



PARTICIPANT INFORMATION AND CONSENT FORM

Title of Study: **Effectiveness of Digital Storytelling in Increasing Living Kidney Donor Recruitment in Canada**

Principal Investigator:

Meghan He, BSc | Medical Student, Faculty of Medicine, UBC | hemeghan@student.ubc.ca, 604 838-1066

Co-Investigators:

Dr. Christopher Nguan, MD | Associate Professor, Urologic Sciences, UBC | chris.nguan@ubcurology.com, 604-875-5003

Dr. Erika Escamilla, MD | Research Assistant, Urologic Sciences, UBC | tram.nguyen@cw.bc.ca, 604-875-2291

Dr. David Harriman, MD | Assistant Professor, Urologic Sciences, UBC | david.harriman@ubcurology.com

Background and Study Justification

In Canada, more than 48,000 patients live with end-stage kidney disease (ESKD) and 29,000 receive weekly dialysis (1). The benefit of kidney transplant, especially a living donor kidney transplant (LDKT), for ESKD patients has been well-established to increase both length and quality of life (2-8). However, the number of solid organ kidney transplants has failed to match the increasing number of ESKD patients in Canada (1). There is thus a large gap between the need for organs and the number of transplants, resulting in 3% of patients dying on the organ waitlist (1).

The need for LDKT is even higher among racialized communities than white patients. Indigenous, East and South Asian, African, Caribbean, and Black communities are 50 to 75 percent less likely to be referred for LDKT, identify donors, complete evaluation, and receive transplant in comparison to white patients in Canada (1). In the United States, African American patients are less likely to receive LDKT than white patients at every transplant center in the country (9). A recent American Society of Transplantation Consensus Conference called for improved transplant education and outreach efforts to target racial barriers to LDKT (10).

Multilevel barriers to LDKT transplant among minority populations have been identified (11). At the individual recipient-donor level, barriers include medical mistrust, low health literacy, religious concerns, and clinical unsuitability for donation. At the healthcare provider level, barriers include a lack of cultural competency in transplant education, racially biased perceptions of donation suitability, and limited time for healthcare staff to provide education that addresses racial disparities (12-15). And finally, at the population-community level, there exists a high chronic disease burden among minority populations due to social determinants of health that may reduce the potential donor pool for racialized potential recipients (16-19). Low community awareness about the benefits of and

need for LDKT, low availability of mandated sick leave from work and donor reimbursement further decreases the accessibility of LDKT among racialized populations (20).

Standard of care didactic LDKT education materials have faced numerous health literacy and sociocultural barriers to supporting racialized patients with ESKD (21-23). Namely, no significant change in donation rates resulted from a targeted public education campaign about organ donation in the East Asian communities in British Columbia, Canada (24). This demonstrates the need for culturally appropriate education on kidney transplant that reaches beyond didactic teaching methods.

Storytelling holds the promising potential to close the gap in LDKT access across diverse communities. Recent research has posited that first-person storytelling (FPS) overcomes health literacy and sociocultural barriers to breast cancer, diabetes, hypertension, and smoking cessation interventions (25-31). Several narrative-based transplant education interventions have also proven to be effective in increasing LDKT pursuit among Black patients in America (32-35).

While effective, these education interventions are labour and time intensive and fail to reach the general public and social circles who are not present at the location of transplant education (36). Additionally, the efficacy of interpersonal education interventions has yet to be evaluated in Canadian minority populations, predominantly comprised of South Asian, East Asian and Indigenous communities (37). There is thus a need to analyze the impact of humanities-based LDKT education to narrow the gap in LDKT access in Canada without burdening already limited healthcare resources.

The Living Donation Storytelling Project (LDSP) is an online video library of living donation first-person narratives aiming to inspire more people to consider becoming living donors (36). As of 2020, the library has 118 stories from living donors and kidney recipients sharing their experiences with the challenges, fears, and joys of transplant (36). LDSP is a health-literate and culturally safe approach to LDKT education by virtue of storyteller diversity and its patient-driven approach. The library thus holds the potential to support minority groups in learning about LDKT as a supplement to traditional educational strategies without additional burden for healthcare providers.

Study Purpose

The purpose of this study is to test the effectiveness of the LDSP as a narrative-based transplant education intervention in encouraging patients with ESKD to pursue LDKT. We will investigate if exposure to the LDSP changes patient readiness and motivation to pursue LDKT to ultimately increase the number of donor inquiries and donor evaluations. We will also test if the LDSP serves as a health-literate and culturally safe education approach that can effectively support racialized communities who have a disproportionately higher need for LDKT.

Study Objectives

The objectives of this study are to:

- 1: Elucidate if allowing waitlisted transplant patients to watch two videos from the LDSP will increase their readiness and motivation to pursue LDKT.
- 2: Examine if allowing waitlisted transplant patients to watch two videos from the LDSP will increase the number of donor inquiries and donor evaluations.
- 3: Test if the LDSP serves as a health-literate and culturally safe education approach that can effectively support racialized communities in pursuing LDKT.

Outcomes

Outcomes	Description	Timeline
Readiness and motivation to pursue LDKT	7 questions assessing stage of change 12 questions assessing decisional balance	Baseline + 1-month post-intervention survey
Transplant Knowledge	16 questions assessing knowledge about LDKT	
Video Preference	Rate liking after each video Rate which of the two videos they preferred	Immediate post-intervention survey
Material Accessibility	1 question assessing ease of understanding LDSP stories	
Cultural safety	2 questions assessing LDSP's respect for cultural diversity and trustworthiness	
Video Impact	7 questions assessing patient's attitudes towards LDSP	
Donor Inquiries	Requests for more information about living donation to the transplant nurse coordinator	3-month post intervention EMR review
Donor Evaluation	Initiation of the first phase of the clinical pathway for living donor evaluation	

Design

We will conduct a pilot parallel-group, 2-arm randomized control trial comparing the impact of standard LDKT patient education and narratives from the Living Donation Storytelling Project (LDSP) on the attitudes and behaviors of LDKT candidates.

Population

Inclusion Criteria

- Waitlisted and newly referred kidney transplant candidates at the Vancouver Kidney Transplant Program
- 18 years of age or older

- Able to provide informed consent
- English literate

Exclusion Criteria

- Inability to understand English and provide informed consent
- Transplant candidates excluded from transplantation based on clinical criteria or other contraindications for transplant
- Unwilling to disclose information on race or ethnicity

Recruitment

Study participants will be recruited from Dr. Christopher Nguan and Dr. David Harriman's transplant clinics at Vancouver General Hospital with fully informed consent. Prospective participants will be identified by Dr. Nguan and Dr. Harriman via chart review. A research assistant will describe the study objectives and methods, provide participants with a study information sheet, and ask them if they are interested in participating.

Details of Study Procedures

Participants visiting the transplant clinic at the Vancouver General Hospital will be asked to complete a survey on REDCap following their physician's visit to document their demographics, readiness to pursue transplant, and stage of change in pursuing transplant. Transplant candidates will be randomly assigned to 1 of 2 conditions: (1) a control group that will receive standard-of-care transplant education, and (2) an intervention group that will receive two LDSP videos as a supplement to the standard education.

Participants of the intervention group who self-identified as Caucasian or East Asian on the baseline demographics survey will be shown a series of two videos selected based on race concordance between the viewer (participant) and the storyteller: (1) race non-concordant, (2) race concordant video. Gender will be concordant for all participant-video pairs. The non-concordant video will be shown prior to the concordant video for all participants, and participants will be asked to rate their liking of each video after viewing them one by one. Participants who self-identified as an ethnicity other than Caucasian or East Asian on the baseline demographics survey will be randomly shown two race non-concordant videos. All participants in the intervention arm will also be advised on standard program resources for living donation options.

Patients of the control group will be counseled in standard fashion and connected to recognized resources for living donation options.

A post-intervention surveys will be given via email 1 month after the clinic visit to document their readiness and motivation to pursue LDKT.

3-month post-intervention, we will conduct a chart review to document the number of donor inquiries received and donor evaluations initiated.

Statistical Analysis

Basic descriptive statistics on participants will be reported as percentages, means, medians and standard deviations. Differences between LDSP versus standard education groups in pre- to postintervention changes in motivation and readiness to pursue LDKT will be examined using linear regression. Results will be summarized as odds ratios and 95% confidence intervals. All analyses will be conducted using R statistical software.

Planned sample size: A convenience sample of 80 patients will be recruited.

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