/her way of “feeling” when reflecting on his/her health status and on the use of the technology); and the consequent behavioural competences related to the self management of his/her own care (his/her “acting” attitude towards the disease and the use of the technological platform).

This multi-technique method (Denzin & Lincoln, 2000) allowed for the detection of multifaceted data to obtain a composite view of the implemented technology and of its potential benefits for the rehabilitation process.

The patients also filled in a number of self-report measures in order to provide descriptive data about their own experience with the technology. More specifically, mental workload (Hart & Staveland, 1988), system usability (Brooke, 1996), and possible negative emotional responses (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983) were assessed. Furthermore, the Patient Activation Measure (Hibbard, Stockard, Mahoney, & Tusler, 2004) was employed in order to assess important aspects of patient engagement. Figure 3 illustrates the main outcomes of the user experience analysis and shows which aspects need to be considered in order to evaluate the effectiveness of the platform for medical treatment.

4.2 What Are the Implications for Patient Engagement?

Generally speaking, observations, interviews, and self-report showed that the H-CIM platform allows for the efficient tele-monitoring of patients' status and the physiological effects of exercise rehabilitation. Furthermore, HCIM has a positive impact on the patient care experience, thus promoting the enhancement of their health engagement. We will now examine in more detail some clinical cases that exemplify the patient interaction with technology according to the PHE model.

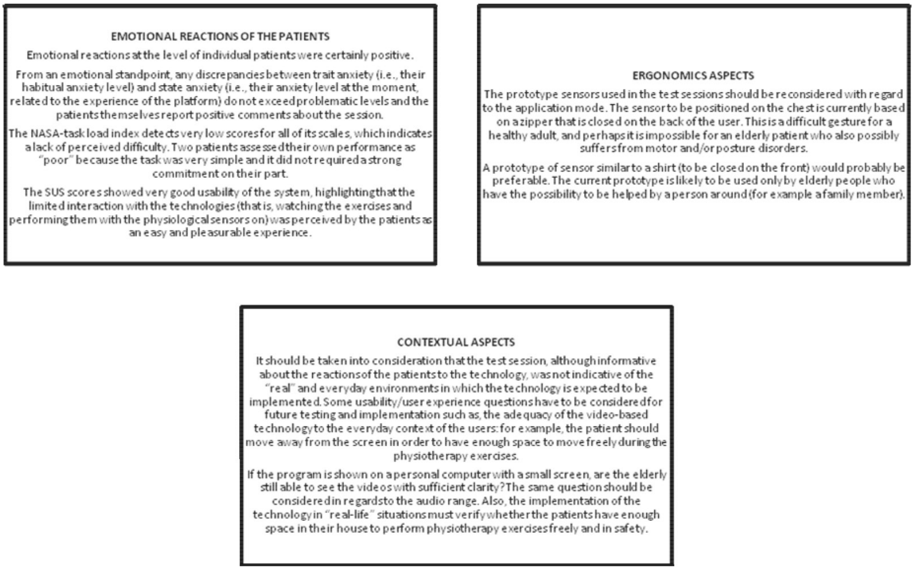
Across the clinical cases a positive attitude towards the technology was observed. However, the patient engagement position (according to the PHE model) orientates the patient's ways of interaction with the platform and the patient's disposition to utilize it in the long term.

Patient case 1: Maria, 68 years old – phase of arousal
Maria has been prescribed physical rehabilitation after a diagnosis of osteoporosis. She is worried about the consequences of this diagnosis for her health (feel) and she doesn't feel confident with the information the physician gave her about disease management (think). She generally feels a lack of skills to autonomously manage the medical regimen (act). In this framework, the patient mindset about her availability to use the technological platform is low. Unless the patient shows a positive attitude towards the technology, she has not fully its purpose, nor the way in which she could use it in her daily life.

> "… I was only there and I just did the exercises but I have no idea, I am totally incompetent…… they are investigating many things no? Reactions, the reaction rate, but in the end I cannot understand because they did not tell me …"

Patient case 2: Giovanna, 72 years old – phase of adhesion
Giovanna has been involved in a rehabilitation program after a meniscus injury. She feels confident concerning the rationale behind the rehabilitative prescriptions (think) and aware is of the disease implications for her life (feel). She describes herself as highly effective when managing her symptoms and the disease (act) and is satisfied with the relationship with her doctors. However, the patient shows some difficulties when she has to maintain the life style changes in the long term.

This makes the continuative use of the platform difficult if administered at home without clinical supervision. She needs to be monitored and still supported in effectively using it when alone.



EMOTIONAL REACTIONS OF THE PATIENTS

Emotional reactions at the level of individual patients were certainly positive.

From an emotional standpoint, any discrepancies between trait anxiety (i.e., their habitual anxiety level) and state anxiety (i.e., their anxiety level at the moment, related to the experience of the platform) do not exceed problematic levels and the patients themselves report positive comments about the session.

The NASA-task load index detects very low scores for all of its scales, which indicates a lack of perceived difficulty. Two patients assessed their own performance as "poor" because the task was very simple and it did not required a strong commitment on their part.

The SUS scores showed very good usability of the system, highlighting that the limited interaction with the technologies (that is, watching the exercises and performing them with the physiological sensors on) was perceived by the patients as an easy and pleasurable experience.

ERGONOMICS ASPECTS

The prototype sensors used in the test sessions should be reconsidered with regard to the application mode. The sensor to be positioned on the chest is currently based on a zipper that is closed on the back of the user. This is a difficult gesture for a healthy adult, and perhaps it is impossible for an elderly patient who also possibly suffers from motor and/or posture disorders.

A prototype of sensor similar to a shirt (to be closed on the front) would probably be preferable. The current prototype is likely to be used only by elderly people who have the possibility to be helped by a person around (for example a family member).

CONTEXTUAL ASPECTS

It should be taken into consideration that the test session, although informative about the reactions of the patients to the technology, was not indicative of the "real" and everyday environments in which the technology is expected to be implemented. Some usability/user experience questions have to be considered for future testing and implementation such as, the adequacy of the video-based technology to the everyday context of the users: for example, the patient should move away from the screen in order to have enough space to move freely during the physiotherapy exercises.

If the program is shown on a personal computer with a small screen, are the elderly still able to see the videos with sufficient clarity? The same question should be considered in regards to the audio range. Also, the implementation of the technology in "real-life" situations must verify whether the patients have enough space in their house to perform physiotherapy exercises freely and in safety.

Figure 3: The multi-technique research design.

> "I can't imagine using the platform all days. If I am alone I do not feel motivated to complete my exercises..."

Patient case 3: Anna, 66 years old – phase of eudaimonic project

Anna has been attending the rehabilitation program for one year after being diagnosed with lumbosciatica some years earlier. The patient is confident (feel) and resilient in her health management (think), even when troubles with therapeutic prescriptions emerge. She is also able to ask her physician for help on demand (act). She has integrated the use of the technological platform in her daily life and she perceives it as a means to having control over her body signals.

> "The experience with technology is super positive. I feel protected, perhaps because there was a doctor and the physical therapist ... it's as if they are always there. In think that technologies can be useful, they are definitely an incentive to be more active in your health management"

The concept of technology is now available and present in the minds of the patients, who understand the value and the potential associated with the use of tools such as computers, smartphones, and tablets, but also other tools for monitoring the clinical condition in everyday life (e.g., holter, remote alarm). The perception of technology is positive. Indeed, the technology is perceived as a means by which patients feel monitored and followed up by the physician, who can control the parameters during the execution of the rehabilitation exercises.

Patients also perceive the technology as a means of amplifying the attention of the doctor towards them, promoting care continuity. This also makes them more secure and confident while performing the rehabilitation exercises, because they feel that they are in a safe environment. Finally, patients recognize the value of therapeutic prescriptions being transferred from the hospital setting to the home.

In general, the patients' testimonies reveal the value of being personally involved in the management of their own health, gradually acquiring information and tools provided by professionals and adapting them to their everyday lives.

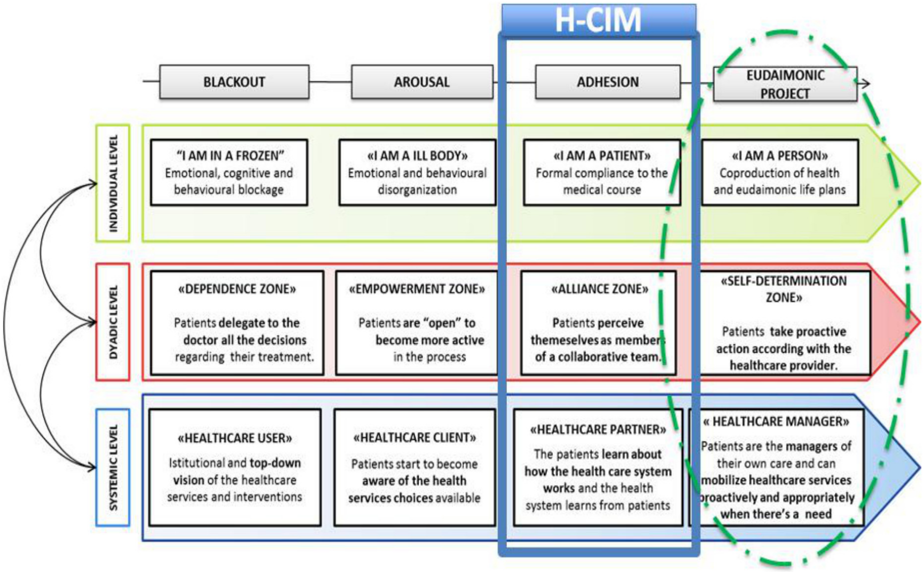
Health appears to be a theme emerging from the reports of patients who, also in connection with the phase of life in which they find themselves, feel the need to be able to face their own life issues by maintaining a healthy and active lifestyle. Patients report a positive attitude with respect to the use of technology to support the rehabilitation process, provided it does not limit them in their daily lives.

For these reasons, the the technology designed to support the rehabilitation must take account of these needs expressed, as it is considered useful only if it does not imply renunciation and constraints for the user. What mainly hinders the involvement of patients in the use of technology seems to be related to the absence of clear information about the rationale behind the use of the platform and about its value compared to traditional rehabilitation methods. In addition, the technology is perceived by patients as possibly making them "passive", not-autonomous.

This case provides clear indications for enhancing the experience and effectiveness of the H-CIM technology in sustaining patient engagement.

The experience with H-CIM appears to be related to positive sensations and emotions of the patients. The patients are clearly compliant with the interaction possibilities and with the affordances the technology offers to perform their rehabilitation exercises in an innovative way. In general, this positive attitude is an encouraging cue about the H-CIM technology constituting an effective tool in order to engage the patients in a specific aspect of their own care process.

On this basis, the H-CIM intervention can be analyzed in the light of the Patient Engagement Model (see Chapter 2 in this book). Using H-CIM technology, the patients are accompanied through the phase of adhesion since they positively and actively adhere to the rehabilitation prescription and also become more curious about their own therapy as it is administered via a new communication technology. At the same time, they raise concerns about how to effectively manage the technology use in the context of their everyday life, which consists of daily needs, tasks, and opportunities. Moreover, despite the positive feelings they have, they often ask for further explanations about how the technology works and why exactly is it useful for their health. In this sense, H-CIM can position itself at the third phase of the patient engagement process (see Figure 4), which is a very desirable position for a technological product at its first stages of testing. Moreover, in order to become an excellent tool for engaging patients in their own care process, H-CIM has a goal of reaching the eudaimonic project phase (see Figure 4), that is, it has to be effectively included in the patients' daily life and their needs.



Figue 4: Implications of the PHE model for the H-CIM technology.

5 Conclusion

In the present chapter, we described a prototypical evaluation of a new technology-based intervention, from the joint viewpoint of user experience and patient engagement. According to this methodological approach, both usability measures and qualitative instruments can be employed to understand not only if the technology works as it should from a technical viewpoint, but also (1) if it is effectively understood and used by the patients and (2) appears consistent with their engagement level. We showed that the PHE model and the PHE questions may be helpful for clinicians when having to assess the effectiveness of a technology-mediated rehabilitation program and its attunement with patient engagement expectations.

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Serena Barello, Guendalina Graffigna

Engagement-sensitive Decision Making: Training Doctors to Sustain Patient Engagement in Medical Consultations

Abstract: 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 is increasingly advocated as an ideal model for medical consultations, as it has the potential to deliver better health outcomes and a more efficient use of resources through retaining patients’ autonomy and self-determination. However, beyond the evident benefits of patient engagement in healthcare, it should be also considered that doctors – 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 engaging patients in daily clinical practice asks doctors to be able to recognize that patients’ different clinical statuses 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 discussing the opportunities offered by an “engagement-sensitive decision making” in order to orientate doctors’ relational skills and decisional style according to patients’ needs at each phase of the health engagement process. Insights for medical education and the potential value of new technologies aimed at improving doctors’ relational strategies to improve patient engagement will be also provided.

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

1 Introduction

Patients and consumer advocacy groups are 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 the US, is recognized to sustain the creation of more informed and engaged patients as decision makers in the care process (Cassel & Guest, 2012).

Doctors and managers are thus increasingly more committed to actively engaging patients in the whole care process – thus favoring an effective and productive exchange between the demand and supply of health services. In particular, if we consider the setting of the clinical consultation, patient engagement finds its best realization in a two-way active partnership between the patient and his/her doctor in making decisions about treatments plans.

In this chapter, authors will discuss the usefulness of the People Health Engagement (PHE) model (see Chapter 2) to orientate both clinicians and managers when they relate with patients. We advocate the need for considering the engagement phases 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 also has the aim to show to the reader the relevance of the PHE model for planning educational interventions for doctors to help them in practicing communication models which are truly aligned with the patient's engagement needs and expectations.

2 PHE Model as a Road Map for Guiding Doctors Engaging Patients in Decision Making

Although great efforts have been made to ensure that patients are informed and actively engaged in decisions about their treatment options during medical consultations (Kitson et al., 2013), patient passivity in this process has been neglected so far. The focus has been often on supporting the process if and when a patient is just engaged, rather than working out how to effectively engage patients and to accompany them in understanding the features and the benefits of shared decision making with their doctors (Oates et al., 2000; Tinetti & Fried, 2004; Tinetti et al., 2012). It is as if the value and opportunities of being actively involved in decisions are taken for granted without the possibility of a voluntary and beneficial patient passivity in decisional situations. An active role in decision making could be unexpected for many patients and may even be uncomfortable due to the high cognitive and emotional burden requested. We cannot expect patients to change their desired decisional behaviors just because they are given an opportunity to actively engage in their health management. It is curious that the majority of educational interventions were substantially invested in shifting clinician's attitudes, despite their not having invested similar efforts in preparing patients for this new type of patient-doctor relation.

Beyond the demonstrated benefits of patient engagement in healthcare (Hibbard et al., 2013), we should also consider that doctors – 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, engaging patients in daily clinical practice consistently asks doctors to be able to recognize that patients' different clinical statuses and engagement dispositions might require different ways of interaction with them. Clearly, different situations require different communication approaches and doctors should be trained to adapt their relational style according to the specificities of such situations (Barello & Graffigna, 2014).

Let us consider that patients' preferences for being actively involved in medical consultations may be affected by demographic variables (Kaplan et al., 2005; Belcher et al., 2006), their socioeconomic status (Fraenkel et al., 2007), their health literacy level (Mistry et al., 2010), their illness and care experience (Barello et al., 2014), their diagnosis and global health status (Barello et al., 2014), the type of decision they need to take (Barello et al., 2014), the amount of knowledge they have acquired about their condition, their attitude towards engagement, and the ways of interactions and relational styles they have experienced with their doctors (Fraenkel et al., 2007; Chewning et al., 2012). Moreover, it is matter of fact that patient's attitudes towards engagement in their health decision making are likely to change over time as they become experienced in health management and may change at different stages of their illness journey (van den Brink-Muinen et al., 2006; Mistry et al., 2010)

So, while patients' preferences for being engaged in decision making are variable, doctors – at the same time – should be prepared and skilled enough to adapt their communicational behaviors and decisional style according to the patient's psychosocial, cultural, and medical condition. However, in contrast with this requirement, a growing body of research has showed that doctors often do not take into account patients' engagement preferences; rather, they often promote or recommend specific treatments rather than consider the patients' expectations of being involved in their care decision making process (Floer et al., 2004; Fraenkel & McGraw, 2007; Légaré & Thompson-Leduc, 2014). Thus, research in the medical education field highlighted the importance of designing medical training aimed at shaping doctors communication and relational skills according to the principles of patient-centered care (Bensing, 2000; Makoul, 2001; Stewart, 2003).

Active patient engagement in decision making about care, in which both physicians and patients exchange information, communicate expectations and preferences, share values, and make decisions together – more known as shared decision making – has been widely recommended by clinical guidelines and embraced in academic literature (Barry & Edgman-Levitan, 2012; Berello & Graffigna, 2014). Also, the Institute of Medicine (IOM) has recommended including it in medical school curricula as a core strategy to improve care quality and delivery (Institute of Medicine, 2004). However, if we observe daily clinical consultation we can easily notice how the picture is more complex and varied than the one described by a handbook of communication in medicine. It is a matter of fact that there are a wide variety of roles and communication preferences for doctors and patients when involved in clinical decision making tasks. In the light of the PHE model, those preferences are strictly connected to the patient engagement phase the individuals are in. Whilst research has consistently shown that doctors underestimate the patients desired level of involvement in the care process (Arora, & McHorney, 2000), it is less clear how much patients actually want to be involved in making decisions about their treatment and what really affects their preference for being engaged.

As previously shown in this book (see Chapter 3), the PHE model allows us to map the journey of patient engagement in care and to highlight the specific mindsets featuring in each phase. Due to the complex interactions existing among the patient's cognitive, emotional, and behavioral enactment towards their health – which changes along the process – patients' are characterized by specific needs depending on the phase they are in. As a consequence, a patient-doctor relationship which would be effective in creating a sustainable partnership between the actors should take into account such specificities of the engagement process. Let us consider that the doctors become a privileged interlocutor for the patient from the moment of the diagnosis and along the whole care process. If doctor and patient fail in building a solid and trusted relationship, the risk is that the patient could enact dysfunctional behavioral responses, often ending with care dropout.

3 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 professionals 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 consumers of health services. Readily available access to health information and treatment options via new technologies – such as the Internet – has increased over time (Baker et al., 2003). Moreover, social movements – such as female rights movements – 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 as helping meet the 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 have been shown to be greater when 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 decisional tasks (Couët et al., 2014). Finally, patient engagement also reduces costs to the healthcare system and clinicians are less involved in legal arguments (Duncan et al., 2012).

Given these extraordinary premises about the positive implications of patient engagement in decisions on their health, readers 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 is probably that beyond the uncountable and demonstrated value of this decisional style, this model poses important challenges to clinicians. Let us examine these challenges in more detail.

In order 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 PHE model and the specificities of each phase for the patients' mindset towards their management, engaging patients in decision making could be effective only if both patients and doctors are committed to the process and when the patients' emotional and cognitive status corresponds 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, and emotional availability to participate as skilled and aware partners in shared decision making (Gaston & Mitchell 2005). Considering all these aspects together is a complex task for doctors in providing the best communication and relational style for each patient, when also having to take a critical decision regarding 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 apply a participatory approach in decision making.

In order to be effective in engaging patients in decision making, clinicians should consider the overlap between the different relational and communicational approaches and flexibly combine them in order to improve their patient-centered practice along the unique patients' illness journey.

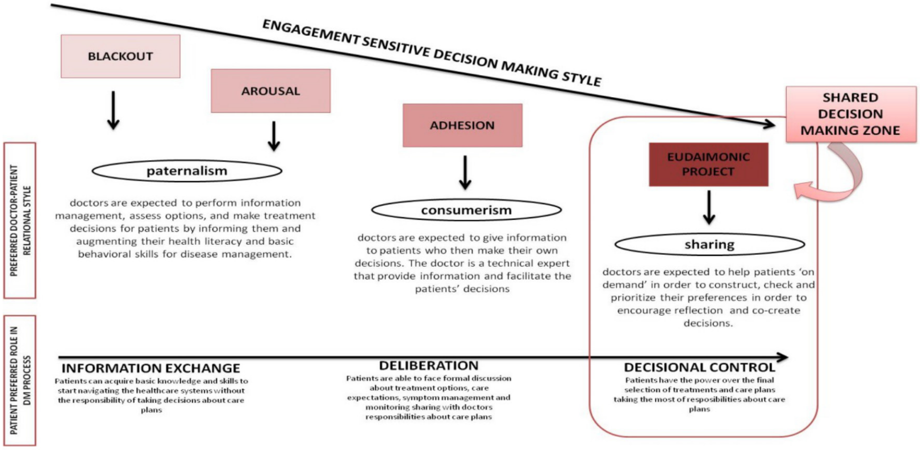
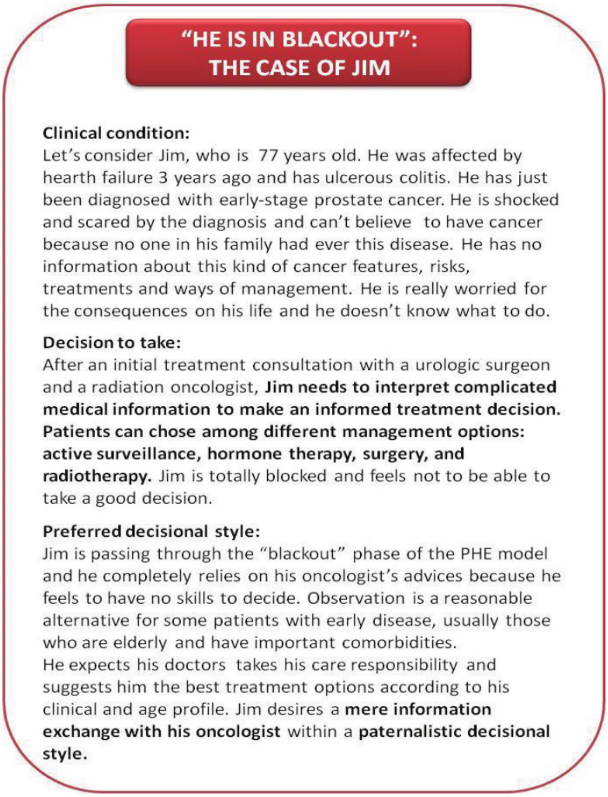


Figure 1: Engagement-sensitive decision making framework. Guidelines for doctors.

4 Towards an “Engagement-sensitive” Decision Making Style: the PHE Model as an Orienting Framework for Doctors Communicational Behaviours

Patient engagement in medical decision making could be a challenging act as interacting with the healthcare system can be understandably unsettling for patients, thus, uncomfortable feelings may inhibit patients from accomplishing this task (Judson et al., 2013). We would like to extend this reflection by 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). A lack of synergy between these dimensions may inhibit the patients’ ability to engage in the whole process of care, and compromise the decision making process. During 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 available to be engaged in shared decision making along their illness journey and might require different decisional styles according to their emotional, cognitive, and behavioral mindset (see Figure 1).

As discussed in Chapter 3, 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 doctor that strongly dependent on the phase of the process through which the patients is passing. To illustrate medical consultations in which different decision making styles are appropriate, we will consider three clinical cases that exemplify the situations of patients’ in different states of the PHE model and their preferred role in decision making. Let us consider that in the early post-diag-



“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 PHE 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.**

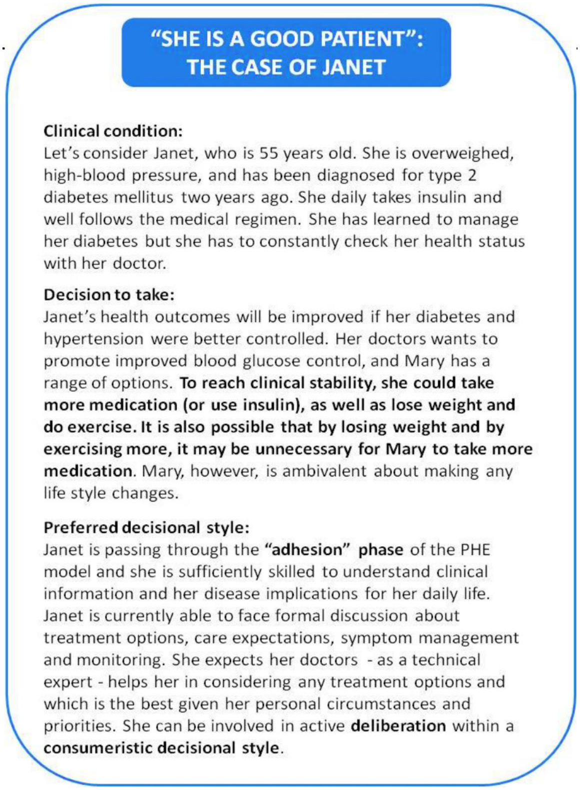
Figure 2: Decision making style with a patient in the blackout phase.

nosis phases– namely the phases of blackout and arousal of the PHE model– many patients may be not ready to make decisions due to negative emotions and/or fatigued cognitive functioning (see Figure 2).

In these phases paternalism should be the preferred 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 patients’ 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.

In a more advanced phase of the process – the “adhesion” phase – patients are more available to be involved in decisions regarding their treatments, but still need to be encouraged in taking part and require being empowered in regard to their ability to co-produce their health (see Figure 3).



“SHE IS A GOOD PATIENT”:
THE CASE OF JANET

Clinical condition:
Let’s consider Janet, who is 55 years old. She is overweighed, high-blood pressure, and has been diagnosed for type 2 diabetes mellitus two years ago. She daily takes insulin and well follows the medical regimen. She has learned to manage her diabetes but she has to constantly check her health status with her doctor.

Decision to take:
Janet’s health outcomes will be improved if her diabetes and hypertension were better controlled. Her doctors wants to promote improved blood glucose control, and Mary has a range of options. **To reach clinical stability, she could take more medication (or use insulin), as well as lose weight and do exercise. It is also possible that by losing weight and by exercising more, it may be unnecessary for Mary to take more medication**. Mary, however, is ambivalent about making any life style changes.

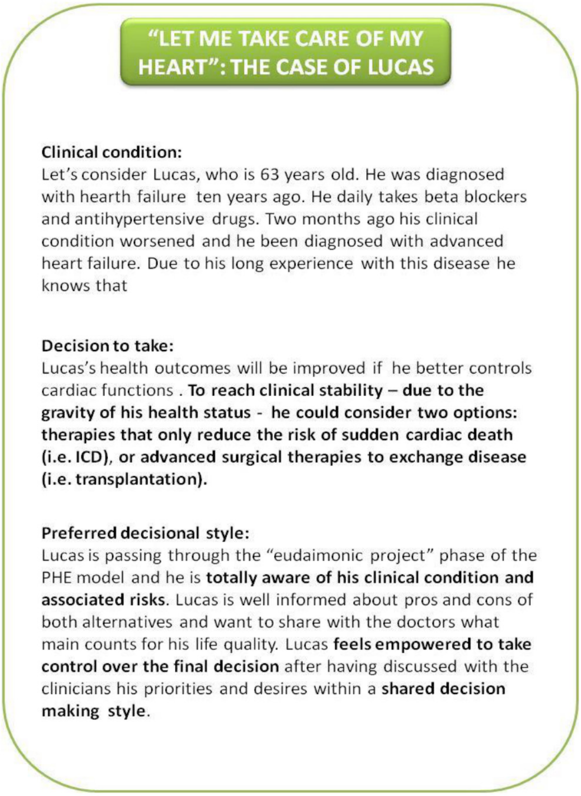
Preferred decisional style:
Janet is passing through the **“adhesion” phase** of the PHE model and she is sufficiently skilled to understand clinical information and her disease implications for her daily life. Janet is currently able to face formal discussion about treatment options, care expectations, symptom management and monitoring. She expects her doctors - as a technical expert - helps her in considering any treatment options and which is the best given her personal circumstances and priorities. She can be involved in active **deliberation** within a **consumeristic decisional style**.

Figure 3: Decision making style with a patient in the adhesion phase.

In this phase, a consumerist style of decision making seems to be the best approach to 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, who 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.

A completely shared decision making process arrives when the patients are in the phase of “eudaimonic project”, and have finally acquired the knowledge, skills, and emotional balance necessary to effectively engage in their healthcare management, thus devising renewed wellness plans for their future life (see Figure 4).

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 the co-creation of decisions. In this phase patients are able to take decisional control due to the fact that they feel they have power over the final selection of treatments, and the ability to take most of the responsibility for care plans.



“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).**

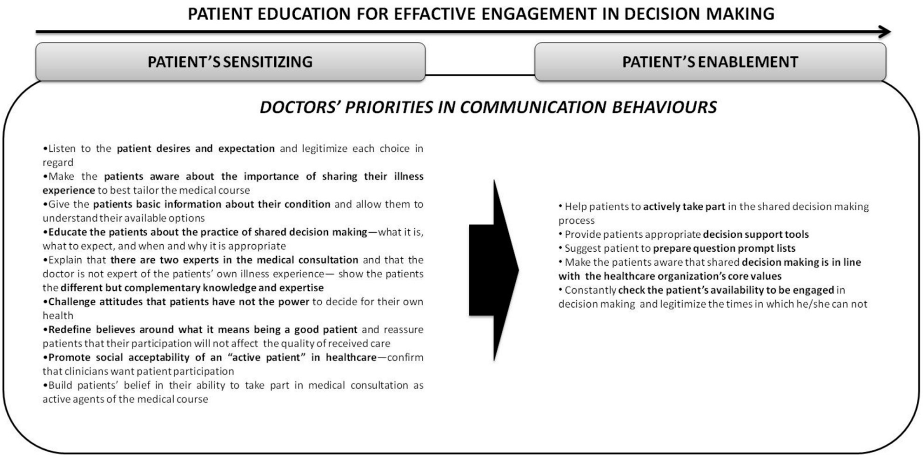
Preferred decisional style:
Lucas is passing through the “eudaimonic project” phase of the PHE model and he is **totally aware of his clinical condition and associated risks.** Lucas is well informed about pros and cons of both alternatives and want to share with the doctors what main counts for his 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**.

Figure 4: Decision making style with a patient in the eudaimonic project phase.

As demonstrated by the the clinical cases provided, the PHE model might help doctors in orienting their communicational behaviour according to the specific relational dynamics required in the different phase of the care process. This process-like modelling of patient engagement potentially leads to the reshaping of medical encounters by posing the basis for a true and sustainable partnership between patients and doctors along the natural course 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 patients’ capacity to gain a positive approach to health 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 are 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. A real "patient-centered communication" includes the 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 their 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 at the right moment. Thus, we suggest that clinical consultation 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 on those behavioral skills necessary to accommodate different models of decisional styles. Moreover, we suggest that patients' should be educated to participate in decision making and cannot 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.

Based on this discussion, we suggest planning education for both patients and clinicians in order to promote a shared enactment of participative decision-making along the care process. According to this framework and in line with what discussed in Chapter 4, new technologies (i.e. electronic medical records, web portals, telemonitoring…) may be particularly useful in improving patients understanding of their medical condition. Consumers have access to a variety of sources for such information, including physicians, friends and family, printed materials such as pamphlets and journal articles, community centers, and the Internet. But the innovation in a participatory decision-making is the use of interactive technology to inform patients and better attune treatments to their needs. This method of informing patients may be applied to a variety of medical conditions, as well as general preventive medicine. Since this approach was first developed in the early 1980s, the use of technology has been increasingly seen as an effective means of helping patients make informed choices about their care. Interactive presentations can inform patients of treatment options, promote health, and teach self-management skills. On this basis, we encourage healthcare innovation through the adoption of eHealth tools (i.e. online services, mobile apps, or other health resources available on computers or smart phones) as models of innovative ways that providers and patients could use health IT to select the most appropriate decisional style and treatment options for the individual patient. Health IT can communicate the individual's choice to other providers (such as specialists, pharmacists, and facilities where the individual receives care) so that additional care sources recognize their preferences. This can avoid unnecessary or unwanted tests and treatments.



- 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

Figure 5: Doctors’ communication priorities to engage patients in shared decision making.

5 Engaging Patients in Decision Making “from Theory into Practice”: Agenda Setting for Medical Education

According to the insights provided by the PHE model, as far as it concerns the patient-doctor relationship, we advocate the importance of preparing patients for a shared decision making clinical encounter, partly by changing attitudes towards engagement, and partly by recognizing the appropriateness of this decisional style based on the patients’ mindset. We also suggest that interventions should be delivered in two stages: firstly sensitizing patients, followed by to the enabling of shared decision making (see Figure 5). Patients should attend a sensitizing intervention that clearly explains to them the meaning of taking a shared decision and the effective ways to do this. Once the patient has made an informed decision to be involved and has a clear understanding of the benefits related to a shared decisional style, the focus moves on to the patients’ enablement of shared decision making. This might be done through helping patients take 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 as 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 their 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 promoting what we called an “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 PHE model – the better they will be at making it a natural part of their routine care practices.

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 the wider implementation of patient engagement could address how consultations are scheduled in chronic patient care, and raise consumers’ expectations or desires for involvement (or un-involvement) by assessing their level of engagement according to the PHE model.

6 Conclusions: Direction for the Future

Consistently engaging patients in their health care across daily clinical practice requires 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. The biological reality of chronic diseases 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 require that communication be viewed as an evolving series of dynamic conversations that take into account the overall health 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 PHE model, a patient-doctor relation merely oriented toward shared decision making alone could be inappropriate. Leading patients in being actively involved in decisions regarding their health is monumentally difficult task for doctors. The PHE model, as demonstrated in this chapter, might contribute to making this task easier both for clinicians and policy makers. The PHE model may be a sort of “relational compass” able to detect the 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 interaction according to the patient engagement phases, alone and in combination, would assist clinicians in achieving a true patient-doctor partnership in clinical practice.

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 the appropriate time and place to do shared decision making and the tools to do it, is amply suggested. Notwithstanding, unless we address the patient health 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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Caregiver Engagement in the Neonatal Intensive Care Unit: Parental Needs, Engagement Milestones, and Action Priorities for Neonatal Healthcare of Preterm Infants

Abstract: During the last few decades, healthcare interventions in Neonatal Intensive Care Units (NICUs) have improved, leading to higher survival rates even for high-risk preterm infants. Such advances have led to a reframing of NICU goals, from granting survival to severely ill preterm newborns, to sustaining quality of life of both infants and their parents. This has raised professionals' acknowledgement of the importance of actively engaging parents in the care of their infant from the beginning as a critical feature of NICU healthcare (i.e. family-centred and developmental care). Nonetheless, these interventions have received only partial validation since NICUs from different countries might dramatically vary in the adopted policies of caregiver engagement and patents with a child in a NICU experience a dramatic psychological burden with regard to being engaged. In this chapter, the experience of preterm infants' parents in the NICU is examined in the light of the People Health Engagement (PHE) model. The application of the PHE model to caregiver engagement in NICU has the advantage of taking into account the interwoven dynamic of both parental needs and NICU caregiver engagement interventions as they change from birth, across the NICU stay and after the discharge. Insights for neonatal health care practice will be provided.

Keywords: Caregiver engagement; Neonatal health care; NICU; Parents; Preterm birth

1 Introduction

Preterm birth is one of the more frequent direct and indirect causes of neonatal death (Lawn, Cousens, & Zupan, 2005; Liu, Johnson, Cousens, Perin, Scott, Lawn et al., 2012) and a critical risk factor for long-term detrimental consequences later in life, such as neuro-developmental delays, learning impairments, visual disorders, and physical diseases (Blencowe, Cousens, Chou, Oestergaard, Say, Moller et al., 2013). Despite survival rates are increasing, there is a concomitant increase of the risk for adverse developmental outcomes and disabilities (Stoll, Hansen, Bell, Shankaran, Laptook, Walsh et al., 2010; Vincer, Allen, Joseph, Stinson, Scott, & Wood, 2006). Nowadays, 1 of 8 infants in the United States is born preterm. Even in absence of a severe illness condition, preterm infants are at risk and require long-term hospitalization in the Neonatal Intensive Care Unit (NICU) (Lester, Miller, Hawes, Salisbury, Bigsby, Sullivan et al., 2011).

The NICU is essential to grant prematurely born infants' survival, nonetheless it is a highly medical and technological environment that is clearly not a surrogate of the maternal womb and it has been found to be stressful for both infants and their parents. On the one hand, physical stimulations (i.e., chronic exposure to high-intensity lights and sounds; Brown, 2009; Ozawa, Sasaki, & Kanda, 2010), medical interventions (e.g., skin-breaking procedures, Grunau, 2013), and maternal separation (Latva, Lehtonen, Salmelin, & Tamminen, 2004) constitute a well-known set of stressors that can alter infant development during the first months and years of life (Ranger, Chau, Garg, Woodward, Beg, Bjornson et al., 2013; Smith, Gutovich, Smyser, Pineda, Newnham, Tjoeng et al., 2011). On the other hand, NICU parents usually experience high stress levels with risk of significant emotional burden during the post-discharge period (Alkozei, McMahon, & Lahav, 2014; Lefkowitz, Baxt, & Evans, 2010). Core dimensions of parental distress are the NICU environment (i.e., physical stimulations), the look of medically fragile infants (i.e., tubes and insertions), and a delayed onset of parenthood (i.e., early separation from their own infant) (Franck, Cox, Allen, & Winter, 2005; Miles, Funk & Caspers, 1992; Montirosso, Provenzi, Calciolari, Borgatti, & NEO-ACQUA Study Group, 2012). Overall, the delayed parenthood is valued as the greater source of parental NICU stress, and a mere informational provision from medical and nursing staff might not be sufficient to take care of parental wellbeing (Montirosso et al., 2012). However, it should be noted, that NICU-related parental stress might lead to further affective disorders during the first post-natal period (Miles, Holditch-Davis, Schwartz, & Scher, 2007), with heightened risk for post-traumatic stress disorders (Misund, Nerdrum & Diseth, 2014), anxiety (Correia & Linhares, 2007), and depression (Gulamani, Premji, Kanji & Azam, 2013).

In the present chapter the authors apply the People Health Engagement (PHE) model (see Chapter 3 for further details) to the caregiver engagement of preterm infants' parents within the NICU. As mentioned above, preterm infants are especially non-autonomous and necessitate highly specialized interventions from both clinicians and their parents. From this point of view, preterm infants' parents are among the main interlocutors of neonatal healthcare systems and need special attention to be actively engaged across the NICU journey. Accordingly, caregiver engagement milestones and priority actions tailored on parental experience and needs in NICU are provided and discussed in the following paragraphs, underlining the benefits of the application of the PHE model in the context of neonatal healthcare. Snap-shots from prototypical experiences of parents of preterm infants in NICU will be offered as illustrative windows into different time points and engagement phases. Parental needs will be discussed according to three core dimensions derived from previous engagement literature (Graffigna et al., 2013; Graffigna et al., 2014): informational engagement needs (think), emotional engagement needs (feel), and parenting engagement needs (act).

2 The Emerging Need to Engage Parents in the NICU

As a great number of preterm infants are now surviving and requiring long-lasting NICU stays and specialized interventions, a shift has occurred in neonatal healthcare goals. NICU staff acknowledge the importance of engaging parents in order to promote interventions aimed at sustaining quality of life of both infants and their families (Lester et al., 2011). Consistently, during the last decades two main areas of interventions directly aimed at engaging parents in the NICU have been proposed: family-centred care and developmental care (Westrup, 2007).

A family-centred philosophy of care aims at recognizing the central and active role of families in managing the healthcare of their infants with special care needs (Griffin, 2006). In the NICU, family-centred care implies a relational framework of proactive partnership between NICU staff, primarily nurses, and parents in managing and taking decisions about the planning and delivery of care (Byers, 2003). For example, the adoption of single-room NICU environments has been associated with reduced infection risk for infants and a reduced stressful impact of NICU sensorial environment (i.e., lights, sounds) and an enhanced sense of privacy for parents (Carlson, Walsh, Wergin, Schwarzkopf, & Ecklund, 2006).

Developmental care is a wide category of different interventions aimed at reducing the inherently stressful nature of the NICU (Stevens, Petryshen, Hawking, Smith, & Taylor, 1996). Developmental care includes infant pain management and active caregiver engagement in NICU care (i.e., skin-to-skin holding, kangaroo care, breastfeeding). Parents who receive satisfactory information about infants pain and how to sooth them, about the nursing procedures to manage pain, and are supported in the discovery of infants' distress and pain cues, have been shown to be more prepared and self-confident in taking an active role in infant caregiving during the post-discharge period (Franck, Oulton, Nderitu, Lim, Fang, & Kaiser, 2011).

There is wide agreement among professionals about the relevance of caregiver engagement in NICU as a primary goal for infant care (Provenzi & Barello, 2015). Notwithstanding there is controversial literature on the actual effectiveness of family-centred and developmental care interventions. This might be due to a lack of shared guidelines for interventions (Symington & Pinelli, 2006; Westrup, Kleberg, von Eichwald, Styernquist, & Lagercrantz, 2000), so that large variations exist in the care protocols of NICUs in different countries (Ashbaugh, Leick-Rude, & Kilbride, 1999). During the years to come, more shared and grounded protocols for NICU care actions are warranted, since variations in NICU care practices have been shown to exert critical influences on preterm infants' well-being later in life. For example, both developmental care interventions directed to infants – i.e., pain management during medical procedures and inoculations – and family-centred interventions directed to parents – i.e., active participation and engagement across the entire NICU stay – might be beneficial to supporting better preterm neurobehavioral development (Chertok, McCrone, Parker & Leslie, 2014; Melnyk, Feinstein, Alpert-Gillis, Fairbanks, Crean, Sinkin et al., 2006; Montirosso, Del Prete, Bellù, Tronick, Borgatti & NEO-ACQUA Study Group, 2012).

3 The Process of Caregiver Engagement in NICU

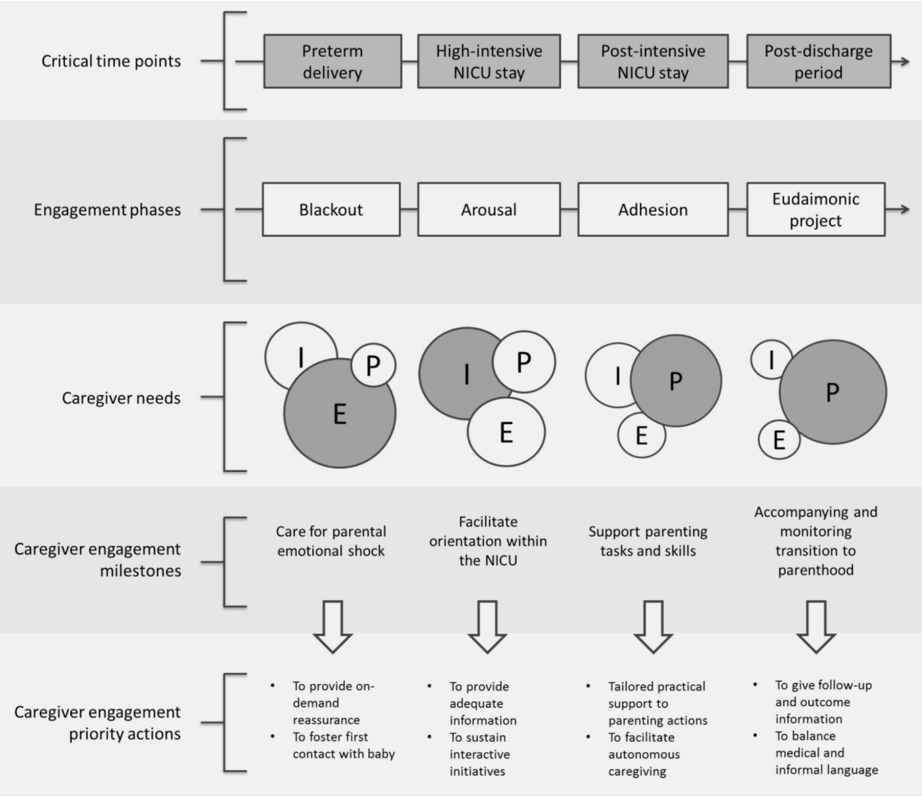
The experience of parents who have a prematurely born infant being hospitalized in the NICU might be segmented into four different critical time points: preterm delivery, high-intensive NICU stay, post-intensive NICU stay, and post-discharge period. During their healthcare journey in the NICU, parents experience the engagement phases previously shown in relation to patients own healthcare and described in the PHE model (Graffigna et al., 2013; Graffigna et al., 2014) (see Chapter 3 for further details).

A schematic representation of the healthcare journey is reported in Figure 1, illustrating different levels: from the time segmentation of parental experience to parental needs, from emerging engagement phases to caregiver engagement milestones and descending action priorities. We believe that the process of caregiver engagement is extremely dynamic in its nature and that it emerges at the interface between parental needs, infant health status, and neonatal care interventions. During this process, parents might go forward or backward with regard to caregiver engagement as the healthcare interventions are more or less effective and attuned with their needs and availability.

3.1 The Blackout: Preterm Delivery as an “Out of the Blue” Experience

Preterm birth is often described by parents as a dramatically shocking, unexpected event. Mothers might be much more deeply affected since after the delivery they are not allowed to see the baby for several hours and, sometimes, for an entire day (Latva et al., 2004). Fathers are somewhat facilitated in facing the black-out since they can immediately have a look to their prematurely born infant (Arnold, Sawyer, Rabe, Abbott, Gyte, Duley et al., 2013 ; Provenzi & Santoro, 2015). Sometimes they may take pictures or record videos of the baby to be shown later to the mother at the bedside. As reported in Figure 2, parental needs at this stage are mainly emotional.

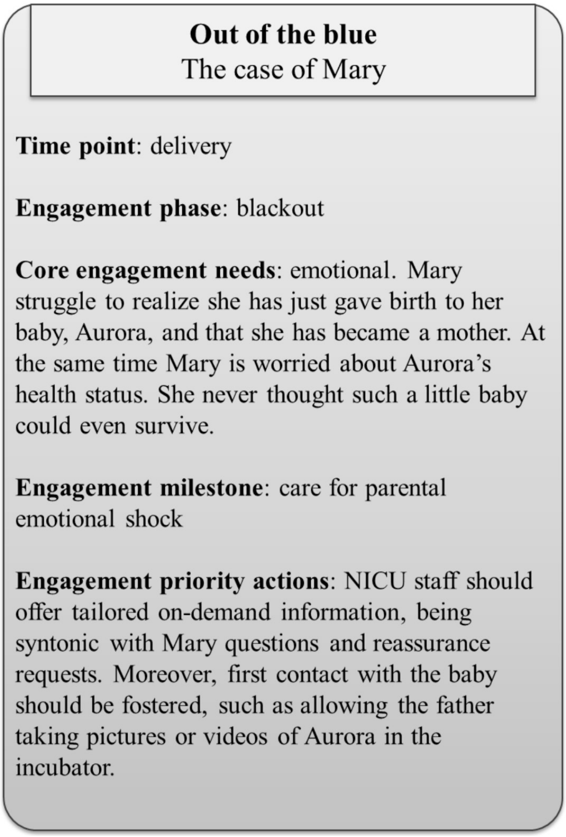
Despite the black-out experience leaves little or no room at all for immediate psychological and emotional elaboration, parents need to be reassured about what is going on with their baby. Sometimes, they had never heard about preterm birth and they need to know where the infant is, what the NICU staff are doing to them, and obtain reassurance about health status and survival. For what regards caregiver engagement, this is a critical time point for both parents and NICU staff, since at the very beginning physicians and nurses have little information on the health status of



Note. Caregiver needs: I = informational engagement needs; E = emotional engagement needs; P = parenting engagement needs. Bigger and darker circles indicate core needs per phase.

Figure 1: Caregiver engagement process for parents of preterm infants in the NICU.

the infant and they cannot give precise reassurance to parents. Nonetheless, parents have been found to feel better if NICU staff assumes a syntonic perspective and takes care of the emotional burden of parents in this initial phase of the journey, taking relief from a human, warm, respectful approach (Skene, Franck, Curtis & Gerrish, 2012). In order to facilitate the onset of effective emotional elaboration, two main priority actions are: allowing at least one of the parents to see the baby and take pictures of him/her to be shared with the partner; assuming an available attitude, providing information calibrated and tailored on moment-by-moment parental needs and requests, even if the response could not be exhaustive or definitive (Guillaume, Michelin, Amrani, Benier, Durrmeyer, Lescure et al., 2013; Provenzi & Santoro, 2015). The first action is thought to foster and catalyse the initial contact with the baby, which is critical since preterm infants' parents might suffer for long time from the delayed parenthood onset. The second action is aimed at opening a space of shared elaboration and mentalization on what is happening to both themselves and the infant, co-constructing integrated and adaptive representations.



Out of the blue
The case of Mary

Time point: delivery

Engagement phase: blackout

Core engagement needs: emotional. Mary struggle to realize she has just gave birth to her baby, Aurora, and that she has became a mother. At the same time Mary is worried about Aurora's health status. She never thought such a little baby could even survive.

Engagement milestone: care for parental emotional shock

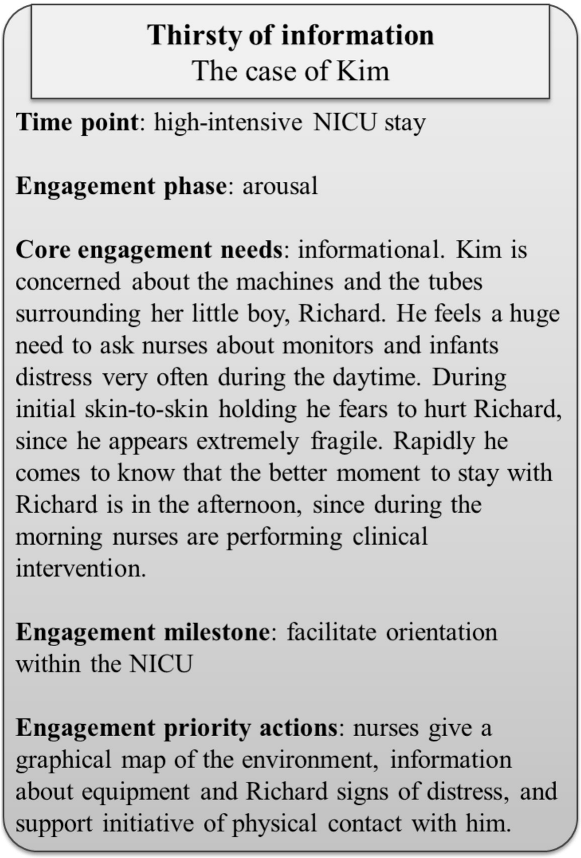
Engagement priority actions: NICU staff should offer tailored on-demand information, being syntonic with Mary questions and reassurance requests. Moreover, first contact with the baby should be fostered, such as allowing the father taking pictures or videos of Aurora in the incubator.

Figure 2: Snap-shot of a prototypical case of caregiver engagement at blackout.

3.2 The Arousal Phase: Activate to Gather Information During the High-intensive NICU Stay

The first period of NICU stay involves hospitalization in a high-intensive environment characterized by a technological device that dramatically reduces the possibility of direct contact with the baby. Parents are now experiencing a sort of one-way-only pathway and they start to associate their own well-being with the day-by-day bulletin of their infants' health status (Skene et al., 2012). They feel that the only obliged way is strenuously going on toward the final horizon of NICU discharge. The visual and auditory stimuli of the highly technological NICU might exert a profound impact on both mothers and fathers (Miles et al., 1992) and, consistently, in this phase the core engagement needs are informational (De Rouck & Leys, 2009).

Parents need to know what the lights and sounds mean, how they are related to the health of their baby, and how to behave in this alienating environment. Moreover, during the initial contact with the infant, parents may fear hurting them simply through touching their body, due to the fragile nature of the infant. As a consequence



Thirsty of information
The case of Kim

Time point: high-intensive NICU stay

Engagement phase: arousal

Core engagement needs: informational. Kim is concerned about the machines and the tubes surrounding her little boy, Richard. He feels a huge need to ask nurses about monitors and infants distress very often during the daytime. During initial skin-to-skin holding he fears to hurt Richard, since he appears extremely fragile. Rapidly he comes to know that the better moment to stay with Richard is in the afternoon, since during the morning nurses are performing clinical intervention.

Engagement milestone: facilitate orientation within the NICU

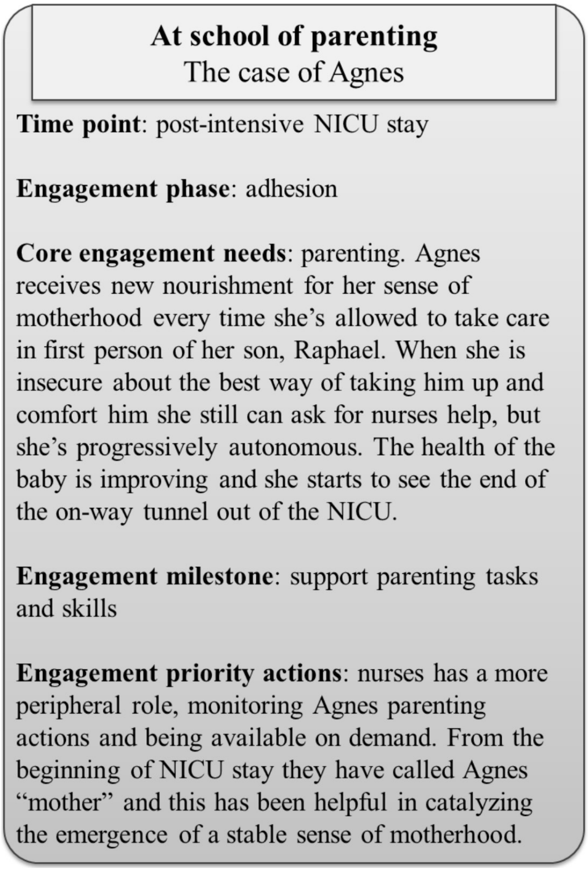
Engagement priority actions: nurses give a graphical map of the environment, information about equipment and Richard signs of distress, and support initiative of physical contact with him.

Figure 3: Snap-shot of a prototypical case of caregiver engagement at arousal.

of this, we suggest that the staff should provide clear information about: the policy of parental presence in the NICU, the schedule and meaning of clinical interventions, information to read infant's crying and other signs of distress, a map of the allowed and forbidden parenting actions, and of the modalities through which perform first contact actions with the baby – i.e., use of breast pump, skin-to-skin holding, and kangaroo care (see Figure 3).

3.3 The Adhesion Phase: Learning Parenting Skills During the Post-intensive NICU Stay

As the health status of the baby improves, he/she is moved out of the incubator and the entire family moves into the post-intensive environment. Now the contact with the baby is far less restrained and the mothers start to develop a rich and full sense of motherhood, which arises from the possibility of perform normal parenting tasks,



At school of parenting
The case of Agnes

Time point: post-intensive NICU stay

Engagement phase: adhesion

Core engagement needs: parenting. Agnes receives new nourishment for her sense of motherhood every time she's allowed to take care in first person of her son, Raphael. When she is insecure about the best way of taking him up and comfort him she still can ask for nurses help, but she's progressively autonomous. The health of the baby is improving and she starts to see the end of the on-way tunnel out of the NICU.

Engagement milestone: support parenting tasks and skills

Engagement priority actions: nurses has a more peripheral role, monitoring Agnes parenting actions and being available on demand. From the beginning of NICU stay they have called Agnes "mother" and this has been helpful in catalyzing the emergence of a stable sense of motherhood.

Figure 4: Snap-shot of a prototypical case of caregiver engagement at adhesion.

such as changing diaper and feeding the infant without asking for NICU staff permission (Fegran, Helseth & Fagermoen, 2008). Their core needs are now related to parenting (see Figure 4).

During this phase, parents initially have to adhere to NICU staff teaching regarding how to perform parenting skills, how to swaddle the baby, how to hold them to feel at ease, how to distinguish between different sources of distress related to temperature shock, anger, or sleep needs (Reis, Rempel, Scott, Brady-Fryer & Van Aerde, 2010). Nurses are thought to provide active sustain and to encourage autonomous caregiving. Modelling interventions might be useful in the initial period of post-intensive NICU stay, especially for parents who appear less at ease when interacting with the baby. Active teaching of adequate strategies to support and comfort the baby should be provided. Progressively, as the moment of discharge approaches, nurses are asked to monitor for parental autonomy and self-comfort when taking care of the baby, since this is one of the fundamental criteria to favourable decide that the family can finally go home.

The normal life after NICU discharge
The case of Robert

Time point: post-discharge period

Engagement phase: eudaimonic project

Core engagement needs: parenting. Robert has now resume to work on a regular basis and he needs to conciliate the time spent at work and with the family. When at home, he performs parenting tasks with one of his twins, shifting with his partner. He is no long worried about the survival of Kevin and Brett and he feels to be even stronger in other areas of his everyday life.

Engagement milestone: accompanying and monitoring transition to parenthood

Engagement priority actions: follow-ups are critical time points after NICU discharge. Professionals are required to adopt a mix of technical language and human-like metaphors in order to target both the reassurance need that all is going well with regard to infant health and to let parenthood grow in a normal way.

Figure 5: Snap-shot of a prototypical case of caregiver engagement at eudaimonic project.

3.4 The Eudaimonic Project Phase: the end of the NICU Journey and the Everyday Life of the New Family After NICU Discharge

After NICU discharge, parents prepare to project the new family life in their home environment. Parenting and physical contact with the baby are now free of restraints and mothers and fathers develop their own interaction style (see Figure 5).

Mothers may prefer physical contact during this phase, since they feel that this could be useful for both the infant and themselves. Free and at-will physical interactions convey a need to recover from the NICU experience due to the lack of intimacy and closeness and many mothers may need this as an affective reimbursement. In some cases, fathers may prefer to play in different ways, such as talking and singing with the baby in order to still avoid direct physical contact (Pohlman, 2005). Nonetheless, especially when the couple have twins, fathers have to conciliate the return to work to grant economic stability and the care of the infants. Again, many fathers may feel to be the “male-mother” of the couple, performing actions that are culturally associated with the maternal figure, such as feeding the baby and helping them fell asleep. Both parents are developing a representation of the baby as a strong one and of themselves as super-parents. The NICU experience might have lowered the anxious feelings deriving from further signs of distress of the baby or seasonal diseases and infections. Nonetheless, a subtle state of vigilance about the health of the infant is present throughout the first year of life, with the main concerns being focused on the infants' motor and cognitive development. Follow-ups become critical time points for the parents, as they stand for reassurance about the health of the baby and, in some cases, might be seen as a sort of necessary accompaniment conveying continuity between the previous adhesion phase of NICU stay and the growing autonomy of family life and eudaimonic project. Despite parents might have learned a new medical-driven vocabulary during the hospitalization and might now be at ease with caring procedures – i.e., the use of the aspirator for nasal mucus – now they need to gain a sense of "normal" life. In this regard, physicians are required alternate between both medical and informal language. On the one hand, precise medical language is necessary to refer to health and clinical aspects and to provide clear explanation of the medium and long-term possible outcomes. Nonetheless, at the same time, the adoption of human-like metaphors and informal language is suggested in order to help parents think and represent the baby as a whole developing human being and not only as a fragile being.

4 Conclusions: Advantages of the PHE Model Application to Caregiver Engagement in the NICU

Nowadays, caregiver engagement is recognized as a fundamental and critical feature of family-centered and developmental care interventions for preterm infants in the NICU (Gallegos-Martinez, Reyes-Hernandez & Scochi, 2013). Several NICUs have now included policies on parental participation, sharing of schedules, and active involvement of parents in healthcare since the first period of hospitalization (Lester, 2011). Nonetheless, parents of preterm infants are known to face several sources of emotional distress that could lead to an unbearable psychological burden and to long-lasting affective disorders which could affect the infant's development at multiple levels (Alkozei et al., 2014).

Taking into account caregiver engagement in the light of the PHE model (Graffigna et al., 2014) has a series of advantages: 1. The model offers a dynamic view of caregiver engagement, which is compatible with the ongoing nature of the healthcare journey of preterm infants and their parents; 2. The four phases of the model – i.e., blackout, arousal, adhesion, and eudaimonic project – synthetically depict and integrate the level of parental experience and needs together with caregiver engagement milestones; 3. As the family moves toward discharge from the NICU environment, emergent priority actions for caregiver engagement could be provided to professionals to orientate their practice in a sensible and effective way with regard to parental dynamically changing needs; 4. The definition of specific milestones and priority actions is operationalized and potentially grants criteria for the evaluation of the effectiveness of caregiver engagement interventions in the NICU.

The clinical vignettes reported in the present chapter show how the PHE model could improve the clinicians-parents relationship, ameliorate the care provided to both infants and parents and reduce unnecessary suffering for infants and their families. The principles of the PHE model can and should be used to improve many aspects of infants' care, from issues such as prescribing medicines to complex clinical care, from pain relief to active involvement of parents in NICU, from nutrition to parent-infant relationship. According to this model, clinicians could orientate their practice and attune it with the real needs of the infants and their families along the care process.

We strongly advocate that promoting processes thought to customize parental care experience is warranted be a key strategy to overcome the fear, anxiety, and stress associated with having an infant unexpectedly and suddenly hospitalized for a long-lasting period in a highly technologically intensive unit. Encouraging parents' engagement and empowerment, including them in the experience of their infant's hospitalization and focusing on how to create a more homelike experience are critical priority actions for neonatal care professionals in NICUs. Clinicians basing their practice on the principles of health consumer engagement – i.e., PHE model – could facilitate the delivery of effective and equitable care (Barello, Graffigna, & Meyer, 2015; Provenzi & Montirosso, 2015). We hope that the process of change toward caregiver engagement in the NICU will continue during the years to come, bringing long-lasting improvements and beneficial effects for preterm infants and their parents.

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Serena Barello, Mariarosaria Savarese, Guendalina Graffigna

The Role of Caregivers in the Elderly Healthcare Journey: Insights for Sustaining Elderly Patient Engagement

Abstract: Along the healthcare process, ensuring and coordinating services that result in patients' positive health outcomes requires strong and effective partnership between patients, families, and healthcare require. On these factors, the current scientific debate is devoting increasing attention to the role of caregivers in supporting elderly patient health engagement. This chapter discuss experiences from the field about the caregivers' role in sustaining the care process and helping patients both to cope with complex medical regimes and to manage changes in their daily life. In the light of the PHE model, the authors will propose specific supportive actions that caregivers may enact to effectively address their loved ones' needs along the engagement process.

Keywords: Caregiver engagement; Elderly; Chronic care; Patient engagement

1 Caregiver Engagement for Elderly Care: What Matters?

In Europe, over 20 million people self-identify as informal caregivers of frail and non-autonomous individuals and this number is expected to increase in the coming decades (Arno et al. 1991; & Snell, 2002; Shahly et al., 2013). Informal caregivers play the role of the backbone of the long term care system, helping and supporting their loved ones in managing different aspects of their health condition. Since the world's healthcare systems are facing the challenge of increasing demand for complex and multifaceted care, it is becoming increasingly crucial to consider caregivers as direct consumers of healthcare because they are more and more involved in navigating the health services in order to support their loved ones.

To this regarding, along the care process it is essential to best capitalize resources there are actually present in the care environment, not only on the professional side, but also within the lay community network (e.g., families and peers). There is the need to favour a knowledge transfer from the traditional clinical settings (i.e. hospital, ambulatory...) to the daily care environments and to actively engage caregivers of medically frail elderly individuals along the care process. Informal caregivers need to learn how to effectively manage their loved ones' conditions and how to help them in recovering – where possible – a satisfying state of autonomy.

If healthcare systems are devoted to truly recognizing the potentiality of informal caregivers, a shift from a patient-centred care model to a family-centred one is required in order to effectively include them in the care process. On this basis, we advocate not only patient engagement, but also we underline the importance of caregiver engagement in order to guarantee effective home based self-care interventions which would allow for the achievement of positive long-term health outcomes. Caregiver engagement might be particularly critical in the care management of medically frail and non-autonomous individuals, such as the elderly. At the same time, it is important to note that caregivers engaged in the care of their loved ones might experience psychological, physical, and social challenges – otherwise known as caregiver burden (Bastawrous, 2013; Adelman et al., 2014) – that can negatively affect their quality of life (Martín et al., 2013; Shahi et al., 2014; Feeley et al., 2013; Nayak et al. 2014; Peters et al., 2013; Boele et al., 2013; Buijck et a., 2013).

This chapter attempts to highlight the value of implementing the PHE model principles in caregiver engagement, as they are a key, but largely unrecognized member of the healthcare team. The goal is to distil evidence on what is currently known—and what information is still needed—on making family caregivers active partners with professionals in providing health-related care during the elderly care process in order to best face the transitions across settings, especially from hospital to home. We will examine the roles family caregivers play in providing care during the patients' engagement transitions, how they characterize their experiences and needs for support, and how family caregiver engagement might improve outcomes for patients.

A central focus of the chapter will be on describing the main roles caregivers could assume along the patient engagement journey, assessing the extent to which healthcare providers should actively involve family caregivers, and identifying barriers to greater engagement. Promising approaches and tools to make family caregivers full partners with professionals during transitions between health care and home settings will be suggested. The chapter concludes with recommendations for practice, research, quality improvement, and public policy to more meaningfully engage family caregivers as partners in transitions across settings. This chapter will demonstrate how the PHE model could be used as a reading framework to assess caregiver needs and priorities to better sustain their engagement in the care process as well as their actions to make their loved ones autonomous in the care process.

2 When Engaging Caregivers Becomes Essential? Lessons Learned from Elderly People Care

2.1 Challenges and Opportunities of Engaging Carers in the Care Process: an Overview

Due to advances in medical science and technology and the development of healthcare services, contemporary society have to face a series of challenges regarding the management of elderly chronically ill patients. Furthermore, more than half of elderly individuals with one chronic condition have multiple chronic diseases, thus increasing the complexity and the burden of managing their own health. Chronic conditions require a life-long perspective, thus implying long-term care plans which inevitably require the active involvement of family caregivers in supporting the care requirements.

In order to answer to this healthcare challenge – as previously discussed in Chapter 1 – guaranteeing supportive actions for home-based care management is essential. The active presence of carers in the care process has been found to enhance patient-centered care and promotes patient autonomy in health management (Brown et al., 1998; Schilling et al., 2002; Hubbard et al., 2010; Clayman et al., 2005). Family caregivers are strongly involved in healthcare management with patients who are elderly, in poor health, or who have high disease burden (Wolff et al., 2008). Moreover, the central value of carer engagement in the patient's medical course has been demonstrated in life-limiting conditions. Particularly in this situation, carers are required to be skilled and proactive in taking care of their loved ones in order to make them as autonomous as possible (Hogden et al., 2013). To gain this goal, clinicians and policy makers strongly agree in making carers engaged in elderly patient care for its crucial implications for making the care actions effective in the long term (Ventura et al., 2014; Woo, 2014).

2.2 Engaging Relatives in Elderly People Care: Voices from the Research Community

Caregiver engagement is mainly conceived as information seeking and decision making enacted by the family members of the patients (DuBenske et al., 2010; Bevan & Pecchioni, 2008), considering not only information regarding treatment and therapy regimen and different care options, but also on the disease course and on life perspectives and plans (Imes et al., 2011). Given their role in collaborating and managing the chronic condition of an elderly individual, the carer is often engaged first person in the relationship with health providers. Resesrch has demonstrated that caregivers are present at the majority of visits and that they ask more questions than the patients themselves (Cegala et al., 2000; Street, 1991). In fact, some authors underline that the carers support, and in some cases their substitution with the patient in terms of interacting with the health professionals, are key components of caregiver engagement. This fact has important consequences for information exchanges about the disease, on specific procedures and the technical aspects of care, as well as on care costs (Quam et al., 2006). The problem of continuous learning of the part of the carer is that information given during visits and hospital discharge are often difficult to understand due to their technical nature (Friedman & Quinn, 2008).

Other authors focus on changes in the carers' lives, in their relationship with the ill relative and, as a consequence, changes in their own daily life (Luttik, et al., 2007). In particular, the management of a chronic disease implies a reorganization of the relationship between patient and his caregiver, generating changes in daily routines (like work and travel), in roles and the division of family duties, and a reduction of social inclusion/life. The caregiver themselves perceives changes in their emotional status, feeling stress, depression, anxiety, and poor physical health, with these changes needing to be taken into consideration by those who organisecare programs and services (Pressler et al., 2009). Another major theme debated by authors concerns the practical aspects and daily problem solving involved in managing a chronic disease condition (Sarkan & Bates, 2014). Some key aspects are: dealing with patients' dietary restrictions and meal planning, controlling weight and physical exercises, supporting adherence to treatment and medications, and in maintaining long term rehabilitation (Harris et al., 2010).

As we have seen so far, both academics and policy makers recognize the key role of caregivers, as a key source of care for an ill person who lacks autonomy when managing their health condition. In this particular situation, the caregiver becomes the real consumer of healthcare services because of their direct involvement in taking healthcare decisions and choosing healthcare services, and it is their task to navigate the various services of the healthcare system. Finally, some research has found that health professionals often consider carers as supporters and gatekeepers of the patient, or, in some situations, as co-patients (Hogden et al., 2012). Moreover, the engagement of carers allows them to become surrogate care managers in the absence of multidisciplinary care, bridging service information and coordination gaps to providing long-term care for patients (Bolmsjö et al., 2001).

3 The Multiple Roles of Relatives When Taking Care of Their Loved Ones: Insights from the PHE Model

Nowadays, more and more countries are recognizing the key role of family caregivers in supporting the management of a chronic condition of a loved person. Elderly patients affected by chronic disease, undertake a long and arduous journey in which, day by day, they learn to live as well as possible alongside their compromised health condition. However, along this journey, they aren't alone, they have the support of their informal caregivers that, in the case of an elderly person, is mainly the partner or the sons. Progressively, the patient crosses a process of care, that includes the management of the clinical condition (i.e. management of the therapeutic regimen or the changes in life style…), emotional difficulties, and economic burden. Increasing engagement in disease management requires, as a consequence, the engagement of both the patient and of their relatives.

Unless engaging both patients and families in self-care is recognized as crucial, readers may ask *what exactly does it mean to engage family in the care process? What roles do family caregivers play in providing health care, especially during transitions across settings*? And finally, how *do family caregivers characterize their experiences of providing healthcare and their needs for support*? We will try to answer to these questions in the following paragraphs.

While health care professionals interact with the healthcare system regularly, it is important for us to remember that for many patients, as well for their caregivers, healthcare can feel like a complex and intimidating maze that they are forced to navigate without the benefit of a map or a guide to help them find their way—a metaphorical Oz minus the helpful and ever-present yellow brick road. Patients and caregivers do their best to steer a clear course, but many report feeling left to wonder "hy?", "what now?", and "what if?", with inadequate support from healthcare providers to help answer these pressing questions.

These patient and caregiver experiences reinforce the importance of systems and tools to assist caregivers and their loved ones in anticipating what to expect for the duration of time that they are in the process of care, to address their anxiety and questions, and to help them plan for their needs once they leave the hospital. Providing information on the discharge plan from the onset of treatment (and in some cases, even before) is an extension of this work to foster continuity of care, equipping family caregivers and patients with the knowledge, skills, and confidence that will enable them to better manage their health once they are no longer in the institutional settings of care.

By providing health consumers with the tools and information they need to manage their own healthcare needs, clinicians and policy makers are emphasizing the important role of the patients and caregivers as the one constant for the duration of their health care experience. In clinical setting oriented toward making patients and family actively engaged in the medical course, care is delivered in a manner that is coordinated among numerous caregivers and that involves the patient and family in the exchange of information between providers.

In the case of elderly care, caregivers play a crucial role in supporting their loved ones' engagement in health management. In the light of the PHE model, we know that patients pass through different engagement phases, characterised by specific needs at different levels (e.g. emotional, cognitive, and behavioral). Due to the lack of autonomy characteristic of elderly patients, caregivers become crucial in addressing the patients' needs in the following areas: disease management (i.e., monitoring clinical

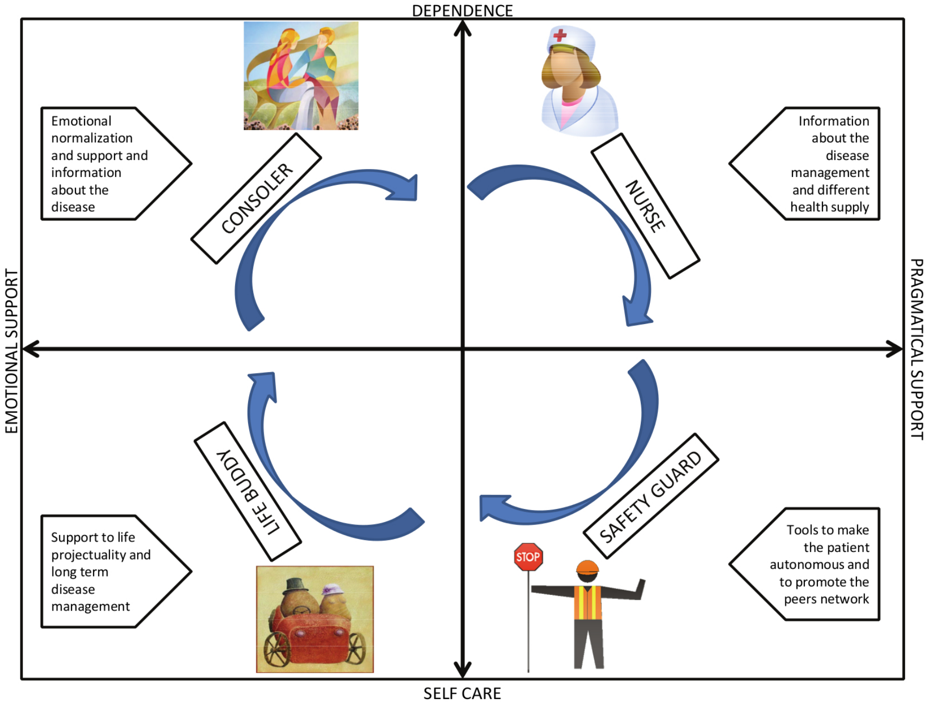

Figure 1: The many roles of family caregivers when engaging in the care process of their loved one.

parameters), health maintenance (i.e., following diet prescriptions), emotional scaffolding (i.e., helping in managing the distressing consequences of illness), acquiring knowledge (i.e., being an alternative interlocutor for health providers), and social inclusion (i.e., supporting the patient's social role despite the limitations caused by the disease).

Considering the PHE model and the peculiar features of each engagement phase, the role of family caregiver isn't unique and definitive, but it fits in order to reply to the patient's journey and needs and be described on two axes. The first one describes the patient's level of autonomy in self-managing his/her health condition (dependence vs self-care); the second one describe the patient's main supportive needs related to his/her care (emotional support vs. practical/informative support).

Taking into account these axes, the role of caregivers' changes based on both the level of the patient's autonomy in self care and to his/her main supportive needs. Thus, caregivers may assume different roles when supporting their loved ones as described below. These roles are also featured by specific unmet needs that clinicians have to consider when interacting with the caregivers. We suggest asking the caregivers an adapted version of the PHE questions (see Chapter 3), in order to better assess the caregivers' emotional, cognitive, and behavioral mindset towards their loved one's health status and management.

3.1 “Now I Need a Consoler”: the Case of Marriot, Diabetic Patients, 74 Years Old

After having being diagnosed with diabetes mellitus, Marriot faced a moment of despair and disorientation for what happened and will happen. She is in blackout and can’t self manage her health condition *(see the blackout phase of the PHE model*). In this situation, the patient features a low level of autonomy in self care and mainly needs emotional scaffolding. Her daughter Angela, assumes the role of a consoler, because the patients has to accept and manage the new health condition. For this reason the caregiver requires basic information on the disease and its consequences for everyday life, to understand the ways in which to better manage her mothers’ condition, in a period where she is not ready to do that, and understand the possibilities of effective integration of the disease into daily life. On the other hand, Angela needs emotional support herself from the formal care network (e.g. the clinicians, the nurse…), that could help her to find a way to normalize what happens and hold the psychological and physical burden of her mother.

3.2 “Please, Be a Nurse”: the Case of Carlos, Cardiological Patient, 76 Years Old

Carlos was diagnosed with heart failure 8 months ago and needs to take a complex medication regimen, but he is not able to manage it due to the level of anxiety and confusion he is still passing through (*see the arousal phase of the PHE model*). After an initial period of disorientation due to the disease onset, Lucy, his wife, takes the reins of the care and cure of her husband. Now, she is ready to assume the role of the nurse, who provides for all of the needs of Carlos. She compensates for the disease management related activities that the patient is not able to do by himself. To do this, she needs to know all the information about the practical management of the patients’ health condition, such as information about the medical prescription and the necessary changes in daily life style, the diet restrictions, and the physical activities required to manage a chronic condition and to maintain positive health outcomes in the long term. Moreover, she temporarily replaces the patient in taking clinical choices.

3.3 “You Are My Safety Guard”: the Case of Samantha, Cancer Patient, 69 Years Old

Samantha was diagnosed with breast cancer 3 years ago and undertook chemotherapy. Now, she is taking oral therapy and having to attend medical follow ups. Gradually, the clinical and emotional condition of the patient has improved and she learned to self manage her condition (*see the adhesion phase of the PHE model*). Jonathan, her husband, has progressively assumed the role of a “safety guard”, committed to making his wife more and more autonomous in her care. Now, Jonathan requires support in the process of slowly relinquishing his care duties to Samantha. The informal caregiver has to become able to stay with the patient without being the manager of the patient’s condition, and the care network has to support this process. The caregiver keeps on being a key figure for the patient, who is present only in the case of emergency. For a long time the caregiver lived closely to his ill loved one, in some cases giving up to a part of their life and individuality. Now, it is necessary to allow the caregiver to dismiss the role of caregiver and to regain their role of partner, accepting that some resistance will occur in this difficult handover. During this process, the role of peers becomes fundamental: the comparison and the sharing of the care experience with others with the same experience can help the process of returning back to life, that is, the life before the onset of the disease.

3.4 “Stay With Me, Like a Life Buddy”: the Case of Luis, Diabetic Patient, 69 Years Old

Luis was diagnosed with diabetes 10 years ago and takes insulin. He had to radically change his life habits concerning his diet and physical activity. After many years struggling with his health condition, the disease has become a part of his daily life and both Luis and Lena – his wife – became able to accept the consequences and the impact of such a chronic condition on their daily routine (*see the eudaimonic project phase of the PHE model*). They have faced the process of the normalization of the disease, in all its aspects; doing so they have become able to manage all of its clinical and emotional outcomes. Now the caregiver can attend the patient as a partner and friend, who shares with them the their life experience. The key needs of the caregiver in this case are being supported in finding again a life direction and to build a new foundation for their life with their patient. For the partner, it means to rediscover life as a couple, characterized by private and social exchanges. Unless the chronic disease condition is still present, the capabilities acquired during the care journey allow for the complete management of the disease, with all the awareness and the ability of a veteran of the situation.

4 The Role of the PHE Model in Redesigning the Boundaries of Family Centred Care

Taking an overall view at the insights obtained from the research presented here, documenting the experience of informal caregivers of elderly chronically ill patients, three main core dimensions of caregiver engagements are of particular concern.

First of all, the cognitive, emotional, and behavioral features of caregiver engagement are not fixed in time; rather they change across the healthcare process, mainly paralleling patients' health journey and clinical progresses. In the case of elderly chronically ill individuals, the role of carers as informal caregivers changes as a function of the actual patient engagement and their autonomy in managing the disease. As a consequence, at each step of the care process the caregiver engagement agenda should be sensible to both the patient journey and the informal caregivers' needs in order to involve parents and carers without exacerbating the caregiver burden (Adelman, 2014).

Moreover, partially as a consequence of its time-dependent nature, caregiver engagement strategies need to be continuously managed by healthcare professionals, balancing informational and pragmatic support as well as supportive and autonomy-eliciting interventions. In the case of elderly chronically ill patients, caregiver engagement needs different supportive actions across the patient's health journey. These actions vary from providing emotional normalization and basic information to understand the disease, to practical skills thought to be useful in managing the medical regimen and the clinical prescription; from providing tools that help caregivers in making the patient autonomous and able to connect with peers to supporting social inclusion and long term life (and disease) management.

Finally, informal caregivers appear to pass through a similar engagement journey previously highlighted for patients (Graffigna et al., 2014). As mentioned elsewhere in this book (see Chapter 3), the Patient Health Engagement Model (PHE model; Graffigna et al., 2014) states that patient engagement is comprised of four phases: blackout, a state of emotional, behavioral, and cognitive block due to disease onset; arousal, a state of patients' hyper-attention to critical signals and activity toward obtaining information; adhesion, a state in which patients acquire information and behavioral skills to confidently comply with medical prescriptions; eudaimonic project, a state in which patients are capable of enacting a meaningful and autonomous health management with improved quality of life. Carers of elderly chronically ill individuals pass from a state of emotional and behavioral blackout followed by an activation towards gaining information and details about the concrete management of their loved one disease; then they become able to autonomously sustain their loved one in disease management and finally to reframe their role in terms of life buddies according to renovated eudaimonic life trajectories.

In conclusion, in order to be effective in sustaining autonomous care management and to promote quality of life in a broader family-centered way, caregiver engagement strategies need to account for the risk of a complex multi-dimensional burden for informal caregivers (Strawbridge et al. 1997; Thommessen et al., 2002; Sherwood et al., 2005; Pinquart & Sörensen 2011). From this perspective a sort of "mirroring effect" could be traced between patients' health status and informal caregivers' engagement along the course of the patients' health journey. From this perspective, if from one side caregiver engagement emerges as a critical dimension for health care policies and medical strategies capable of reducing the societal impact of managing the health of chronically and non-autonomous ill individuals, further attention should be given to the needs of informal caregivers. We believe that such a broader sight to patients and their carers journey across the health care process would contribute to facilitating and catalyzing families autonomy, resulting in benefits for both quality of life and reduced financial resources in healthcare systems.

5 Conclusions

Hospitals that are committed to being responsive to consumers' needs and expectations understand the invaluable role of family caregivers in the process of care. These are the people who know the patient best and those who, simply by their presence, can help to reassure patients in times of uncertainty, anxiety, or vulnerability. Clinicians who desire to work in line with the PHE model principles shall welcome family members by not only lifting many of the restrictions that have limited their engagement, but also by actively encouraging their participation as members of the care team.

Healthcare providers treat thousands of patients with cancer, heart disease, and other chronic and terminal illnesses every year. Many of these patients are elderly or critically ill and may undergo difficult medical treatments that require lengthy and/or frequent hospital stays or outpatient visits. During their treatment, family caregivers are often a critical source of care for their loved ones. Family caregivers can offer providers a valuable source of help, as well as information about the patient‘s history, routines, symptoms, and more. For these family members, participating in this manner is essentially an extension of the ongoing care giving role they play at home, both before and after hospitalization. The clinical vignettes presented in this chapter represent ways to effectively engage caregivers to provide optimal patient care according to the phase of engagement they are passing through.

Clinicians orientated toward practicing a patient engagement model of care not only strive to meet the full range of patient needs, but also those of their informal caregivers. This chapter underlines the importance of considering care giving not only as as activity to support and care of a loved person, but also as a complex dynamic which involves a gradual engagement of the caregiver in the care process that requires healthcare systems to fine-tune their relationship with the informal carers. Health providers cannot take for granted the skills and the availability of caregivers to effectively manage the patients' condition. Caregiver engagement is a multifaceted and complex process that requires an accompaniment of the informal caregivers and a progressive education by the professional care network, favoring the knowledge transfer from the inside to the outside of the hospital setting. In this aim, we also advocate for a wider implementation of new technologies to facilitate skills and knowledge transfer from the providers to family caregivers. Resources such as online web portals or mobile phones might sustain better access and more timely delivery of health services, thus supporting the caregivers' effective engagement (Davis et al., 2011).

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Hospital Innovations in the Light of Patient Engagement. Insights from the Organizational Field

Abstract: Nowadays, National Healthcare Systems are confronted with an increased demand for high quality and patient centred services worldwide, but the limits of resources challenge their sustainability. The mandate to “do more with less” encourages policy makers, healthcare managers, and professionals to look for innovative ways to redesign healthcare services in order to meet the challenges of the new social and economic trends. In this scenario, healthcare researchers and policy makers increasingly acknowledge patient engagement as a pivotal lever to improve the effectiveness and efficiency of healthcare provision.

The chapter presents a frame of the current trends and challenges related to the development of sustainable innovation in healthcare by specifically focusing on the hospital change from the perspective of both new hospital positioning in the wider healthcare ecosystem and organizational reengineering. Hospital innovation is discussed in terms of its connection with the concept of engagement, which is articulated both at multiple levels and across multiple stakeholders composing the healthcare ecosystem.

The work is grounded on the analysis of the recent theoretical perspectives in healthcare innovation and on some illustrations and examples from relevant organizational case studies.

Keywords: Hospital innovations; National Healthcare Systems; sustainable healthcare; organizational sustainability; engagement; multi-stakeholder partnership; patient centred hospital model.

1 Introduction

As underlined in Chapter 1, nowadays, National Healthcare Systems worldwide are confronted with an increased demand for high quality and patient centred services, but the limits of resources challenge their sustainability. The mandate to “do more with less” encourages policy makers, managers, and professionals to look for innovative ways to redesign healthcare services in order to meet the challenges of the new social and economic trends. In this scenario, patient engagement is increasingly acknowledged as a pivotal lever to improve the effectiveness and efficiency of healthcare provision.

This chapter, grounded on the analysis of recent theoretical perspectives and on some illustrations and examples from relevant organizational case studies, presents a frame of the current trends and challenges related to innovation in healthcare in the light of patient engagement. The specific focus is on hospital change in terms of new hospital positioning in the wider healthcare ecosystem and in terms of organizational reengineering or model change. Hospital innovation is discussed in its connection with the concept of engagement, which is articulated both at multiple levels and with multiple stakeholders composing the healthcare ecosystem. The investment on multiple-lane engagement allows for the construction of a multi-stakeholder partnership, which we believe is a key-asset for guaranteeing an effective healthcare innovation, balancing its economic, environmental, and social sustainability.

The chapter comprises six parts. After the Introduction, Section 2 briefly presents the actual challenges that influence innovating and organizing sustainable healthcare. Section 3 analyses the ways in which hospitals are trying to respond to these challenges through a number of initiatives aimed at reconfiguring the centeredness of patients with respect to both the broad external ecosystem (designing an “embedded hospital”) and to the internal model and structures (designing new patient centred care delivery models). Section 4 introduces the link with the concept of engagement and subsequently with the idea of engaging in multi-stakeholder partnerships. Section 5 presents some concluding remarks.

2 Innovating and Organizing for Sustainable Healthcare

Innovation is a key word of these times and plays a role both in the field of private companies and in the public sector, including welfare and healthcare organizations. Manifold pressures for changing care delivery systems can be identified as common trends affecting healthcare systems worldwide, as summarised in Chapter 1. Many of these pressures are of course interrelated, meaning that they produce a combined effect that altogether challenges the healthcare systems. Nonetheless, for reasons of clarity, the pressures for change can be classified into the following clusters:

1. *Economic and financial pressures*. The crisis of the welfare states is producing a vast array of measures aimed at controlling total spending and at constraining both demand and supply. The mandate to “do more with less” specifically goes in this direction and asks healthcare systems to create new balances between private and public expenditure, as well as among hospitals’ budgets and other care budgets (e.g., related to primary care, homecare).
2. *The socio-demographic pressures*. Recent progress in medicine and the discovery of new therapies, drugs, and diagnostic tools are capable of overcoming the effects of some diseases, increasing the population’s average age. This means that health systems deal with an increasingly aging population affected by multiple comorbid and often chronic diseases. Other factors that modify the

disease pattern are the changing migration movements, different patterns in diets, and the rise in hospital acquired infections (for more details, see McKee, Healy, Edwards, and Harrison, 2002). Beside these demographic changes, the last decades have also been characterized by the changing role of the patients' in care delivery (McKee and Healy, 2002; Lega, Mauri, Prenestini, 2010). The growth of patients' literacy and awareness of their rights are leading to new and legitimate public expectations for more patient centred services. Access to clinical information via the internet means that many patients ask for a more participative management of care and for shared decision-making about their clinical choices (Broom, 2005; McMullan, 2006). The increasing demand for homecare, the need of internationalization of the health systems, patients' claims for a more engaging and equal access to healthcare are other examples of the changing behaviours of patients.

3. *Technological pressures*. The developments in health technology and in clinical knowledge have increased the range of available interventions and the need for renewed relationships between tertiary and secondary care facilities. The technological development entails two main innovations: the diagnostic-therapeutic innovations and Information and Communication technologies (ICT). Both types of technological innovation modify hospitals and other care providers' boundaries and range of action. The progress in the first type of innovation entails the pooling of costly and highly specialized technologies in well-developed acute hospitals while the progressive routinisation of simple and non-invasive surgical operations means that they can be performed away from the hospitals in ambulatory services or community care centres. The second type of technological innovation (ICT) leads to a progressive virtualization of the hospitals throughout the development of telemedicine and the improved imaging technology, which offers the possibility of distance delivery of medical reports (Edwards et al., 2004). Virtual care expands the possibility of hospital services beyond the hospitals' physical boundaries and calls for a reconfiguration of the entire network of healthcare providers.
4. *Environmental pressures*. Healthcare organizations are increasingly asked to reduce the emissions and the environmental effects of their activities and products; they are pushed to develop and manage supply-chains that do no ecological harm; they are asked to be increasingly aware of how their negative environmental effects influence citizens and patients' health.

As discussed in Chapter 1, these pressures appear to substantially reshape and modify the healthcare scenario, affecting both the demands for healthcare services and the traditional ways of organizing the care delivery. These trends seem destined to continue, at least in wealthy countries, and they encourage healthcare systems to sustainably redesign themselves in order to simultaneously address the economic, environmental, and societal concerns. The sustainability issue in healthcare is in effect gaining worldwide attention, and it has become a hot button for policy makers, managers, and professionals, "The greatest challenge to the sustainability of healthcare is therefore to find new organizational approaches that deliver the value that society needs and is able and willing and able to pay for" (Mohrman et al., 2014: 15).

Although sustainability may appear as an "umbrella" term, sometimes abused, we here refer to this concept as the capacity of a healthcare system to improve health and increase societal and ecological values through viable economic models capable both growing over time and in saving resources for future generations (Mohrman & Shani, 2012). According to the picture described above, the new demands for healthcare should therefore be addressed in ways that do not accelerate the consumption of economic and environmental resources. The costs of clinical and technological developments should be monitored and contained, and the demand for high quality and patient centred services should be balanced with the increasing limitations of public and private resources (Mohrman & Shani, 2012; Pencheon, 2013).

3 Addressing the Sustainability Challenges: A Changing Hospital in the Overall Network of Care Providers

Healthcare systems are trying to respond to the new challenges through a number of initiatives (Mohrman et al., 2010). Some of these initiatives aim to integrate healthcare pathways and processes, starting from the hypothesis that unintegrated care is a major obstacle to services' quality and overall sustainability. For example, several works have been devoted to building better connections among various agencies, organizations, departments, and facilities that are involved in care, and to rationalizing this configuration in order to avoid costly redundancy and diffusion of expertise (Lifvergren, Docherty, & Shani, 2011). Moreover, recent studies have described the efforts made by several organizations to systematically improve clinical and administrative processes to achieve better integrated, technologically advanced, and accountable care pathways that address the life cycle of disease and/or the coordination of the steps of acute treatments (Gooch et al., 2009; Weisz, Mohrman, & McCracken, 2012). Another cluster of initiatives is devoted to redesigning primary care, for example, by creating "medical homes" or designing experiments utilizing a community-based approach to the delivery of care; developing new initiatives for healthcare prevention and promotion to increase the overall health status and thus reduce the global demand on the system (Gorli et al., 2013). The third group of initiatives is devoted to educating patients and their families by providing them with information on how to take responsibility for their health and how to use health services more effectively (Eriksson et al., 2010).

While the pressures for change described above challenge the entire network of healthcare providers, some authors agree that in the scenario described above, the hospital is the organizational actor exposed to the wider changes and transformations (McKee and Healy, 2002). Indeed, hospitals are pushed towards transformation processes that influence their prerogatives, mission, jurisdictions, internal processes, and role in the wider network of healthcare providers (Carbone et al., 2006). This is not to say that hospitals' role is somehow decreasing or becoming less important. On the contrary, hospitals remain the cornerstone of all healthcare systems because 1) they absorb a large portion of the health expenditure (up to 70%), 2) they constitute the main employer for doctors and nurses, 3) along with a clinical role, they play a fundamental role in educational and research activities, and 4) they are imbued with symbolic meanings in that they offer a tangible sign of the presence of the healthcare systems in a territory (McKee and Healy, 2002; Lega, 2005; Lega, Mauri, Prenestini, 2010).

The increasing expectations on the demand-side, along with the evidence of the unsustainability of the current organization of health care, call for a reconfiguration of the hospital to put the patients at the centre. From an organizational point of view, this means that the hospitals' infrastructure and structure need to be redesigned with an aim of putting the patient at the centre of the health delivery processes rather than focusing only on health professionals' needs and development. For these reasons, in most industrialized countries, health policies are calling for a revision of hospitals' position and boundaries in wider healthcare system (3.1) as well as hospitals' internal organizational structure and care delivery (3.2).

4 Beyond the "Cathedral in the Desert": The *Embedded* Hospital

The traditional autonomy of the hospital has been hindering the establishment of a network vision for several decades, whereby the hospital becomes integrated with territorial services or other hospitals. This network vision is nowadays more crucial than ever. In fact, due to the sustainability issues highlighted above and to the pressure to provide high quality healthcare services, hospitals are increasingly concentrating on acute care, shifting rehabilitation needs, chronic disease management, and long-term care outside the hospital in territorial services or community centres. These changes are made possible through the above-mentioned technological innovations (e.g., the ones that allow a distance-management of chronic patients) and the increasing complexity and responsiveness of the healthcare service network comprising of different care providers. The network vision entails both a vertical integration between hospitals and territorial services (e.g., the joint management of patients' transfer through the establishment of new professional roles, such as the discharge manager, the sharing of electronic patients' records between hospitals and territorial services, and the sharing of care procedures and protocols) and a horizontal integration across different hospital structures. In this scenario, the main four structures that compose the healthcare systems are the following:

1. Structures for primary care are multi-specialty and multifunctional centres. In addition to daily services, these structures should offer 24/7 assistance for first aid in all the cases of low or moderate urgency, thus freeing the hospitals from this duty.
2. Diagnostic centres and ambulatory care, separated from the hospital or functioning through separate patients' flows, are in charge of all the diagnostic procedures. Thus, the diagnostic procedures delivered by the hospital can be limited only to internal patients.
3. Intermediate assistance centres include country or rural hospitals and long-term care or rehabilitation settings. Ideally, these structures are well connected and integrated with the main hospital that discharges patients in the post-acute phase.
4. Hospitals address the urgent emergencies and the acute cases, and they are well connected with other structures to regulate both admissions and discharges.

To sum up, the "embedded hospital" is a highly technological structure that delivers secondary care to acute patients, which is vertically integrated with primary and post-acute services and horizontally connected with similar hospital structures.

5 Beyond the Professional-centered Hospital: The *Patient Centered Model*

Such a new definition of the hospital role, boundaries, and position in the care providers' network, together with the pressures toward more effective and patient centered hospitals, entails also a redesign of hospital internal functioning, organizational structure, and processes. It is increasingly acknowledged that the traditional functional structure of the hospital (namely one where individuals with a similar area of expertise are grouped into independently controlled departments, thus defining patients' location according to their prevalent pathology) shows severe shortcomings, consisting mainly of economic losses and organizational inefficiencies (Braithwaite, 1993; Vera and Kunz, 2007; Vos et al., 2011). In fact, individual clinicians often lack the capabilities to control the workflow across departmental boundaries and thus the coordination of care activities within a patient care trajectory. Resources tend to be duplicated, causing inefficiencies and autonomy in using the specialty's resources that often prevail over accountability, in some cases even reducing the effectiveness of treatments (Lega and DePietro, 2005; Villa et al., 2009; Vos et al., 2011).

As Lega and DePietro (2005) noted in their extensive literature review, to address the above-mentioned challenges, hospitals overall appear to be converging towards a patient centered model (henceforth PCM). The central idea of patient centered restructuring is that organising a hospital around care processes increases patient centred care, reduces cost, and improves quality (Vera and Kunz, 2007). Although it is self-evident that care should address the need of patients, in reality, many hospitals are run with more consideration for the convenience of staff. Thus, in the traditional functional model, patients are admitted under individual specialist clinicians who keep them or transfer them to the care of another clinician. Conceptually, the functional model mirrors a professional centered culture, whereby patients are organized and located accordingly to the medical specialties rather than to an assessment of their overall care needs, which might be different in patients' affected by the same pathology. As a solution to this problem, the core principle of the PCM includes the delivery of the adequate amount of cure and care to patients in the most suitable setting according to their health conditions.

To innovate healthcare through the PCM, hospitals usually go through a process of re-engineering, which encompasses several restructuring actions, both in the organizational structure and in the building. The entire hospital system is affected. As summarized in Table 1, such major change concerns first the redesign of the organizational model, which shifts from a functional model to a process-oriented model (1). By structuring differently the care delivery model, many other aspects change accordingly, for example, (2) the concept of an organizational unit able to respond to patients' care needs and consider the relationship among specialities. The criteria for patients' allocation into hospital units no longer overlap with the medical specialties. Patients are grouped in multi-specialty units (that substitute the traditional specialty-based units) differentiated by the level of patients' clinical and nursing care needs (high, medium, or low intensity of care need) instead of their specific pathologies This way, it is possible to achieve greater homogeneity of patient service requirements (McKee and Healy, 2002) and to avoid the delivery of "average level" care to all patients that share the same pathology. The model of care (3) also changes. As the PCM requires integrated care, multi-professional and multi-specialty teams are strengthened and practitioners experience a great pressure toward competencies of integration and collaboration. An example of this new integrated effort is represented by the specific reconfiguration of nurses' position, which sees the passage from the traditional "functional nursing" (where each nurse was specialized in a single care activity) to the new "modular nursing" (that requires every nurse to be responsible for the overall care practices required by small groups of patients inside the ward). Hospitals have to rethink a different use of resources (4): resources such as beds, operating rooms, and equipment are aggregated and shared by all functional specialties and are regulated by a centralized logistical model. Patients are no longer transferred across different units or departments; instead, physicians and technologies move to the patient's bed. This affects the management of the overall service reorganization,

Table 1: Converging patterns of the more recent hospital innovations

	Functional model	Patient centered model
1. Organizational model	Functional /divisional model	Process oriented model / Matrix model
2. The basic organizational unit	Specialty-based units. Practitioners (doctors and nurses) are grouped into semi-autonomous units depending on their specialty of belonging	Multi-specialty units. Units are aggregated in accordance with patients' clinical and nursing needs. Doctors might treat patients located in different units and nurses assist patients with different pathologies.
3. Patients' flow	Mixed (emergency and elective)	Separation of the emergency flow from the elective flow (with dedicated beds and other resources for each).
4. The model of care delivery	Functional model (nurses' task-oriented job: each nurse is specialized in a single care activity)	Pressure toward inter-specialties and inter-professional integration. Modular care (nurses are responsible for the overall care practices required by small groups of patients)
5. Use of resources	Separated resources (beds, operating rooms, equipment, nursing staff, other staff) devoted to the single specialities	Resources pooling: resources are shared by all functional specialties
5. Managerial roles	Head Physicians in charge of their Departments	Bed manager / case manager (as distinct by the clinical activity) for centralized operation management
6. Physical environment	Hospitals are built around fixed and focused spaces, often with isolated wings	Newly built hospitals are designed to maximize resource pooling and patients grouping, flexibility, and modularity of spaces

calling for new managerial roles (5). New professional roles are responsible for the appropriateness, timeliness, flow, and integration of patients' care delivery process (e.g., the bed manager or case manager in charge of establishing patient placements in different inpatient settings or the supply coordinator in charge of managing the logistics flows of goods to different wards). Further and above all, the described changes might require a redesign of the physical environment (6), where newly built hospitals facilitate the aforementioned changes while more traditional hospitals often need to be partially or completely restructured. In such a redesign, the hospital is structured around a few different care areas based on the patients' clinical severity and on the complexity of the assistance required (McKee and Healy, 2002).

While considering these key-aspects, it is important to note that the PCM has been defined as an "organizational philosophy" rather than a fixed model: the local interpretations vary depending on the strategic boards' choices and on hospitals' dimensions, workforce, patient base, structure, and layout. Such diversity also suggests that in practice, re-engineering becomes entangled with a multiplicity of factors, such as the competing voices of policy makers, hospital boards of directors, clinical managers, and frontline clinicians.

6 From *Embedded* and *Patient Centered* to “Engaging” Hospitals: Missing Steps

The above-described innovation of hospitals highlights the need to re-organize services and networks to address the needs and expectations of the patients. Since the publication of the Institute of Medicine report, Crossing the Quality Chasm: A New Health System for the 21st Century, patient centered care is considered a crucial dimension of healthcare delivery and practices. Patient centered care (see also Chapter 3) is nowadays a well-established trend in healthcare, which calls for a re-humanization of medicine through a serious attempt to explore patients’ preferences, needs, and values, ensuring that these latter elements guide all clinical decisions.

The new hospital welcomes the challenges of patient centered care in some innovative ways. First, the criteria for patient placement and resource allocation increasingly consider the patient as a whole person rather than a “sick organ”, which is acknowledged as one of the keystones of the patient centered paradigm (Berwick, 2009; Mead & Bower, 2000; Stewart et al., 2000). Moreover, the patient centered hospital is based on the principle that personnel and technologies, rather than the patients, are the ones that should move inside the hospital. While this shift could appear trivial, it must be considered that the functional hospital model – developed around the growth of medical specialties – has characterized the history of the modern hospital in several countries and contributed to the establishment of a doctor-centered formal and informal organization, often very resistant to change. For this reason, the shift toward an organizational model that “flips” the focus of attention from the needs of professionals to the overall care needs of the patients can be regarded as a rather disruptive cultural change. A second fundamental innovation entails the focus on the care process rather than on the single treatments, which calls for an increased movement tiward vertical and horizontal integration among providers and for the enhanced inter-professional and inter-disciplinary collaboration among health practitioners. In fact, patients should not be burdened with the responsibility of linking and integrating different providers and should not experience inconsistencies of opinions and decisions. Rather, the organization must be in charge of integrating and coordinating the different care actors, thus also safeguarding the quality of the care process.

Third, once the new hospital starts working properly, the model should ensure shorter time of hospitalization, better integration, and shorter waiting lists for operations and other care services.

All these elements are consistent and well respondent to the broad indications of the patient centered philosophy. Nonetheless, for the purpose of this book, we suggest it would be interesting to focus more closely on how the concept of patient engagement may support a true innovation of hospital care organization.

As discussed in the first section of this book, the concept of patient engagement has emerged in the broader framework of patient centeredness, although it raises specific issues that focus on the degree of patient participation in their healthcare experience. The concept of patient engagement qualifies the type of relationship that the patients establish with their healthcare system of reference (the provision of medical services) at different levels (Carman et al., 2013; Graffigna et al. 2014). The notion of engagement refers both to patient activation (namely patient's knowledge, skills, ability, and willingness to manage his or her own health and care, e.g., by adopting measures of preventive care, following a balanced diet, or exercising regularly) and to a broader set of interventions designed to increase patients' participation in designing and managing the healthcare delivery systems themselves. Patient engagement is regarded as one of the main strategies to improve health outcomes and healthcare services. Moreover, according to some recent research (Carman et al., 2013), patient engagement might also contribute to lower cost and expenses, one of the main concerns of the sustainability issue described in section one.

Patient engagement is still a challenge for the new hospitals, as this redesign does not guarantee engagement for several reasons.

First, the patient centered model and its related restructuring actions do not explicitly address patients' role and activation in the design or improvement of the care delivery process. While the patient centered hospital is created to better address patients' expected needs, taking into account both their clinical treatment and their overall health conditions, it appears that patients themselves do not have a say in managing their hospitalization experience. This could be partly explained by the fact that the average hospital patient is acute, requiring intensive or very specialized treatments, which substantially limits activation and participation. Second, while overcoming a strict focus on patients' pathology, the new hospital does not explicitly consider patients' social belonging, cultural differences, and potential divergent expectations in the care delivery process. Patients' pathways and hospital personnel are organized according to the severity of the conditions of different groups of patients (basing on their clinical and care needs); thus, shifting the focus from a provider centered to a patient centered view. Nonetheless, such a patient centred view mirrors an image of the patient as a rather "standardized" subject, and it might fail to account for the complexities introduced by the specific familial, social, and cultural contexts of the patients. Patients and families' carry specific expectations and worldviews, which must be considered and included in the dialogue with the healthcare providers and organizations to achieve patient engagement.

Several authors have emphasized that patient engagement requires an actual cultural shift, namely "some radical, unfamiliar, and disruptive shifts in control and power, out of the hands of those who give care and into the hands of those who receive it” (Berwick, 2009:557; Barello et al 2014; Graffigna et al. 2014). To achieve this, the hospital, regardless of whether it is organized according to a patient centered model, should look for innovative ways to engage the patient in the management of his care plan and in the improvement of the overall healthcare delivery processes. Hospitals might need to design and implement specific organizational devices to engage patients and families at least as privileged informants of the perceived quality of care and of the overall care services and, whenever possible, as active co-producers of their care services. As said above, this means transforming hospital as one hub of a complex network of other, increasingly crucial, care providers, and, as suggested in Chapter 2, the PHE model presented in this book might provide a framework to achieve these goals.

The recent international literature offers some examples of practices addressing the complex challenges posed by the need to engage patients. From the analysis of these practices, hospitals might strengthen their capacity to engage patients and families in several ways and at many different levels. First, they may increase patients and families’ participation in the direct care. Second, hospitals could systematically gather patients’ feedback and suggestions for improving the organization of the care delivery. Finally, they could employ patients and families in strategic positions in the healthcare system.

1. Patients and families’ participation in direct care.

   This form of engagement refers mainly to patients’ active role in decision-making practices (Barry and Edgman-Levitan, 2012; Charles et al., 1997; Coulter, 1997) and to other initiatives, which allow patients and providers to co-manage the decision involving their treatment and care delivery process. In participated decision-making, patients and clinicians take joint decisions based on the medical evidence, clinical judgment, and patients’ characteristics. In these decision-making processes, both parties – doctors and patients – share information, i.e., the clinician suggests different options and describes their risks and benefits and the patient expresses their preferences based on personal lifestyles and values (Barry and Edgman-Levitan, 2012). There are various ways through which participated decision-making can be achieved in the hospital (please see Chapter 9 of this book for a discussion of this point). One example is the implementation of formal programs where decision aids (leaflets, books, videos, websites, and other interactive media) are used to give patients information on the risks and benefits of various treatment options and to help them make a choice consistent with their expectations.

   One practical example is the development of the Pre-Visit Preparation Packets[1] for annual visits for the elderly and children, which contain information to prepare

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[1] Developed and tested in the John D. Stoeckle Center for Primary Care Innovation at Massachusetts General Hospital (Johnson et al, 2008).

patients and families to be active partners during the visit, namely by helping them formulate their questions to clearly convey their needs and expectations to utilize the time during the visit effectively. Another example of improving participated decision-making concerns the development and provision of balanced, expert-patient reviewed decision materials that the patients could use to assist them with their decision-making. Moreover, in some cases, hospitals directly assist patients in reaching out to disease-specific associations. Such organizations are particularly crucial for patient engagement because they can strengthen patients and families' health knowledge of their specific conditions, provide information about patients and family rights, develop guidelines for practice, and offer pragmatic as well as emotional support (Johnson et al., 2008). Similarly, hospitals can sustain the development of peer support programs. In these cases, patients, especially when suffering from chronic diseases, are encouraged to join both online and in person communities aimed at empowering their members through information exchange, orientation, and mutual support. A final example of enhancing patients and their families' engagement is their direct activation and involvement at points of care, for instance by facilitating families' access or by sustaining their inclusion in the hand-off process (Luxford et al. 2011). These procedures help patients and families become "partners in care" (Luxford et al., 2011), making their voices heard in real time along their care journey.

2. Systematic collection of patients and families' feedback and suggestions.
   Monitoring and measuring hospitals' performance from the point of view of patients is another strategic asset that contributes to the engagement of patients and their families. It allows patients and caregivers to be active co-evaluators and co-designers of their own healthcare system of reference. Some studies (Greene et al., 2012; Johnson et al., 2008; Luxford et al., 2011) have shown that hospitals, which utilize the best practices in the field of patient centeredness, conduct regular surveys on patients' care experience, the results of which are used to identify opportunities for improving the organizational structures and work systems as well as individual professional performances. Thus, patients and families' feedback directly improve care processes and structures, making them safer and/or more supportive of patients' overall wellbeing. Some hospitals, moreover, have developed new Offices[2] or organizational roles that are specifically aimed to provide patients and families with services and tools to become active partners in their care. For example, in order to map not only the safety and quality of the clinical flows, but also patients' emotional needs and expectations, specific investigations need to address the stress and anxiety associated with illness and determine the effect of the outcome of such distress on the engagement process.

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[2] I.e. the Office of Patient Experience in Cleveland Clinic, Ohio (Johnson et al, 2008).

In other cases, the monitoring of patients’ experience is used for identifying care gaps, patient and caregiver needs, or unmet opportunities, which could help rethink and improve clinicians’ skills. For these purposes, new unconventional methods have also been recently documented, such as the use of video-recorded material (Neuwirth, 2012). Videos portraying patients and caregivers in their daily activities are used to reveal to clinicians, in a concrete and striking way, their own assumptions about their practices and to shed light on the mismatches between practitioners and patients’ expectations.

Finally, surveying patients’ preferences can help shape broader responses on a societal scale. An example is the implementation of public campaigns aimed at exploring patients’ attitudes and choices about sensitive topics, such as, the end-of-life. Such initiatives, on the one hand, encourage patients to clearly communicate their wishes and, on the other hand, guide providers in organizing care services consistent with patients’ choice[3]. All these procedures allow hospitals to become better learning organizations (Luxford et al., 2011), willing and able to redesign both their care practices and their overall organizational functioning and layout to increase their capacity for engaging patients.

3. Employing patient and families in meaningful positions.
   Another level of engagement consists of creating meaningful part-time or full-time paid positions for patients and family leaders to facilitate their systematic participation in strategic decision-making and to promote hospitals’ connection with the local communities. Some examples of these initiatives include the creation of stable patients or community advisory committees, which are integral to healthcare organizations’ work by offering support in several ways. The different forms of support include 1) the evaluation and implementation of patient centred structures and clinical facilities (as illustrated above); 2) providing linguistic and multicultural training to hospitals’ workforce; and 3) connecting with the local communities through informative campaigns, basic health education, health screenings, local caregivers’ training, and/or services’ orientation (Johnson et al., 2008). Patients and families’ engagement is a crucial factor in enhancing hospitals’ capability to connect and build partnerships with other organizations (i.e., patients’ associations) and with the broader local community. Thanks to the bridging function of patients and families, hospitals have the chance to contribute to the creation of more integrated services, i.e., by joining in community-based healthcare initiatives or by providing resources to provide health education to households.

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[3] For example, the “Conversation Project”, initiated by the journalist Ellen Goodman and colleagues, is a public campaign that encourages citizens to express how they would like to spend their last days and to discuss it with care providers and families. See Carman et al. (2012).

All of the above-described experiences recognize that patients and families can provide expertise, insights, first-hand knowledge, and social networks that are of immeasurable value for sustaining hospitals' improvement and engagement capabilities. Following Berwick's (2009) "confessions of an extremist", we suggest that new organizational models or new ways to organize the healthcare delivery process cannot be actually labelled "patient centered" if they are built without patient and family involvement at all stages of organization.

Such experiences and practices also show that a hospital that aims to engage patients and families should work and develop initiatives at different levels, including the healthcare delivery level (patients' participation in choices about their care plan), organizational and managerial level (patient involvement in the renovation of healthcare settings' processes, structure, and layout), and political and strategic level (involving dialogue between patients and experts, usually more involved in the design of care services). Such considerations reflect upon and suggest an "action plan" in the field of patient engagement, as discussed in the next session.

7 The Challenges of Partnership: Engaging Patients and Stakeholders to Improve Healthcare Organizations

The reasoning presented in the previous section allows us to reflect on the meaning of engaging patients and their families and on different ways in which a hospital can promote such engagement. Two elements are particularly crucial.

On the one hand, engaging patient means engagement at multiple levels, i.e., both individual care delivery and organizational/systemic, to plan the adequate healthcare provision and support strategic decision-making programs. These considerations allow the broadening of the concept of patient engagement beyond the exploration of patient-physician relationship and to involve patients as co-producers of the structural, procedural and political dimensions of healthcare organizations that might influence the quality of care, as suggested in Chapter 2 of this book (Bergson & Dean, 2006; Graffigna *et al*, 2014; Greene *et al*, 2012; Hernandez *et al*, 2013; Luxford et al., 2011; Shaller, 2007).

On the other side, engaging patient requires the reciprocal engagement of multiple stakeholders who inhabit the healthcare ecosystem in order to guarantee its effectiveness. These are managers, physicians, nurses, and the broad hospital workforce involved in the care and cure of the patients as well as other health providers, local communities, and associations that contribute to patient care via various care initiatives.

Engagement should therefore be a multiple-lane process activating every potential stakeholder for hospital and healthcare paths development, rather than simply a reciprocal two-lane process.

This multiple-lane investment allows for the construction of multi-stakeholder partnerships, that we believe are a key asset for guaranteeing an effective healthcare innovation that balances economic, environmental, and social sustainability.

In considering the many system actors, this engaging partnership certainly presents highly complex challenges. Literature advises that such partnerships are not a simple, linear, and straightforward process. Developing partnerships in effect requires each actor 1) to identify with whom they wish to engage/build a partnership (O'Higgins, 2010); 2) to negotiate the purpose and the nature of their relation according to each other's stakes and concerns (Selsky & Parker, 2010) and according to the perceived reciprocal autonomy and mutuality (Thompson et al., 2009).

This process may imply that each actor has to consider the different interests at stake; manage tensions and differences among the many views, needs, and powers in play; and adapt accordingly (Galuppo et al., in press; Selsky & Parker, 2010; O'Higgins, 2010). Multi-stakeholder partnerships therefore yield potential tensions among the different actors, and it its outcomes are not predetermined or always foreseeable (Gorli et al, 2013; Worley and Mirvis, 2013). Every (healthcare, in this case) organization therefore has to find its own situated and specific way to develop an engaging partnership.

In order to meet these challenges, hospitals are therefore asked to review their taken-for-granted ways of relating with patients and with the other actors in the overall ecosystem. At least two distinct and inter-related capabilities are in effect needed. First, there is a need for internally oriented capabilities, such as openness to bottom-up change and transformative learning, information seeking strategies, and governance processes capable of coping with multiple and competing demands (Smith and Lewis, 2010). Second, externally oriented capabilities are required, such as skills in joint problem solving, flexibility, adaptability, openness to influence, cooperation, and conflict management capacities.

We believe that these represent key assets for making the innovation of hospitals' towards patient engagement effective and sustainable. At the heart of sustainability, there is in fact the idea that meeting competing pressures for change requires building multiple stakeholders efforts and long-term alliances. Since complex challenges cannot be addressed through simple and individual responses, the action plan for innovating hospitals' sustainably therefore implies multi-perspective answers based on collaborative ventures. Patients and their families represent unavoidable stakeholders, and making their voices heard must be a priority in all the other actors' agendas.

8 Conclusions

This chapter provided an organizational view of the concept of engagement related to the current hospital innovation trends for coping with new societal demands.

The recent pressures for change call for a more patient centered hospital, a fascinating (and fashionable) label that is difficult to operationalize in practice. Patient centeredness does not easily connect to the concept of patient engagement, which requires a multi-level focus that engages different stakeholders in multiple-lane partnership processes. Patients and patients' families are critical stakeholders who can be involved, together with other actors, on various fronts, considering the care process as well as the design and the political strategies used in changing the hospital's strategies.

New partnership capabilities are necessary for the purpose of innovating and organizing sustainable healthcare. For hospital managers and policy makers, the new challenges therefore consist of the development of the capabilities, which can be directed both internally (within the hospital) and externally (towards the wider healthcare ecosystem). The more partnership strategies that are activated, the more a system (i.e., a hospital organization) is ready to welcome new changes internally. At the same time, the more a system is ready to innovate, the more it is capable of welcoming different strategies introduced by its partners; subsequently, it is more is capable of establishing partnership ventures.

Thus, considering the concept of engagement from an organizational perspective, with the hope that the organizations will be capable of investing across their boundaries and from both the inside and outside, patients and families will develop an increasingly active role in a virtuous circle of healthcare development.

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