

Identifying the needs of kidney transplant recipients that can be addressed by a web-based self-management program

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Background

Kidney transplantation improves the quality of life (QoL) of patients with end-stage renal disease, however, post-transplant recovery of physical health and other aspects of QoL remain well below age- and sex-matched norms. While members of the health care team are focused on optimizing the biological responses to transplant, patients may have few or no tools at their disposal to engage in behaviors that optimize QoL.

Methods

We used 4 strategies to identify areas of concern post-kidney transplantation:

- 1) a pilot study that used the patient-generated index (PGI) to identify areas of QoL that are affected post-transplant;
- 2) review of the outcome domains suggested by the Standardized Outcomes in Nephrology-Transplantation (SONG-Tx) international initiative;
- 3) review of the domains included in QoL questionnaires for kidney transplant recipients and patients with chronic kidney disease;
- 4) focus groups (FG) and key informant interviews (KII) with patients, clinicians, and researchers.

We linked the identified themes to the International Classification of Functioning's (ICF) code list and created a saturation table to visualize the most common areas of concern.

Results

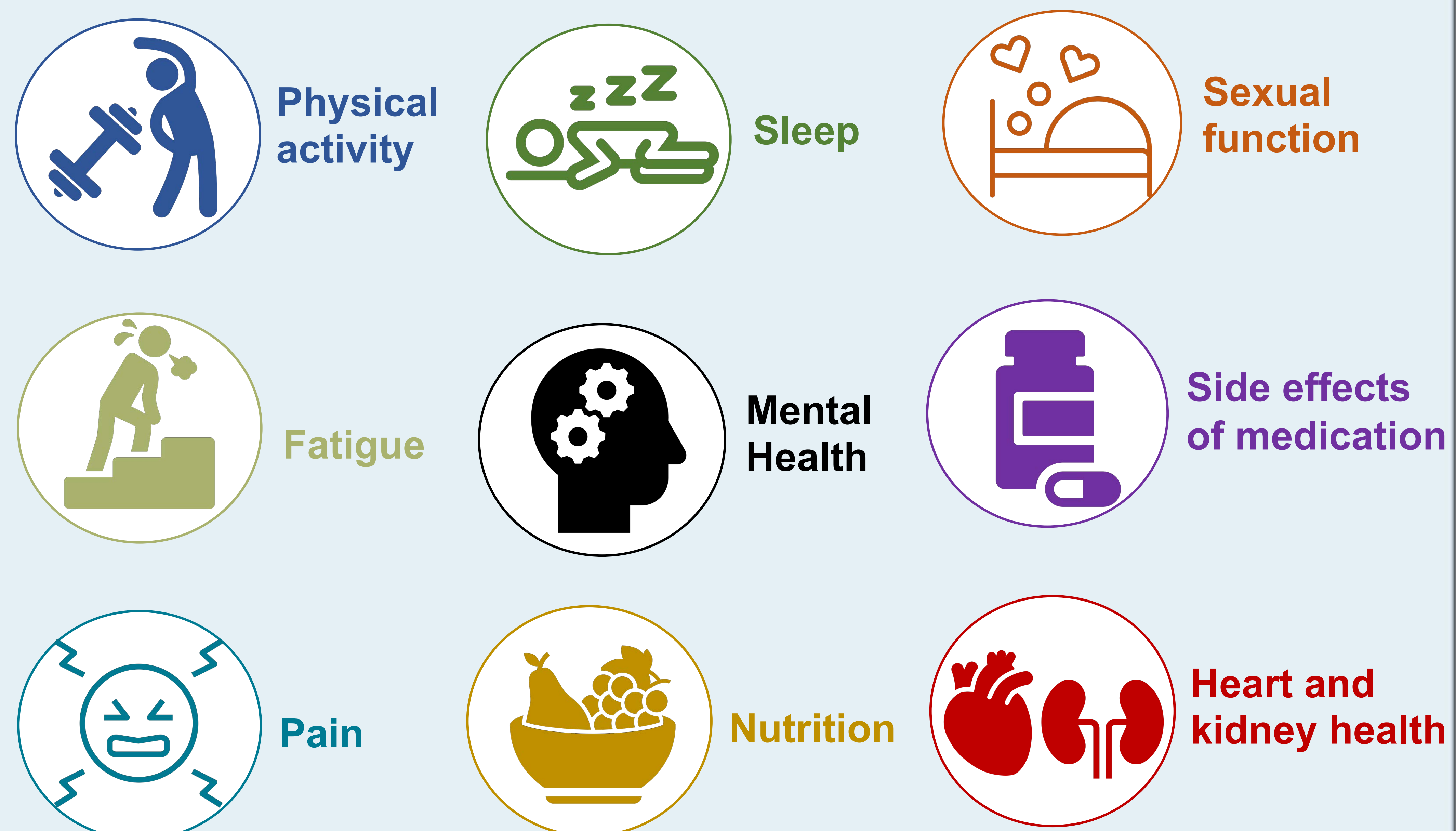
Table 1. Most prevalent ICF domains covered by each strategy

	Pilot	SONG-Tx	Domains QoL quest.	FG1/KIIs	FG2	FG3
BODY FUNCTIONS (B)						
Mental Functions (B1)						
Energy and drive functions (B130)- e.g.: motivation; function of energy level; appetite	√			√	√	√
Sleep function (B134)	√	√	√	√	√	
Emotional Functions (B152)- e.g.: anxiety, fear, anger, sadness	√	√	√	√		√
Mental functions, other specified (B198)- e.g.: depression		√		√		√
Sensory functions and pain (B2)						
Pain (B280)	√	√		√	√	
Functions of the cardiovascular, haematological, immunological and respiratory systems (B4)						
Heart functions (B410)- e.g.: cardiovascular disease/dysfunction		√	√		√	
Blood pressure functions (B420)- e.g.: hypertension		√	√		√	√
Exercise tolerance functions (B455)- e.g.: fatigue; exercise	√	√	√	√		
Functions of the digestive, metabolic and endocrine systems (B5)						
Functions related to metabolism and the endocrine system, other specified and unspecified (B559)- e.g.: diabetes; high cholesterol		√		√	√	
Genitourinary and reproductive functions (B6)						
Sexual functions (B640)- e.g.: libido; early menopause	√		√	√	√	
Procreation functions (B660)- e.g.: pregnancy; fertility		√	√	√		√
ACTIVITY AND PARTICIPATION (D)						
General tasks and demands (D2)						
Handling stress and other psychological demands (D240)- e.g.: health crisis	√		√	√		
Domestic life (D6)						
Preparing meals (D630)- e.g.: nutrition	√			√		√
Interpersonal interactions and relationships (D7)						
Informal social relationships (D750)			√	√		√
Intimate relationships (D770)			√	√		√
Major life areas (D8)						
Remunerative employment (D850)	√	√		√		√
Community, social and civic life (D9)						
Community life (D910)- e.g.: life participation		√	√	√		√
Recreation and leisure (D920)- Usual Tasks/Leisure	√		√	√	√	√
ENVIRONMENTAL FACTORS (E)						
Products and technology (E1)						
Products or substances for personal consumption- Drugs (E110)- e.g.: side effects			√	√	√	√
Support and relationships (E3)						
Immediate family (E310)- e.g.: social support			√	√	√	√
Acquaintances, peers, colleagues, neighbours and community members (E325)- e.g.: peer-support			√	√		√
Strangers (E345)- e.g.: social support			√	√		√
Attitudes (E4)						
Individual attitudes of immediate family members (E410)- e.g.: impact on family		√			√	√

Table 2. Themes not covered by the ICF domains

	PGI	SONG-Tx	Domains QoL quest.	FG1/KIIs	FG2	FG3
Not covered items by ICF						
Surgical complications/consequences	√	√				
Graft health		√	√			
Mortality		√				
Hospitalization		√	√			
Treatment		√	√			
Burden of kidney disease		√	√			

The most prevalent identified topics (identified in ≥ 3 strategies) were:



Conclusion

Kidney transplant recipients have many areas of concern post-transplant. The next steps will include the development of a comprehensive, evidence- and experience-based self-management web-based program tailored to this patient population to improve their QoL.

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