

# Chapter 15

## Best Practices to Promote Patient and Donor Engagement to Care in Living Donor Transplant

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### ABSTRACT

*Increasing evidence has demonstrated that patients' involvement promotes better health care outcomes and cost-effectiveness of services. However, limited literature is available about the experience of living donor kidney transplantation and best practices to promote patients and donors' engagement. Aim of the present chapter is to review the literature about patient engagement in the context of chronic kidney disease, and to introduce an innovative protocol developed to promote potential donors and recipients' participation and adherence to care at the Niguarda Ca' Granda Hospital in Milan (Italy). Results are critical to reflect on the identification of best practices for patients' engagement in the context of chronic kidney disease. Through a better understanding of the emotional and affective dynamics and the relational implications that may influence the elaboration of the information given by health care providers, it will be possible to develop evidence-informed interventions.*

### INTRODUCTION

Increasing evidence has demonstrated that patients' involvement in decision making about their treatment and care promotes better health care outcomes, higher satisfaction with care and cost-effectiveness of services (Majani & Cavallini, 2010; Stockie, 2012; Berwick, 2010; Ocloo & Fulop, 2012; Hibbard & Greene, 2013; Provenzi, Borgatti, Menozzi, & Montiroso, 2015). With increasing demand for a more

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active role of patients in the management of their health (Crawford et al., 2002; Davis, Schoenbaum, & Audet, 2005; Bellardita et al., 2012; Barello, Graffigna, Savarese, & Bosio, 2014a; Barello, Graffigna, Vegni, & Bosio, 2014b; Menichetti, Libreri, Lozza, & Graffigna, 2014; Graffigna, Barello, & Riva, 2013; Barello & Graffigna, 2015), patient engagement (PE) is more and more considered as a key factor in the improvement of health behaviors and outcomes in the context of chronic diseases (Graffigna, Barello, Libreri, & Bosio, 2014). However, limited literature is available about the experience of living donor kidney transplantation and best practices to promote patients and donors' activation and engagement (Boulware et al., 2013).

Until sixty years ago kidney insufficiency was a lethal disease. Nowadays the scenario has changed, although this illness is still a life-threatening disease in some underdeveloped areas where dialysis is not provided by the healthcare system. Despite its severity, symptoms of the progressive loss of renal function are often absent and the patient does not perceive to be "ill" or the individual is simply not aware of the seriousness of the condition. It has been noticed that the body of the patient suffering from renal insufficiency often adjusts to the disease and its evolution over time, with the consequence that indications from the medical team about changes in diet or medications are difficult to be negotiated (Polaschek, 2003). It therefore follows that a discrepancy exists between the recommendations of the medical team and the subjective experience of the patient, who often becomes non-compliant if the changes in care and treatments are not well-communicated (Kugler, Vlaminck, Haverich, & Maes 2005; Schell, Green, Tulskey, & Arnold, 2013). It follows that behavioral changes and best adherence to therapies are achieved only if patients internalize the need for self-change (McCarley, 2009).

The provision of information to the patient is critical since the moment of diagnosis for two main reasons. First, an effective communication with the patient is essential to address concerns and questions about the medical treatment (in particular, the surgery). Second, as the individual will need to take several medications and undergo numerous medical examinations, it is important that the process is clearly explained and understood in its complexity. Hence, information is key to engage patients evaluated as clinically and psychologically eligible for a transplant (Saita, Zanini, & Fenaroli, 2012).

The practice of living-donor kidney transplantation has significantly increased in the recent past and it represents an effective way to address the growing demand for organs (Fehrman-Ekholm, Duner, Brink, Tyden, & Elinder, 2001). Furthermore, it ensures a shorter waiting period and fewer complications. Within the context of chronic kidney disease, living-donation has registered a growing interest among individuals with this illness, their relatives and friends. As family members and close ones have started to consider themselves potential donors, greater demand for information has occurred and an increased number of health care professionals are now involved in explaining practices and evaluating potential kidney donors and recipients (LaPointe Rudow et al., 2015).

In the midst of this complexity, the present chapter has two objectives: (1) to review the literature about patient engagement in the context of chronic kidney disease and (2) to present an innovative protocol developed at the Niguarda Ca' Granda Hospital in Milan (Italy) to promote patients and relatives' participation and adherence to care.

## **BACKGROUND**

Chronic kidney disease has been defined as a "reduced glomerular filtration rate, increased urinary albumin excretion, or both" (Jha et al., 2013; p. 260) and represents an increasingly concerning public

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