

Living with end stage renal disease: Towards a ‘we-disease’ perspective

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End stage renal disease (ESRD) is a life-threatening condition, with rising prevalence worldwide. Patients must undergo some form of renal replacement therapy, usually haemodialysis (HD) in order to survive. HD demands radical lifestyle changes, as patients have to adhere to a complex regime of HD sessions, medication, fluid and dietary management, vascular access care and exercise. Family support has been recognized as an important determinant of patient's adherence and self-management in chronic conditions, but a family approach to ESRD remains understudied. The project “Together We Stand” (POCI-01-0145-FEDER-030228) aims to add some light to this issue. In 2019, the research team observed that patients and families are aware about the vascular access

care demands, crucial to patients' survival, but lack of knowledge and skills was also evidenced, suggesting the need of educational interventions on a family base within a close cooperation approach with healthcare providers in dialysis settings. This work was distinguished at the International Congress of Vascular Access and published in *The Journal of Vascular Access*. Furthermore, support from family, friends and significant others has been consistently linked to better health outcomes for patients across several chronic conditions. However, social support has never been systematically investigated in relation to dialysis adherence. Our recent systematic review published in *Seminars of Dialysis* tried to fill this gap. We have found that in 75% of the included studies, social support was a significant predictor of treatment adherence. After adjusting for confounding factors, 58% of these associations remained significant. Particularly, family support was significantly associated with fluid, diet and medication adherence pointing to the need of including family in psychoeducational interventions as part of innovative renal rehabilitation programs. This work has gained attention from the Physician's Weekly.



together
we stand

Promoting adherence in end-stage renal disease
through a family-based self-management intervention