

Chapter 5

A Relational Perspective on Patient Engagement: Suggestions from Couple-Based Research and Intervention

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ABSTRACT

Research on the engagement of patients and their partners and the literature on couple relationships have remained surprisingly separated. In response to this gap, the first aim of the chapter is to show the advantages of an integration of these two lines of research in the context of promoting engagement in patients and their partners. Particular attention is devoted to couples' stress and coping literature and to those few studies that investigated the role played for patient engagement by characteristics of patients, partners, and their relationship. Couple-based research can inform engagement literature about facilitators and barriers to couples' coping with illness and about how to promote engagement in the context of the couple. Within this research, the concept of dyadic coping can be especially helpful in understanding how partners can effectively deal with the stress related to acute and chronic illness as well as the barriers to this process. A second aim of the chapter is to connect the suggestions from couple-based research with the field of engagement promotion.

INTRODUCTION

Today's increasing demand of care challenges healthcare systems to pool all available resources in the care environment. To face such a challenge health care systems need to effectively rely not only on professionals, but also on the patient himself/herself and on the patients' informal networks (e.g., the partner, relatives, and friends). Home-based self-care is considered in fact essential for the success of the

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treatment and to avoid re-hospitalization (Agren, Evangelista, Davidson, & Stromberg, 2013). Patient engagement in disease management, that is regarded as the conjoint cognitive, emotional, and behavioral enactment of patients towards their disease management (Graffigna, Barelo, & Riva, 2013), is therefore a pivotal element for making patients co-producers of their health and enhancing their care experience as well as gaining improved health outcomes and lower healthcare costs (Barelo, Graffigna, & Vegni, 2012; Carman et al., 2013; Graffigna et al., 2013).

Patients, however, considerably vary in their ability and will to actively engage in the treatment, with patients' self-care being less-than-adequate in many cases (e.g., Jaarsma & Stromberg, 2014). Thus, pooling those resources that can enhance the patient self-care and support his/her engagement in the treatment is essential (Riegel, Lee, & Dickson, 2011). According to the interdependent self-perspective (Kayser, Watson, & Andrade, 2007) these resources are primarily relational, as *human beings are essentially connected to each other and that this connection among individual must be maintained in order for the self to be complete. In other words, the person is fully human only in relation to others* (p. 416). Along with this perspective, the patient is a person-in-relationships and the patient's close relationships are necessarily involved in the disease. Within patients' close relationships, especially the couple relationship plays a central role for partners' well-being and the care process and can be an important factor influencing the patient engagement with the treatment in both positive and negative ways (Bertoni, Donato, Graffigna, Barelo, & Parise, 2015).

Research on the engagement of patients and their partners and the literature on couple relationships, however, have remained surprisingly separated. In response to this gap, the first aim of the present chapter is to show the advantages of an integration of these two lines of research in the context of promoting engagement in patients and their partners. The role of the caregivers, and of the partner in particular, has been for a long time considered within an individual perspective and mostly analyzed in terms of the caregiver's burden. Only recently, a call for a dyadic perspective has been made within the health literature (Vellone et al., 2014). At this regard, particular attention will be devoted to couples' stress and coping literature and to those few studies that -only recently- started to investigate the role played for patient engagement by characteristics of patients, partners, and their relationship. In general, findings from couples' stress and coping literature underscore that patients and partners disease and health management cannot be understood only at the individual level, but require a dyadic and couple perspective in order to reveal the complexities of such a process and to effectively promote patients' and partners' engagement in it.

A second aim of the chapters is to draw implications from couples' coping research for the promotion of patients' and partners' engagement. Awareness of the dyadic and relational features of each partners' cognition, emotions, and behaviors is in fact essential for partners' to cope effectively with the challenges of the care process along its development. Moreover, those skills and cognitions that are necessary for patients' and partners' participation in the care process need to be understood and trained also at the dyadic level and not only at the individual level.

Before starting, some caveats need to be considered. First, we will focus our discussion on patients in couples as for a substantial proportion of patients the spouse or partner is generally among the primary caregivers, together with adult children (Li & Loke, 2014). Moreover, partner support cannot be easily substituted by other sources (Coyne & DeLongis, 1986). It is arguable, however, that some of the present suggestions could apply to patient-caregiver dyads more generally. Second, our discussion presents studies that in most cases refer to a specific disease and not to a range of illnesses. In particular, cardiac

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