Approaching Empowerment Holistically: are Physicians Willing And Able?
The Case of Hematological Malignancies

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ABSTRACT

Patient empowerment is evident nowadays through the increased role undertaken by patients in the evaluation of healthcare, shaping health policy and involvement in clinical research. But are physicians willing and able to empower their patients? The biopsychosocial model offers a holistic approach to care by including the subjective experience of illness into clinical processes. Within this context, effective communication is key as it can contribute towards better clinical outcomes for patients as well as protect physicians from burnout due to emotional exhaustion. Hematological malignancies are the focus of this contribution as their nature and management pose serious challenges for patients to understand and physicians to explain. Physicians can play a pivotal role in encouraging patients’ empowerment by educating them about their illness, supporting them in self-management and involving them in their care. Communication skills training, availability of consultation tools and e-health applications can support physicians in their new role.

KEYWORDS
Hematological Malignancies, Medical Education, Patient Beliefs, Patient Empowerment, Patient-Physician Communication

THE EVOLVING PHYSICIAN-PATIENT RELATIONSHIP

The World Health Organization (1998) defines empowerment as “…a process through which people gain greater control over decisions and actions affecting their health…” The physicians’ role is therefore pivotal in equipping patients with the knowledge and skills required to participate in their care and navigate within the healthcare context. The paternalistic model assumes that the physician, having all the medical expertise, should set the agenda, goals and make the decisions. In other words, he/ she should act as a guardian in the patient’s best interest (Roter, 2000). Conversely, in the collaborative model there is balance of power since the model assumes that both parties can offer to the medical dialogue. On the one hand, the physician can contribute expertise, namely the medical details of an illness and its treatment, whereas on the other hand the patient can contribute his/ her illness experience, values, preferences etc. The relationship is a partnership where the agenda, goals, and decisions have been negotiated and jointly decided upon (Roter, 2000).

The relationship between patients and physicians has greatly evolved over time. The observed changes in the patient-physician relationship should not come as a surprise if one considers the changes in the model of the illness. The biopsychosocial model of illness was put forward by Engel in the
late seventies (Engel, 1977) as a holistic alternative to the dominant biomedical model. Unlike the biomedical model, which operated under the assumption that biological factors alone are responsible for causing an illness, the biopsychosocial model proposed that illness results from an interaction of biological, psychological and social factors. Therefore, the physician should look beyond the affected organ and attend to the patient as a whole. Engel, through the biopsychosocial model envisioned an empowered role for the patient, one that would drastically change the typical patient-physician relationship, characterized by a power differential.

The biopsychosocial model constituted a novel paradigm whereby the patient’s subjective experience of illness is included into clinical evaluation and processes. This is currently expressed by the consideration of patient reported outcomes alongside biomedical data. Furthermore, it contributed towards the placement of patients at the center of care and the promotion of their active participation (Borrell-Carrió, Suchman, & Epstein, 2004). As a theoretical model, the main criticisms addressed at the biopsychosocial model concern the lack of testability, its generic nature and lack of method (Smith, Fortin, Dwamena, & Frankel, 2013): in other words, the model is criticized for essentially lacking scientific evidence. However, this is a somewhat unfair criticism of the biopsychosocial model. Many chronic illnesses, nowadays accounting for most of the morbidity and mortality in the Western world, have psychological and social components in their etiology. For example, research evidence indicates that stress can trigger psychological (i.e. increase of risk taking behaviors) (Andersen, Kiecolt-Glaser and Glaser, 1994) and physiological changes (i.e. immunosuppression) which have been associated with disease outcomes (Segerstrom & Miller, 2004). Research also suggests that social support can influence patients’ health status or psychological adjustment, reduce stressful impact of illness or encourage adherence (McInerney, 2015). Essentially, the true challenge is whether physicians will be able to efficiently identify biopsychosocial data from patients and apply the model in clinical practice (Smith et al., 2013; Gritti, 2017).

A biopsychosocial-oriented clinical practice has been suggested by Borrell-Carrió et al. (2004) based on learning to self-monitor one’s performance, building patient trust, recognizing one’s own biases, cultivating empathic curiosity, observing emotions, communicating clinical evidence in ways it can be understood and using informed intuition, in other words, the insights one has arrived at using both cognitive and emotional capabilities.

**THE ROLE OF PATIENTS’ ILLNESS AND TREATMENT BELIEFS**

The self-regulatory model of illness (SRM), first described by Leventhal and colleagues (Leventhal & Cameron, 1987), conceptualizes illness as a problem and the patient’s behavior as an attempt to solve that problem. The model also makes the hypothesis that patients create mental representations of their illness according to whatever information they have got available in order to make sense of the problem. Sources of information can include: a) ‘lay’ information, which refers to a cultural knowledge of illness, b) external social environment, which refers to information received from significant others or authoritative sources such as physicians, and c) information drawn from the patients’ current personal experience such as symptoms. Thus, patients will respond based on their interpretation of the health threat with a plan of action followed by an appraisal of the outcome. The product of this processing, which occurs in parallel at both a cognitive and an emotional level, is the formation of individuals’ representations of illness (Leventhal Meyer & Nerenz, 1980). Research has indicated that illness representations are structured around 5 components or illness beliefs: identity (concrete symptoms or signs of illness), cause (perceived ideas about how one gets the disease), consequences (perceived outcomes in physical, psychological and social terms), time-line (the likely course of the condition and how long it will last), and cure (person’s beliefs about cure and control) (Meyer, Leventhal & Gutmann, 1985).

Evidence for the validity of illness representations constructs and their relationship with coping behaviors and illness outcomes has been brought forward by a meta-analytic review of 45 empirical
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