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Title

Defining Patient Burden: Analyzing living kidney donor patient blog posts

Priority 1 (Research Category)

Qualitative research

Presenters

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Abstract

Context: Burden varies across patients and medical encounters. The variability influences the patients' persistence to comply and persist with their care. Historically, patient burden definitions have focused on disease management and treatment, surrogacy, and caregivers. Little is known about the burden experienced by those undergoing voluntary, episodic, non-disease management care. Living kidney donors (LKD) are an ideal population to explore patient burden, especially during the pre-donation evaluation stage. Their medical encounters are voluntary and episodic. This study strives to identify the types of burdens experienced and how burden interacts with facilitators to influence their persistence through the process. These findings may be translatable into primary care as it provides additional insight into helping patients navigate their care. Objective: To identify burdens and facilitators experienced by LKDs during the pre-donation evaluation and how the burdens interact with facilitators to help advance LKDs through the donation. Also, the study will conceptualize and explore components of a new patient burden definition for those undergoing episodic care. Study Design: Qualitative thematic analysis. Setting or Dataset: Online patient blog for organ donors. Population studied: 243 LKDs blog posts who are being evaluated for a kidney donation were thematically analyzed using grounded theory. Outcome Measures: The analysis identified the presence of 5 different types of burden and multiple facilitators. The interaction between the burdens and facilitators influenced the persistence of the LKD to continue through the donation process. Results LKDs identified an anticipated level burden. When it was exceeded, affecting their workload and capacity, patients assessed their ability to cope with the increased burden. If they felt capable of managing the burden, they engaged in problem-focused coping and when they did not, they engaged in emotion-focused coping. Both forms of coping influenced LKDs attitude toward donation and likelihood to persist to donation. Conclusions: The analysis confirms the need to expand and reconceptualize a new patient burden definition to encapsulate the experiences of patients undergoing voluntary, episodic care. Further exploration is needed to clarify and validate the definition. Long-term these findings can improve doctor-patient communication and the care of the voluntary, episodic, non-disease management patient.