

Patient Engagement: The Key to Redesign the Exchange Between the Demand and Supply for Healthcare in the Era of Active Ageing

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Abstract. The last decades' changes in the epidemiological trends of chronic disease - also due to the ageing population - and the increased length and quality of life among the majority of Western population have introduced important changes in the organization and management of the healthcare systems. Consequently, health systems throughout the world are searching for new and effective ways to make their services more responsive to new patients and the public's health needs and demands. The idea of patient engagement - borrowed from the marketing conceptualization of consumer engagement - moves from the assumption that making patients/clients co-producers of their health can enhance their satisfaction with the healthcare system as well as their responsibility in both care and prevention by improving clinical outcomes and reducing health delivery costs. To make people aware of their health services options by supporting them in the decision-making process and to engage them in enacting preventive and healthy behaviors is vital for achieving successful health outcomes and preventing waste of resources. In this chapter, we outline a model (PHE model) that explains the patients' subjective experience with their health management process and the levers that may enact the passage from one phase of the process to the other. Based on this conceptual model of patient engagement will be proposed a tool kit of priority actions that may sustain the patient in its process of engagement.

Keywords. Patient Engagement, Chronic Disease, Health Management, Active Ageing, Healthy Living, Patient Empowerment, Patient Activation

1. Tackling the Challenges of Ageing and Chronic Disease

Tremendous changes in medical science and technologies combined with significant shifts in lifestyle and demographics have resulted in a rapid increase in the number and proportion of individuals living longer [1]. Unfortunately, the increased age of the population often correlates with the occurrence of chronic conditions. According to the European Chronic Disease Alliance [2], over 100 million European citizens above the age of 15 are affected by a chronic condition. This figure rises progressively with age

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and, according to the World Health Organization (WHO), Europeans reaching retirement age are more likely than not to suffer from at least one chronic condition [3].

A high incidence of chronic diseases in older people is in contrast with people's growing demand for wellbeing and with the need to guarantee enhanced quality of life in all life stages. This rising tide of chronic illness – and the economic burden linked to the long-term management of chronic condition - also threatens the viability of European healthcare systems, which are ill equipped to cope financially, operationally, or strategically with this increasing numbers of long-term chronic patients [4]. The ongoing management of conditions over a period of years or decades thus calls for an urgent clinical, economic, and organizational reform.

In line with this need, in the long term, Europe's healthcare systems are required to reorient their focus from merely treating illness to promoting health according to a life-course approach. Furthermore healthcare delivery processes need to be revised in order to become more cost-effective and sustainable. In particular, the latter goal implies a shift in medical policies and practices in order to help healthcare organization lead an efficient dialogue with the "outside" of their institutional boundaries [5]. Precisely, the patients affected by a chronic disease cannot be hospitalized for a long time because of the costs of care management. To cope with the problem of the lack of resources, it becomes fundamental to create a virtuous connection between the healthcare organization and the patient's social context, facilitating the sharing of information and communication in the long, and sometimes complex, process of chronic disease management [6, 7]. In other words, the social context in which the patient is embedded plays an increasingly crucial role in the management of chronic illness, even if not yet fully exploited by healthcare organizations. With the expression "patient's social context," we indicate the "outside of healthcare organizations", which represents a context that is conceptually not only limited to the classic notion of territorial medicine, but also inclusive of the network of patient's families and peers. In this revision of the healthcare boundaries, it is important to consider the potential role of new technologies in enabling communication and at distance exchanges between the patient and the sources of care supply (just think of the information portals, social networks, applications of technology to educate and monitor the patient in the process of care, telemedicine) [8-11]. Developing connectivity via electronic or other information pathways that encourage timely and effective exchange flow between the inside and the outside of the healthcare organization may also allow us to capitalize on the resources and potentialities intrinsic to both the "expert system" (the healthcare services and provides) and the "lay system" (the patient-consumer, the social network, and community organizations) by favoring a productive exchange between the supply of health services (the "inside") and the demand ("the outside").

2. Giving (Back) a Role to Patients to Address the 21st Century's Challenges: The Relevance of Patient Engagement

The goal of achieving a better dialogue with the "outside" of health organizations requires new ways to approach patients in order to make them active participant in their health management and informed health consumers able to make appropriate choices and avoid economic waste. Nowadays, patients appear to be more willing to be informed about their disease and treatment [12]. Patients are also increasingly aware of their rights, and they are becoming more demanding in the fruition of healthcare

services. They are better aware of their own needs and preferences, they are more critical in expressing judgments about the quality of received health services, and they have clearer criteria guiding their decision in the disease management [13]. However, healthcare organizations do not always recognize and accept patient's active role. This is because today's healthcare systems are still far away from establishing a true partnership with their customers.

Thus, in the present era, giving (back) a role to patients and allowing them to become protagonists of their care have become a priority to promote the sustainability of healthcare. In this framework, the goal of engaging patients in their health management appears to be the key. Precisely, the concept of engagement may be conceived as a qualifier of the exchange between supply and demand of healthcare services. The English verb "to engage" is polysemous from the point of view of language. It refers to the ability to attract someone's attention, but also to emotionally binding a person to a contract that is long lasting and strongly affective, and finally to "take over" someone to "get him on board," that is, to make someone part of something [14]. Borrowed from the marketing literature, the concept of engagement refers to the relationship that a consumer can experience with a brand or product. In particular, the concept of "consumer engagement" describes and qualifies the complex exchange dynamic between brands/products and the preferred consumer in the domain of a fluid and changeable economic and social context (i.e., the "liquid modernity" described by Bauman, 2000) [15]. In the present era, consumers are more conscious of their preferences and rights. They are more willing to negotiate with companies the contents and the forms of services delivery. Thus, it is very difficult for companies to be successful in satisfying consumers and in maintaining their loyalty in the long term. In this framework, the concept of consumer engagement attempts to offer insights regarding the different components (organizational, relational and psychological) that play a role in the complex exchange between product supply and consumer demand and that can make it more successful [16, 17]. When applied to healthcare, the concept of engagement is conceived as an attempt to describe the complex process of exchange that occurs between the patient (with his/her peer and family support system) and the health system (healthcare organization, health professionals). The goal is to encourage greater empowerment of the patient in disease management within the context of a good partnership with the health system [18]. Indeed, an engaged patient becomes not only more compliant with medical prescriptions [19], but also more aware of his symptoms and diagnosis. He is able to activate the healthcare system properly at the first symptoms of the disease, to contact the physician only in case of emergency, and to use the services offered by the health care system in a more satisfactory way [20]. Moreover, an engaged patient is also a good ambassador of good care practice related to the efficient and effective management of the exchange between "demand" and "supply" of healthcare among the peers and his/her network [21].

3. Modelling Patient Engagement: A Starting Point to Innovate Healthcare

A more in depth patient engagement may be defined as a multidimensional psychosocial process resulting from the conjoint cognitive, emotional, and behavioral enactment of individuals towards their health condition and its management. According to the framework – *Patient Health Engagement* model (PHE) - developed by Graffigna and colleagues [12], patient engagement is a dynamic and evolutionary process that

involves the recovery of life projectuality - even with the disease. This process also features peculiar ways of interaction and decisional negotiation between the patient and the healthcare that depends strongly on the phase of the process through which the patients is passing. The patient engagement process features four experiential positions (blackout, arousal, adhesion, and eudaimonic project). This evolutionary 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 that the success of the patient in advancing along the process depends on how he/she succeeded in the 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 patient has succeeded in incorporating disease management into his/her life. In the following paragraphs, we will discuss the specific features of each phase of the engagement process (see Figure 1).

3.1. Blackout

The onset of the disease condition makes patients fall in a state of emotional, behavioral, and cognitive blackout, which is described as unexpected and out of their control. They feel like “in suspension,” as they are looking forward to obtain a ruling from someone.

Patients describe the disease onset as distressing and unacceptable because they have not yet acquired effective coping strategies to manage their new health condition, and they are not aware of what is happening to their body. This patient’s status determines the diagnosis, often minimizing the signs and symptoms (*emotional denial*); moreover, patients cannot easily elaborate the received information about the disease (*cognitive blindness*). In this phase, patients also feel blocked in acting (*behavioral freezing*) and managing their diagnosis, as they are generally uninformed about its nature and exacerbating causes. They are completely absorbed in their illness experience and often experience difficulty attending to the needs of their life due to a focus on the management of their disease and its treatment. In this phase, the patients’ quality of life strongly depends on the effectiveness in controlling/reducing the side effects connected to treatments and clinical stability. In this phase, the patient has a passive attitude towards the healthcare system and expects to be a «recipient» of care («end user»). In other words, patients have a top-down vision of the healthcare interventions.

Thus, to overcome the emotional confusion connected to the disrupting critical event, the patient needs to delegate to the doctor all decisions regarding the treatment and disease management. In this scope, a trusted relationship with the healthcare provider is crucial for overcoming the blackout phase. The physician is asked to scaffold patients and offer solidarity by making an empathic response and educating patients about their health. This informative action is expected from the referential doctor who becomes, since the moment of the diagnosis, the privileged spokesperson for the patient along the care process. If patients fail to build a solid relation with the healthcare provider, their emotional behavioral responses may become dysfunctional, often leading to patients’ dropout.

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. Patients are equipped with more information about their health condition compared to the previous phase, although their health literacy is still superficial and fragmented (*superficial knowledge*).

Moreover, they feel behaviorally unable to manage their disease and treatment prescriptions effectively (*behavioral disorganization*).

In line with this perspective, the patient’s quality of life depends mainly on patient’s finding an emotional balance as well as the intrusiveness of the disease in their daily life. In this phase, the patients perceive the physician as someone who help them manage events and emotions related to their illness experience with which they have difficulties coping. This allows the patients to begin to learn and test behavioral caring patterns to effectively cope with the disease. Unlike the previous phase, patients start to become aware of the treatments options available to them, and they have matured some first choice criteria for healthcare services decision making.

3.3. Adhesion

In more advanced stages of the medical course, patients finally acquire a broad spectrum of knowledge (*cognitive adhesion*) and behavioral skills (*formal adherence*) to effectively comply with medical prescriptions and feel sufficiently confident in their own emotional strength to cope with their illness and accept their condition (*acceptance*). However, patients are not quite autonomous in managing the rules necessary to be healthy (i.e., healthy life style and correct medication regimen).

These rules are challenged when the patients have to temporarily change their daily routine (i.e., when going to holiday, when travelling for work...). This happens when patients do not fully understand the reasons behind the medication regimen but merely adhere to it. Consequently, patients rely on continuous physician counseling to manage their condition. Accordingly, patients revealed the need to hang on the physicians’ authority and prescriptions, which they conceive as «lifeline», waiting for the time when they will be able and self-confident to self-manage.

The physician is perceived as an authoritative expert, and this allows patients to feel confident and not alone. It generally leads them to employ positive coping strategies and accept the guidance of an authoritative figure as a reliable point of reference. Rather than seeking knowledge to support self-care, participants still prefer to relinquish the responsibility for the disease management to the healthcare. However, in this phase, patients start to become aware of their power to influence their health care. In other words, patients start to perceive themselves as members of a collaborative team of care. This paves the ground for a virtuous mechanism by which the patient learns about how the health care system works. Patients, in turn, inform the health system. According to the specificities of this status, the patient’s quality of life depends mainly on the fulfillment of the patient’s healthcare needs and on the responsiveness of the healthcare provider. The patient’s wellness is closely associated with the experience of a healthcare system that is truly attuned to the care expectations of the patient.

3.4. Eudaimonic project

Finally, in the “eudaimonic project” position, patients have fully accepted their condition and their patients’ identity is only one of their possible selves (*elaboration*). They are also able to recognize internal resources that are useful for projecting satisfactory life trajectories for their future. Patients gradually become co-constructors of their health and capable of enacting a meaningful health management, which allows them to improve their quality of life. Patients are able to effectively search for appropriate information about their disease conditions and medications. This allows them to give full sense to their health experience (*sense making*) and effectively enact healthy behaviors, in due time, even when contexts change (*situated practices*). Patients have also developed a new perspective about their disease, which can now be thoughtful and integrated in a wider life project. The patients in this phase described their doctor as a “trusted ally” on whom they can rely and whom they asked for counselling in order to tailor their care according to their needs. According to this experiential position, patients are the managers of their own care, and they can mobilize healthcare services proactively when there is a need. Moreover, they can advocate for the health of their community (e.g., raising concerns to policymakers, helping others navigate the health care system, and advancing healthcare quality and equity). The patient in this phase becomes an experienced testimonial of good self-care practice

who is able to become a caregiver of others similar to him/her. Given the patients’ reconquered possibility to consider themselves as whole persons despite their disease condition, their quality of life depends strongly on their renewed ability to make realistic life decisions that are consistent with the influence of their disease on their life.

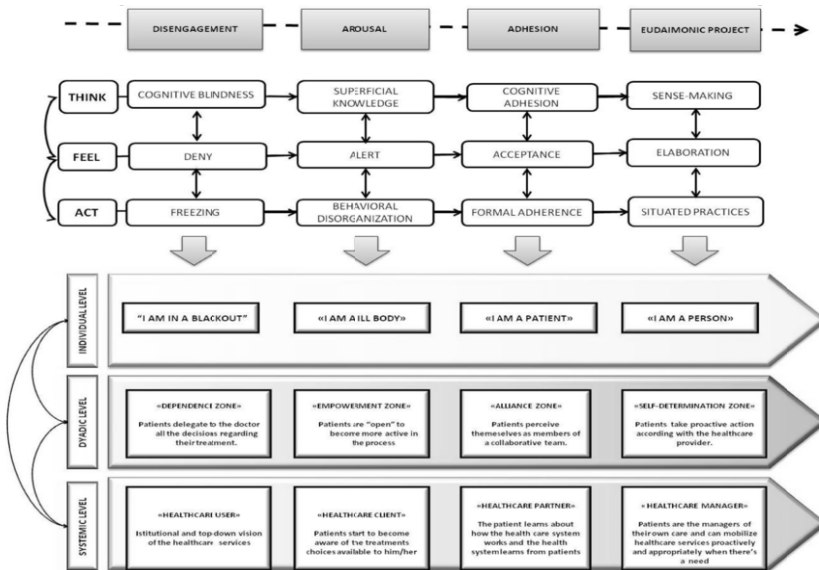


Figure 1. The process of patient engagement: a qualifier of the exchange between demand and supply.

4. Innovating the healthcare delivery in order to sustain patient engagement

As described above, the disease onset has a great influence on the patient psychological functioning. In order to move along the process of engagement; thus, to be able to better dialogue with the healthcare system and receive better satisfying services, the patient need to be sustained in a process of reframing and meaning-making that produces a better balance among the three experiential dimensions implied in his/her health management process (see Figure 2). These dimensions are *think (cognitive level), feel (emotional level), and act (behavioral level)*.

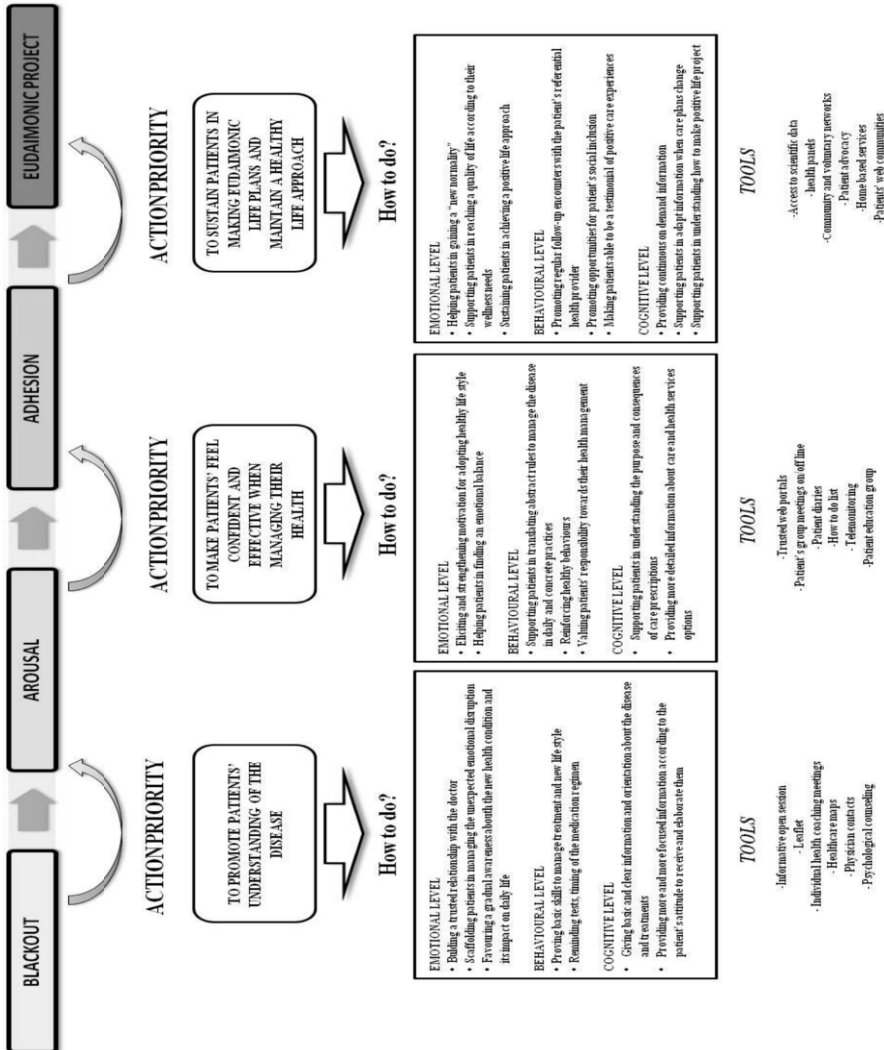


Figure 2. The positions of patient engagement and corresponding action priorities.

4.1. From the Blackout to the Arousal Position

As seen before, in the first instance, the patient has to accept and understand his new health condition, which disrupts and de-organizes the structure of knowledge and beliefs he has about him or herself. In particular, to pass from the position of blackout to the position of arousal (a first step forward in the process of becoming better engaged in health management), the individual has to accept that now he is also a patient, a person with a disease, through health literacy. To overcome the emotional confusion related to the loss of identity, the patient needs to promote the self-reframing by understanding the nature of his own body changes as well as the nature of his own psychological status. There is the need to improve the patient's understanding of his health and related conditions. To address this need, it is necessary to create a safe care environment by fostering the patient-health provider relationship, which may function as the catalyzer of the care process. Moreover, it is necessary to help caregivers understand the patients' reactions to their illness experience.

4.2. From the Arousal to the Adhesion Position

In this phase, patients are emotionally activated and experience loss of control over their body and emotional reactions. Consequently, they feel a reduced agency and power over their disease management and over their daily life. To favor the patients' advancement along the engagement process, the patients need to improve their self-confidence regarding their self-management. They also have to experience a better scaffolding relationship with the healthcare provider, and they have to feel empowered regarding their ability to comply with medical prescription and new lifestyle regimes. To achieve these goals and to become more motivated, patients need to be reinforced in their positive health behaviours. In particular, patients should learn to prioritize their goals, identify obstacles, and build a trustworthy relational care network.

4.3. From the Adhesion to the Eudaimonic Project Position

Patients going through the adhesion to the eudaimonic project position have to overcome the reduction in their life horizons produced psychologically by the critical event. In other words, at the beginning of their engagement path, in order to manage their disease, they have been confined to their patients' role and consequently, they have reduced their daily life spheres, thus often experiencing limitations in daily living due to disease implications. Moving through this state successfully entails patients gaining a positive approach to health management and recapturing an active role in the society by making wellness plans that consider the disease management a part of the patient's life. In other words, patients need to be sustained in re-achieving some form of life projects, even if confined in the next future.

Furthermore, the patients have to be able to incorporate their "new self" and their experience of the disease management into the broader domain of their daily life. In other words, patients need to be able to focus again on another more satisfactory and positive sphere of their private life in order to reframe the influence of the disease on their existence. They need to feel as protagonists of their life again. This delicate psychological process has to be legitimized by the healthcare system and sustained by the society that needs to reframe its vision of the patient not only as a disease carrier, but also as a person with different meaningful experiences that include the disease.

5. In conclusion: Roadmap for the Future of Healthcare Innovation

Nowadays, the increased complexity of healthcare demands due to the increase in chronic conditions and due to the reduction of economic resources call for a more virtuous exchange between the demand and supply of health services. The aim is not only to guarantee the achievement of good clinical outcomes and of improve clients' satisfaction, but also to increase sustainability of a healthcare organization in the process of care delivering. In this context, the patient/consumer of health services is to be considered not only as an active partner, but also as a potential resource for the healthcare system. The individual must be considered as a key player in the dialogic exchange between the inside (i.e., the health authority, the community of care providers) and the outside of care organizations (i.e., social context, the network of peers, the surroundings). In this framework, a marketing approach, conceptualized as a set of activities aimed at facilitating and achieving the exchange between demand and supply [39,40], presents a real heuristics and practical opportunity to orient healthcare innovation. In particular, the concept of patient engagement - borrowed from the marketing tradition applied to brand management [41] - seems to offer interesting opportunities for reflection and action in the era of active ageing.

To promote patient engagement in disease management indicates a more sustainable exchange between healthcare services and demand. However, despite the growing debate in both the academic and professional arena, there is still a lack of shared definition of patient engagement and guidelines to practice.

In this paper, we proposed to model the engagement experience based on the in-depth analysis of chronic patients' experience with the healthcare system in the management of their disease. This model may be the base for the innovation of healthcare delivery that is able to face current societal challenges and make healthcare organizations more sustainable at the economical, relational, and psychological level.

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