

Patient engagement in healthcare: pathways for effective medical decision making

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ABSTRACT

Making patients protagonists of decisions about their care is a primacy in the 21st century medical ethics. Precisely, to favor shared treatment decisions potentially enables patients' autonomy and self-determination, and protects patients' rights to make decisions about their own future care. To fully accomplish this goal, medicine should take into account the complexity of the healthcare decision making processes: patients may experience dilemmas when having to take decisions that not only concern their patient role/identity but also involve the psychosocial impact of treatments on their overall life quality. A deeper understanding of the patients' expected role in the decision making process across their illness journey may favor the optimal implementation of this practice into the day-to-day medical agenda. In this paper, authors discuss the value of assuming the Patient Health Engagement Model to sustain successful pathways for effective medical decision making throughout the patient's illness course. This model and its relational implication for the clinical encounter might be the base for an innovative "patient-doctor relational agenda" able to sustain an "engagement-sensitive" medical decision making.

Keywords: Patient engagement; Patient Health Engagement Model; Decision making; Chronic care; Decision support; Patient-doctor relationship; Shared decision making

1. WHY QUESTIONING ABOUT MEDICAL DECISION MAKING MATTERS?

In recent years patients, physicians, ethicists, researchers and policy makers advocated for a higher collaboration between doctors and patients (Oshima Lee & Emanuel, 2013) in making medical decisions. The reasons for this challenge include the rise of healthcare consumerism and the notion of the patient/consumer sovereignty in healthcare decision making (Huckman & Kelley, 2013; Sarasohn-Kahn, 2013; Rodriguez-Ororio & Dominguez-Cherit, 2008). Engaging consumers in making decisions about their care is today recognized more and more crucial to enhance clinical outcomes and improve patients' satisfaction towards care (Kravitz & Melnikow, 2001; Levinson, Kao, Kuby & Thisted, 2005; Dixon-Fyle & Kowallik, 2009; Orszag & Emanuel, 2010; Coulter, Safran & Wasson, 2012; Oshima Lee & Emanuel, 2013; Graffigna, Barello, Wiederhold, Bosio & Riva, 2013; Barello, Graffigna, Vegni & Bosio, 2014). Currently there is increasing attention to listening to the consumers' voice in care decision making as it appears crucial since each patient has a unique perspective on his/her own life and an own responsibility/right to live it at best (Barello, Graffigna & Vegni, 2012; Sarasohn-Kahn, 2013; Graffigna, Barello, Libreri & Bosio, 2014). However, scholars are still actively debating on issues concerning medical decision making as far as this is still an unresolved healthcare dilemma due to the fact that there is no clarity regarding when and how patients actually want to be involved in making decisions about their treatments and what influences their preference for involvement.

2. HEALTHCARE DECISION MAKING AND MANAGEMENT: AN OVERVIEW ON DECISIONAL STYLES

Currently we assist to a fragmented and often confounding scenario about medical decision making, and no shared guidelines for clinical practice still exist and doctors often feel unprepared in choosing the best decisional style for their patients (Veatch, 1972; Thomasma, 1983; Emanuel & Emanuel, 1992; Levine, Jordan & Huttenlocher, 1992; Roter & Hall, 1992; Mooney & Ryan, 1993; Deber, 1994). Literature discusses several models in healthcare decision making. Among them the more prominent are paternalistic decision making, informed decision making and shared decision making (Elwyn, Laitner, Coulter, Walker, Watson & Thomson, 2010). *Paternalistic decision making* (Emanuel & Emanuel, 1992; Charles, Gafni & Whelan, 1999; Charles, Whelan, Gafni, Willan & Farrell, 2003; Coulter & Col-

lins, 2011; Kasper, Légaré, Scheibler & Geiger, 2012) refers to the decisional model in which the doctor makes decisions on behalf of the passive patient based on clinical expertise and without considering the patient's preferences towards the treatment options. The role of physician depicted in this model is guardian/tutor of the patient's best interest. The patient's role is instead limited to providing consent to the treatment advocated by the physician (Emanuel & Emanuel, 1992). *Informed decision making* (Scholl et al., 2011), features a doctor that fully informs the patient, detailing all treatment options and their implications for the patient quality of life, transferring technical knowledge so that the patient can make a decision alone, based on his or her own preferences (active engagement). This model involves a more collaborative partnership between doctor and patient that is based on a bilateral interaction in which they weigh the choices in light of an individual patient's wishes, expectations, and personal circumstances. Information transfer is seen as the key responsibility and only legitimate contribution of the doctor to the decision making process. Finally, *shared decision making* (Rodriguez-Osorio & Dominguez-Cherit, 2008; Moulton & King, 2010; Scholl et al., 2011) is characterized by doctor and patient exchange information, both detailing their care preferences, deliberating and then deciding the treatment together according to the best shared building decision for both of them. Unless shared decision making is depicted as a gold standard in medical practice, there are no evidence-based criteria that confirm the adequacy of this way of making decision for every kind of patient. It is widely recognized that factors such as demographic variables (Belcher, Fried, Agostini & Tinetti, 2006), the subjective experience of illness and medical care (Strull, Lo & Charles, 1984), the kind of diagnosis and health condition (Den Brink-Muinen, Van Dulmen, De Haes, Visser & Schellevis, 2006), the type of decision they need to make (Redelmeier & Shafir, 1995), the amount of knowledge and information they have acquired about their disease, their attitude towards being engaged (Levinson et al., 2005), and the interactions and relationships they experience with health professionals may determine the preferred decision making style and affect the patient's availability to be active agents in their care decisions (Arora & McHorney, 2000; Walter & Covinsky, 2001; Von Wagner, Steptoe, Wolf & Wardle, 2009; Légaré, Ratté, Gravel & Graham, 2008; Tripathi, Delano, Lund & Rudolph, 2009).

Due to this complex framework currently featuring the scientific debate, the patients' desired role and engagement expectations in the medical decision making is still controversial and the literature doesn't offer choice criteria and action recommendation for health professionals' practice (Coulter, 1997; Tinetti & Basch, 2013; Zuger, 2013; Entwistle, Brown, Morgan &

Skea, 2014). Thus, up to now, medical decision making does not represent singular model or clearly defined healthcare practices.

On these bases, we suggest that only taking into account the subjective experience of patients when facing with medical decisions concerning their healthcare might offer some clarity about this topic. Only in this way we can deeply understand the factors that make the patient available for being actively engaged in decisional processes and autonomous health management. This might contribute to offer patient-directed and tailored guidelines for practice able to address their subjective care needs and achieve evidence-based patient choices.

3. THE PATIENT HEALTH ENGAGEMENT MODEL (PHE): INSIGHTS FOR HEALTHCARE DECISION MAKING

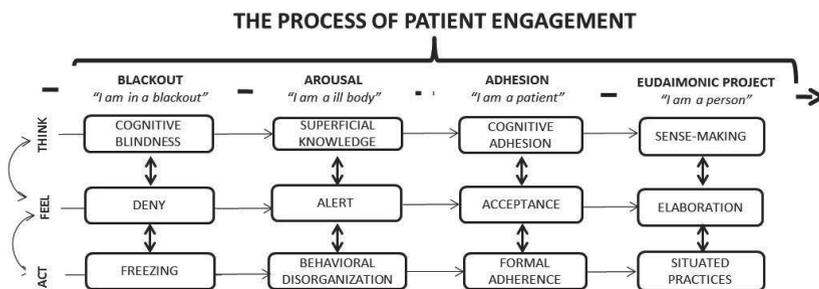
According to the *Patient Health Engagement Model* (PHE) by Graffigna and colleagues, patient engagement may be defined as a multidimensional psychosocial process resulting from the conjoint cognitive, emotional, and behavioral enactment of individuals towards their disease condition and its management (Graffigna et al., 2013b; Graffigna, Barello & Riva, 2013; Barello et al., 2014; Graffigna et al., 2014) (*Figure 1*).

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 depends on the phase of the process through which the patients is passing. 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.

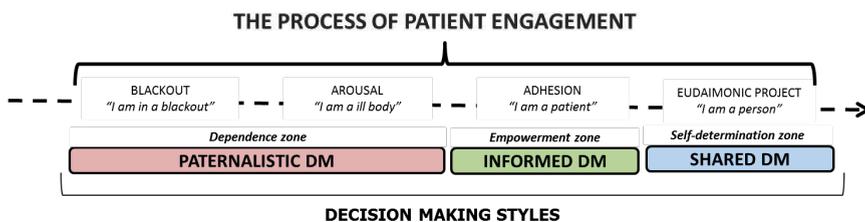
The PHE model allows to highlight specificities in the relational dynamics that feature the patient-doctor encounters along the care process. This process-like modeling of patient engagement potentially leads to reshape healthcare paradigms in research and intervention by posing the bases for a true and sustainable partnership between patients and doctors. In this perspective, while the process of patient engagement evolves, even the patient-doctor relationship assumes different shapes (i.e., from dependence to autonomy) thus implying a continuous realignment of roles and power dynamics (Rodriguez-Osorio & Dominguez-Cherit, 2008). The last position of the engagement process (i.e., *eudaimonic project*) culminates in the patient

capacity to gain a positive approach to health management and to adopt a more active role medical decision making. In this position he/she perceives him/herself as a person (not only as a patient) and is able to build a real partnership with the reference doctor.

In the following paragraphs, we will discuss the specific features of each phase of the engagement process concerning the doctor-patient relationship and its implications for medical decision making (see *Figure 2*).



*Figure 1. The Patient Health Engagement Model (PHE).
The process of patient engagement features four progressive phases resulting from the conjoint cognitive (think), emotional (feel) and conative (act) enactment of individuals in their health management*



*Figure 2. Decision making (DM) styles along the patient engagement process.
A patient results in a "fully engagement" condition when he/she perceives him/herself as a person and when the power dynamics in the patient-doctor relationship are devoted to build a real partnership by enacting shared decision making*

3.1. The “dependence zone”: paternalistic decision making

During the phases of “blackout” and “arousal”, patients are in a state of emotional, behavioral and cognitive numbness determined by the diagnosis (or by a critical event, like a relapse or the exacerbation of a symptom). Furthermore they feel behaviorally unequipped to effectively manage their new health condition. The doctor is conceived as a “vicarious” or “protective father” that should nurture them in working upon facts, impressions, and emotions that are difficult to cope with. For these reasons, the doctor is indeed considered the tutor of the patients’ health and the leader of the decisions regarding the care process. Due to this psychological status, patients completely rely on clinicians for health advices and medical treatments. Patients, thus, tend to delegate to the doctor all the decisions regarding treatment and disease management and they declare to prefer a physician which acts in a paternalistic way when there is the need to make a decision about treatment. This decision making style legitimates the patient in a passive, dependent role toward the physician. Finally, positive health outcomes are assumed to be under the clinician’s responsibility.

3.2. The “empowerment zone”: informed decision making

In the “adhesion” phase, patients have enough knowledge and behavioral skills to effectively adhere to medical prescriptions and feel sufficiently confident in their own emotional strength to cope with their health condition. For this reason patients are now able to understand and manage treatments according to the physician counseling and thanks to the increasing awareness about their health status. However, patients are not totally confident in self-care practices and autonomous decisions and still need to have continuous feedback about the adequacy of their self-care behaviors. Thus, the patient still strongly relies on the doctor’s judgment to make decisions about the disease management. On the other hand, at this stage of the process, they may feel empowered in self-managing thanks to the presence of an authoritative expert – the doctor – that allows them to be confident and not alone. The preferable decision making style is indeed the informed one, where the physician’s role is devoted to information exchange, communicating the needed technical or scientific knowledge to the patient in order to make him/her informed and progressively autonomous in self-care. This decision making style is suitable to in this phase as far as the patients declare the need for a health professional who may supply them when coping by themselves with the disease and the treatments is not possible. Informed decision making

aims at resolving the asymmetry between physician and patient by engaging the latter in a deliberative process. In other words, in this phase, the physician still holds responsibility for treatment decisions, through giving information and eliciting the patient's questions or doubts about the ways to manage the prescribed treatment regimen. Patients wish to be informed but not totally involved in making decisions: they have a high desire for information in order to gain the necessary knowledge to understand their disease and choices available to them, and to be involved in aspects of decision making that will affect their quality of life. However, they do not want to take on the provider's role; they are willing to leave much of the responsibility for tasks that require expertise to the provider. In this phase, patients require their providers to work with them to ensure that they have the needed information to make difficult and challenging decisions.

3.3. The "self-determination zone": shared decision making

After having finally accepted the disease, the patient becomes able to acquire a "new normality" to make again wellness plans – thus passing from the "adhesion" to the "heudaimonic project" phase, which may be considered a full health engagement status. The doctor is now required to support the patients in self-determining tailor-made and context-based disease management strategies and in finding personalized solutions to "situated" problems by enacting a shared decision making. The patients describe their doctor as a "trusted ally" to whom they ask on-demand counseling. The doctor succeeds in this role if he/she is able to provide to the patient a vision for the future and help the patient to reframe care prescriptions into different settings. According to the patient-doctor relational dynamics which occur during this phase, the preferable decision making style is the shared one, as patients can directly take proactive action according to the healthcare provider's suggestions. In this model of decision making the main feature is that there should be a two way exchange not only of information but also of the patients' treatment preferences and care expectations. This is possible because positive health outcomes are perceived by patients to be under their own responsibility and due to the high level of patients' awareness of their health condition that now can be thoughtful and integrated in a wider life project.

4. IN CONCLUSION: TOWARDS AN “ENGAGEMENT-SENSITIVE” MEDICAL DECISION MAKING

Despite its theoretical interest and the increasing academic debate around the topic of decision making in medical care, no shared guidelines to translate theoretical evidences into practice are now available to inform healthcare efficient and effective actions. Moreover, the increasing emphasis on shared decision making is not justified if we consider the patients’ perspective that clearly shows how individuals are not always available to be actively engaged in making care decision with their doctors. According to the more recent literature about clinical decision making models, indeed, patients might change their preferred decision making style over the natural history of their disease (Benbassat, Pilpel & Tidhar, 1998; Elwyn, Edwards, Gwyn & Grol, 1999; Kasper et al., 2012), basing on the fluctuating degrees of illness severity and on the treatments’ impact on their broader life (Elwyn, Frosch, Thomson, Joseph-Williams, Lloyd & Kinnerley, 2012).

In this paper authors have revisited the various approaches to medical decision making and have suggested that the PHE model can be used to better orient “engagement-sensitive decision making pathways” which may lead to more equitable and more favorable outcomes. According to this model, patients require different decision making styles basing on their experiential position along the engagement process. For this purpose, we suggest to opt for a manifold decision making style through which health professionals and patients (and their loved ones) work together – along the care process – and constantly check clinical issues and determine the best course of action according to the patient’s availability to be engaged in decisions and in the health management. Moreover, we outlined a scenario in which the decision making style depends not only on informational exchange or patient’s health literacy (Edwards, Davies & Edwards, 2009), but also on the cognitive, emotional and behavioral enactment of individuals towards their wider health management. In the light of the PHE model (Graffigna et al., 2013a, b; 2014), indeed, the unachieved synergy among the different subjective dimensions (think, feel, act) at each stage of the process may inhibit patients’ ability to engage in their care - thus provoking the cognitive “inertia” when the patient has to take decisions about his/her healthcare (Graffigna et al., 2013a, b). According to this multi-lever vision on patient engagement, health interventions fostering patients’ centrality in medical decision making should not be necessarily reduced to the enhancement of patients’ health literacy – according to a “health literate model”. Rather, these interventions should also include actions aimed at scaffolding patients, in order to help them in elaborating

and “giving sense” to their new condition and to pass a pragmatic tool box of situated practices for their daily health management (Graffigna et al., 2013a, b).

We advocate for a more careful analysis of the experiential position of each patient along the engagement process to determine the best decision making style suitable to his/her current subjective attitude towards healthcare. Yet, not all patients want or are able to participate in decision making to the same degree (Murray, Pollack, White & Lo, 2007; Tinetti & Basch, 2013). Some of them may wish to be active in discussing treatment options, but they may ultimately want to rely entirely on their physicians to make decisions on their behalf. Indeed, different reasons emerging from the field, suggest that a nuanced range of forms of “engagement-sensitive decision making” in order to orient guidelines and choice criteria for a medical practice really fine-tuned with the patients’ expected level of involvement at each phase of the engagement process.

The diatribe around the dialogue among paternalism or partnership in the patient-doctor relation finds some answers in the PHE model (Graffigna et al., 2013a), which suggests the need for a paternalistic approach to care in the early phases of the process where the patients prefer to defer decision making to their doctor. On these bases, it will be important to find ways of engaging patients only when and how it is acceptable, avoiding the risk that promoting a shared care decision – at all costs – could become an unwanted burden for them. The PHE model suggests the need for considering the patients’ direct experience of health engagement in order to give the patients the power to choose their relational position towards the doctor and, more in general, towards the healthcare supply. In our vision, patients should have the right to express their more desirable time and ways of interaction with doctors and their role – more or less active – in making decisions about the medical course. This may lead to the development of a stronger partnership and higher relational quality between the patients and the doctors. It also should allow to obtain more positive and satisfying medical outcomes and also go beyond the “black box of medical decision making” (Edwards & Elwyn, 2006) thus overcoming the still existing gap between theory and policy and routine clinical practice.

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