

**Submission Id: 4142**

**Title**

*Understanding Patient Burden from Living Kidney Donors' Perspective*

**Priority 1 (Research Category)**

Qualitative research

**Presenters**

Kelly Nottingham, PhD, MPH

**Abstract**

Context: Living kidney donors (LKD) have a unique perspective on aspects of patient burden as the evaluation process presents similarly to those engaging in non-disease management, episodic care. The nature of the pre-donation evaluation, whereby potential LKDs undergo multiple tests and medical encounters, results in anticipated and unanticipated burdens. These experiences manifest in the forms of emotional, relational, physical, communicative, and systemic burden which influences the LKDs' perception of the medical encounters. Gaining knowledge about the burden experienced may benefit primary care over time by helping improve the overall patient experience and improve health outcomes. Objective: To confirm the presence of burdens and facilitators and identify how their interactions influence the LKDs' perception of the pre-donation evaluation and their desire to persist. Additionally, the study evaluates and reconceptualizes the components of a newly proposed patient burden definition. Study design and analysis: Inductive qualitative analysis Setting or dataset: Semi-structured interviews. Population studied: 30 potential LKDs, actively being assessed, disqualified as a donor, or withdrew from evaluation. Interviews lasted 60-90 minutes. Outcome measures: The presence and interaction of the 5 types of burden and facilitators were assessed to determine their influence on persistence. By applying concepts of the theory of planned behaviors and minimally disruptive medicine to the findings, a clearer definition of patient burden was identified along with the conceptual structure of an unanticipated patient burden model. Results: The presence of burden and facilitators were confirmed. Participants explained experiencing burdens that were expected (anticipated) and those unexpected (unanticipated). The unanticipated burden impacted and altered interactions and relationships; caused them to question the overall donation process and get frustrated with the bureaucracy. The facilitators aligned with problem-focused and emotion-focused coping mechanisms. Some facilitators, which did not associate with the coping mechanisms, aligned with the concepts of positive psychology and when present the LKD appeared to experience less burden with or without using other coping mechanisms. Conclusion: Burdens and facilitators influence on persistence was confirmed and a conceptual model was defined. These findings serve as a foundation for future patient burden studies.