



## ORIGINAL ARTICLE

# Impact of technology-based interventions on linking potential kidney donors and transplant candidates: a scoping review

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## SUMMARY

Despite the demonstrated survival advantage in end-stage kidney disease (ESKD) patients of a preemptive living donor kidney transplantation (LDKT), there has been a decline in LDKT among African American and Hispanic populations. We performed a scoping review and summarized the evidence about the use of technology-based interventions (TBI) to not only increase knowledge and awareness of LDKT but also link living donors with transplant candidates. We evaluated 31 studies and characterized them into “transplant-candidate facing” TBI, “transplant donor facing” TBI, and “interactive websites” targeting both donors and candidates. For the patient-facing interventions, 60% of studies suggested an increased likelihood of linking possible donors and candidates. The donor-facing interventions showed an increase in donor awareness and 75% of these interventions suggested increasing donor-candidate linkage. This study also demonstrates that TBI (regardless of medium) that are accessible and customized to the specific target population can potentially increase linkage of donors to recipients and serve as effective guides to connect potential donors to transplant candidates.

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## Introduction

Both living donor kidney transplant (LDKT) and deceased donor kidney transplant (DDKT) improve quality and duration of life among patients with end-stage kidney disease (ESKD) [1]. This survival advantage is even more pronounced in those patients who receive a preemptive LDKT [2]. Any exposure to dialysis prior to kidney transplant contributes to worsened morbidity and mortality [2–4].

Living kidney donation remains underutilized in the United States, especially among racial/ethnic minorities [5]. There has been a decline in the number of LDKTs

in African American and Hispanic individuals since 2004, despite the efforts made in 2014 by the United Network for Organ Sharing (UNOS) to improve access [6,7]. Reasons for these disparities include delays in nephrology care experienced by African American and Hispanic patients with chronic kidney disease (CKD), lack of knowledge about how to solicit a suitable kidney donor, and difficulty finding potential donors in social networks (because of a high burden of hypertension, diabetes, and familial clustering of kidney diseases) [8,9]. Additional personal challenges experienced by patients with ESKD include feeling overwhelmed by illness, guilt about the burden imposed on caregivers,

competing psycho-social needs, and uncertainty about the future health of potential donors [10,11]. Boulware *et al.*, identified difficulty initiating conversations, fear of being misinterpreted, and fear of inducing guilt on loved ones as important barriers to solicitation of living donors [11]. The most modifiable barriers to LDKT among minority groups are the lack of knowledge about, or comfort with, the process of getting to LDKT [12]. This raises concern about the effectiveness of current delivery methods of transplant education and assistance by transplant providers for racial/ethnic minorities. Importantly, studies show that attainment of greater knowledge about this process increases transplantation rates [13]. For example, a randomized control trial (RCT) found that the “TALK” intervention (which included video, booklet plus social worker discussions) led to increased probability of achieving LDKT among candidates who received it [14].

Technology-based interventions (TBI), defined here as interactive websites and mobile applications, hold great potential to overcome knowledge barriers and disparities in access to LDKT in individuals with kidney disease. Prior studies have established high rates of TBI engagement and smart-phone ownership among racial/ethnic minority patients [15,16]. To what extent TBI are able to increase the linkage of donors and recipients has not been studied. A review of TBI in increasing LDKT is needed to identify current gaps in strategies for improving LDKT in racial/ethnic minorities.

Scoping reviews are qualitative studies that serve to cover emerging evidence in a specific topic and describe a diverse body of literature. Scoping reviews outline the current literature with a focus on areas or interventions that are not very well described and can serve as a precursor to a systematic review or meta-analysis [17,18]. We decided to use a scoping review format because of the dearth of robust evaluations in this specific topic and the heterogeneous designs/metrics used in those studies that have evaluated the topic. To inform future health interventions using TBI designed to overcome barriers to LDKT experienced by racial/ethnic minorities, this scoping review of the literature will examine uptake and efficacy of past TBI interventions on LDKT knowledge and awareness. We are specifically interested in any increased linkage of transplant candidates with potential kidney donors driven by TBI.

## Methods

This review was performed using the guidelines of Meta-analysis of Observational Studies in Epidemiology

and reported using PRISMA guidelines (Supplementary Materials, PRISMA Checklist) [19]. A review of the literature was conducted of all articles and abstracts related to TBI designed to improve access to LDKT and possibly link potential living donors with renal transplant candidates. Because of the heterogeneity of the study designs and reported data in available articles, a formal meta-analysis was not possible and the authors decided upon a scoping review. The search was conducted on April 14, 2020, within the following databases: Ovid MEDLINE (Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Daily and Versions(R) 1946 to April 13, 2020); Ovid EMBASE (Embase Classic+Embase 1947 to 2020 April 13); Cochrane Central Register of Controlled Trials (CENTRAL); Web of Science Core Collection (1900-present); and Scopus. The full search strategy for OVID Medline is included in Appendix S1.

During screening (as opposed to the search phase) we limited to abstracts and articles to the time-period between January 1, 2005, to April 14, 2020, and to the English language. Articles and abstracts not about live kidney donation or not about the use of TBI to improve LDKT access were excluded. We also excluded review articles, telephone-delivered and in-person only interventions, and non-English manuscripts. Meeting abstracts were included to give a comprehensive overview of data and because of the limited number of manuscripts. The titles, abstracts, and articles were reviewed by two authors (PD and LG). Discrepancies regarding exclusion decisions were discussed openly between the two authors (PD and LG) to reach consensus. A third author was designated as an arbitrator in case consensus was not reached (SJ).

## Data extraction

Data were extracted by two reviewers (PD, LG). We extracted the year of the study, country of origin, target population, type of technology used, study design, data analytic techniques, outcomes, conclusions, and whether or not the TBI linked a potential donor with a transplant candidate (primary outcome for this review). We divided all extracted papers and abstracts into three categories based on design: 1. “transplant candidate-facing interventions,” 2. “transplant donor-facing interventions,” and 3. “interactive websites” which were geared to enhance LDKT knowledge and/or interest exhibited by either potential donors or transplant candidates.

## Data synthesis

To best demonstrate the primary outcome, which is to determine the ability of TBI to connect potential transplant candidates and donors, we identified studies that described TBI in either increased linkage or potential linkage between donors and transplant candidates. We also extracted information about the ability of TBI to increase awareness of LDKT and aid in clinical decision-making as secondary outcomes.

## Assessment of quality and bias

An assessment of the quality of the paper or abstract was independently conducted by LG and PD on all randomized control trials (RCTs), non-randomized trials, and prospective cohort studies using the Newcastle-Ottawa bias tool [20]. Discrepancies were discussed openly between the two authors (PD and LG) to reach consensus. (Appendix S2).

## Statistical analyses

The proportion of the types of TBI within each category (transplant candidate-facing, donor-facing, and web-based) was examined and reported.

## Results

A total of 1355 references were identified. After excluding titles that did not fit inclusion criteria, full-text review was conducted on 151 references by the two authors. Thirty eligible full manuscripts and abstracts were identified. One manuscript was included in both transplant candidate-facing and donor-facing categories; therefore, we reported on 31 studies and 30 publications. Of the 30 publications, 16 were full manuscripts and 14 were meeting abstracts (Fig. 1).

### Transplant candidate-facing interventions

Ten papers and abstracts evaluated transplant candidate-facing interventions. Fifty percent of the digital technologies consisted of mobile health or iPad applications, 30% were web-based applications and 20% were computer-based decision aids. (Table 1) [21–30]. All interventions enhanced knowledge and awareness of LDKT. Axelrod *et al.*, found 86% of patients had an improvement in knowledge [21].

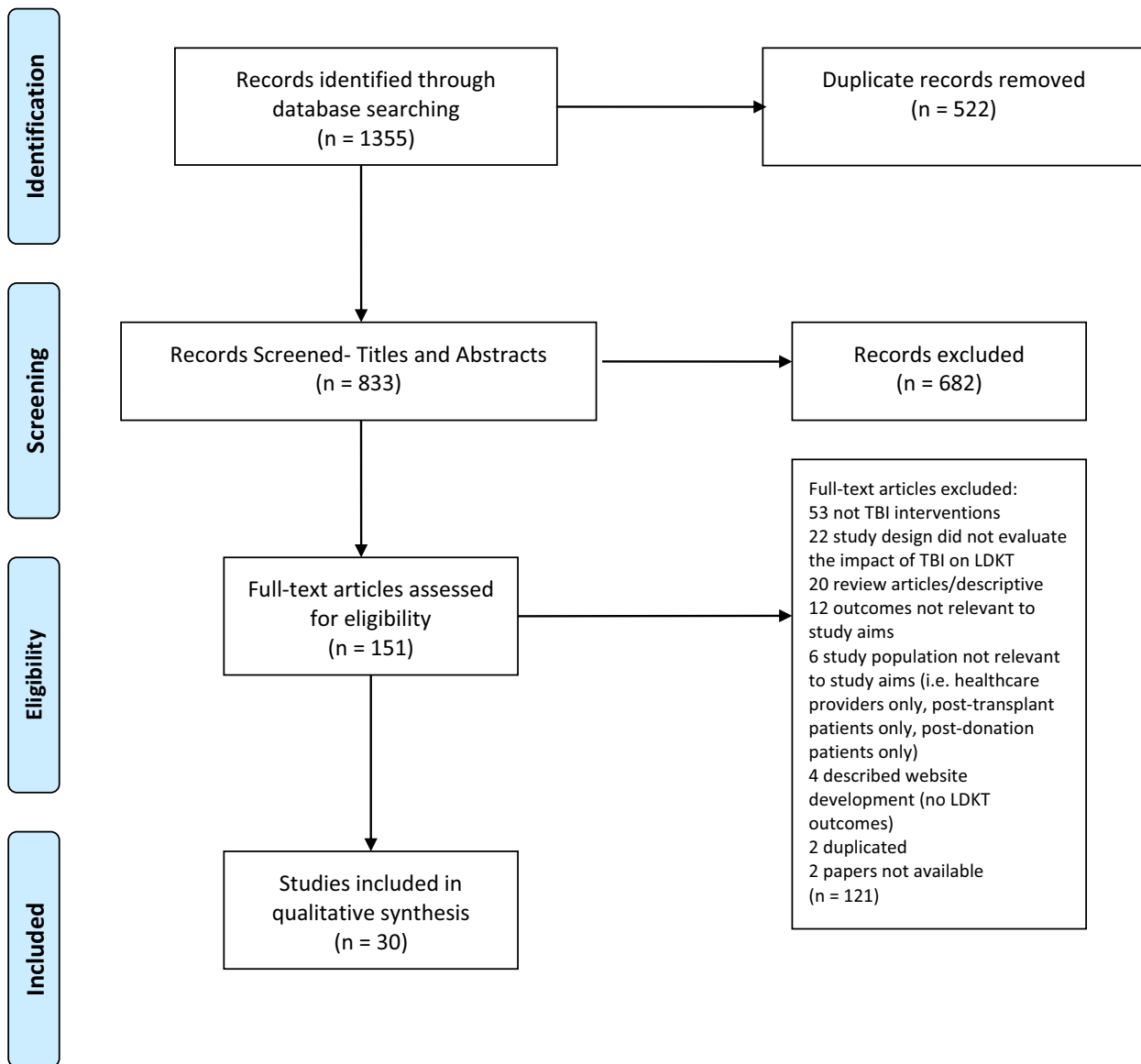
Sixty percent of these studies suggested an increase in the likelihood of linking potential donors with

transplant candidates. (Table 1) [21,23,26–29]. For instance, after using the LOVED application, 100% of patients approached a donor and 36% of patients found a donor who underwent the screening process [29]. In Cameron *et al.*, 26.9% of patients identified a donor after using a smartphone application [23]. Kumar *et al.*, found that patients using the “Donor” app were over 6 times more likely to have a donor come forward on their behalf [26]. Waterman *et al.*, found that the patients using the Your Path to Transplant (YPT) computer-tailed assessment were more likely to approach a donor. [23,26–28].

Transplant candidate-facing shared decision-making tools also improved access to transplant (both LDKT and DDKT) (Table 1) [27,28]. Lee *et al.*, showed an increase in the number of preemptive transplants after using the web-based shared decision-making tool [27]. Patzer *et al.*, showed a trend toward improved access (i.e., having at least one donor or having received an LDKT or DDKT) in the iChoose Kidney group, an intervention designed to increase awareness of the benefits of kidney transplant as compared with the control group [28]. They reported a trend for improved access to transplant (placed on national waiting list, received at least one living donor inquiry or having received an LDKT or DDKT) in the iChoose Kidney group (74.3%) vs. control (71.4%) but was not statistically significant.

Three of the ten studies were RCTs [25,28,30]. In Waterman *et al.*, the group of transplant candidates exposed to YPT were more likely to approach potential donors than those in usual care (69.5% vs. 48.3%,  $P < 0.002$ ). Patzer *et al.*, as described above, showed a trend toward improving LDKT and DDKT access [28]. Gordon *et al.* conducted an RCT with pre/post knowledge surveys and found that website exposure was associated with a 21.7% same day increase in knowledge. At 3 weeks, the *Informaté* group had a 22.6% increase in knowledge compared with the control group (routine transplant education) [25].

While TBI-based education is effective in improving access, its uptake, and acceptability are also critical to ensuring success. Axelrod *et al.*, Sieverdes *et al.*, and Gordon *et al.* showed that TBI are feasible and accepted by potential transplant candidates [21,25,29]. Axelrod *et al.*, found that 86% of patients felt that the “My Transplant Coach” app improved their knowledge, and 67–85% of patients felt that the intervention was culturally appropriate [21]. Sieverdes *et al.*, showed that the attrition rate was 0% and 90.9% of patients were adherent to the videos, suggesting a high acceptability rate [29]. Gordon *et al.*, reported that over 80% of



**Figure 1** Prisma flow diagram.

participants would recommend *Informaté*, understood the website and felt it was made for Hispanic patients [25].

The importance of approaching LDKT in a culturally sensitive manner to target African American and Hispanic patients was stressed by a number of the studies. [24,25,29]. An example of such an intervention is the program developed by Gordon *et al.* (*Informaté*), which was a multi-staged program designed to increase awareness of LDKT in the Hispanic population [25]. Sierverdes *et al.*, also found that the LOVED program, which was culturally targeted toward African Americans, promoted LDKT by enabling patients to approach potential donors about transplant [29].

A formal assessment of bias was difficult across all studies because of paucity of reported process outcomes necessary to make a fair assessment. There was an increased risk of bias among observational trials and the abstracts evaluated. Not surprisingly, this risk was lowest in the three RCTs [25,28]. However, while few and heterogeneous in design, candidate-facing TBIs were feasible, acceptable to patients, and in some cases effective increasing linkage of potential donors and candidates. (Appendix S2).

### Transplant donor- facing interventions

Of the 16 donor-facing TBI interventions, 10 were social media-based (62.5%) and 6 (37.5%) were web-based

**Table 1.** Transplant candidate facing TBI.

Study, IT intervention, and Country	Target Population/ Type of study	Study Aims and Findings	Can potentially link donor and patient?
<sup>a</sup> Sieverdes <i>et al.</i> 2018 [29] Web application- 'LOVED' and peer navigator USA	25 ESKD patients Proof-of-concept study	To report on the feasibility of LOVED in promoting LDKT among waitlisted African American patients. 8 week program; participants in the LOVED program felt more comfortable approaching donors. <b>100% of participants asked a potential donor to be evaluated; 36% of patients found a donor who underwent the screening process.</b>	Yes
<sup>a</sup> Cabacungan <i>et al.</i> 2019 [22] Mobile Application- Talking About Live Kidney Donation Social Worker Intervention (‘TALK-SWI’) USA	15 ESKD patients Qualitative analysis	To adapt a previously validated phone intervention to telehealth (smartphone or tablet) in order to improve potential recipients’ pursuit of LDKT. They found that app was accessible and easy to navigate.	Not studied
<sup>b</sup> Cameron <i>et al.</i> 2016 [23] Mobile Application-social media posting USA	52 ESKD patients Qualitative analysis	To design a smartphone application in collaboration with Facebook in which a patient describes their disease and ESKD experience to their social network and posts links to initiate discussions about living donation. <b>26.9% of candidates identified a donor, who underwent evaluation.</b>	Yes
<sup>a</sup> Gordon <i>et al.</i> 2015 [24] Interactive website- ‘Informaté’ USA www.informate.org	76 patients (ESKD, kidney donors, transplant recipients) Qualitative analysis	To describe the process of developing a bilingual website ‘Informaté’ targeted to increase knowledge about donation in Hispanic patients with ESKD, their families and the public. The website was also very user friendly with high usability ratings and was deemed to be informative.	Not studied
<sup>a</sup> Gordon <i>et al.</i> 2016 [25] Interactive website- ‘Informaté’ USA www.informate.org	155 ESKD patients RCT with Pre/Post-test analysis	To gauge the impact of a culturally targeted bilingual educational website on knowledge gains and retention about LDKT. They determined that exposure to a culturally based website improves knowledge about LDKT in Hispanic patients. <b>Website exposure was associated with a 21.7% same day increase in knowledge and at 3 weeks, the Informaté group had a 22.6% increase in knowledge compared with the control group.</b>	Not studied
<sup>a</sup> Kumar <i>et al.</i> 2016 [26] Mobile application- ‘Donor’ USA/Australia	40 Kidney transplant candidates 14 liver transplant candidates Prospective cohort study	To develop a smartphone application (Donor) in order to help patients share their stories with family and friends to facilitate the identification of potential live donors 12/2014 to 12/2015. <b>27.5% of Kidney transplant candidates had donors contact the transplant center. Overall, compared with matched controls, participants were 6.61 times more likely to have a donor come forward on their behalf (p &lt; 0.001).</b>	Yes

**Table 1.** Continued.

Study, IT intervention, and Country	Target Population/ Type of study	Study Aims and Findings	Can potentially link donor and patient?
<sup>b</sup> Waterman <i>et al.</i> 2019 [30] Computer tailored intervention- 'Your Path to Transplant' (YPT) USA	802 ESKD patients RCT	To compare the effectiveness of YPT against standard care and assessed knowledge 4 and 8 months after. The YPT group had a significant increase in knowledge and pro-kidney transplant attitudes and actions. <b>The YPT group was more likely to approach a donor compared to the standard group (69.5% vs. 48.3%, p &lt; 0.002).</b>	Yes
<sup>a</sup> Lee <i>et al.</i> 2019 [27] Web- based shared decision-making tool Taiwan	67 ESKD patients Prospective cohort study	To explore the distribution of change of treatment modalities for ESKD patients before and after the use of a shared decision-making tool. <b>18 patients (26.8%) received LDKT within one year of using the shared decision-making program and the number of preemptive transplants increased from 1 to 5.</b>	Yes
<sup>a</sup> Axelrod <i>et al.</i> 2017 [21] iPad application- 'My Transplant Coach' (MTC) USA www.exploretransplant.org	81 ESKD patients Pre/Post survey	To describe MTC content, acceptability, cultural competency as well as evaluate its impact on informed decision making and interest in transplant. MTC was piloted over 15 months. <b>After using the application 72% of patients felt they were fully informed about LDKT compared with 40% on pre-survey.</b>	Not studied
<sup>b</sup> Patzer, <i>et al.</i> 2018 [28] Mobile application- 'iChoose Kidney' USA www.choosekidney.emory.edu	433 ESKD patients RCT	To determine if patients using the iChoose Kidney decision aid will improve their knowledge about transplant and be more likely to pursue kidney transplant over the control group. They found that the knowledge increased in all patients but retention was better in the iChoose Kidney group. <b>They reported a trend for improved access to transplant (placed on national waiting list, received at least one living donor inquiry or having received an LDKT or DDKTx) in the iChoose Kidney group (74.3%) vs. control (71.4%) but was not statistically significant.</b>	Yes

The bold text highlights the percentage of transplant candidates who were connected with potential donors.

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<sup>b</sup>abstract.

(web-based portal, interactive website) tools to increase engagement in LDKT, including donor evaluation/screening. (Table 2) [26,31–45]. Twelve TBI strategies (out of 16) showed an increase in the likelihood of linking potential donors with transplant candidates [26,32–38,41–43,45]. Although the effect was still lower when compared to donors with a personal relationship with

the patient, TBI shows promise in linking donors and candidates [41,46]. Dubray *et al.*, found that 53.5% of donors were petitioned by social media. Dreher and Moore found 23.5% of donors were made aware by Facebook. Facebook was the most utilized social media site [26,32,33,35,37]. However, not all social media initiatives led to successful LDKT. For example, one study

**Table 2.** Donor-facing TBI.

Study and IT intervention	Target population/ Type of study	Study aims and findings	Can potentially link donor and patient?
<sup>b</sup> Dreher and Moore, 2016 [33] Social media tool to increase awareness USA	1978 potential donors Retrospective database analysis	To characterize potential donors and better understand how potential donors are made aware of a patient's need for an organ, from 11/2013 to 8/2015. They found that live discussion is the most prominent way for identifying a donor. <b>However, 23.5% of potential donors were made aware by Facebook.</b>	Yes
<sup>b</sup> Webber <i>et al.</i> 2012 [44] Web-based application: BREEZE-MedSleuth USA	215 potential donors Web-based questionnaire	To evaluate a customized web-based software in order to screen potential donors. They found that this interactive web based patient portal facilitates the identification of eligible candidates remotely by eliciting living donor specific medical history. This resulted in reduced time and costs for identifying a donor.	Not studied
<sup>b</sup> Moore <i>et al.</i> 2012 [39] Web-based program to expedite screening USA	448 potential donors Prospective cohort study	To assess the accuracy of screening potential donors using a web-based technology. They found that this platform is effective in screening donors.	Not studied
<sup>b</sup> Dubray <i>et al.</i> 2020 [34] Social Media's role in engaging donors USA	7817 potential donors Retrospective database analysis	To investigate the influence of social media on self-referrals for kidney donation. From 12/2016 to 3/2019, <b>53.5% of potential donors were petitioned through social media. They found that social media is a major avenue for self-referrals in younger, female, and Caucasian respondents.</b>	Yes
<sup>b</sup> Simpson <i>et al.</i> 2012 [41] Social media's role in identifying donors. USA	773 potential donors Retrospective database analysis	To compare the experience of traditional donors (genetic/personal connection) versus non-traditional donors (through social media or internet). Non-traditional donors were evaluated from 9/2009 to 1/2011. <b>They found that traditional donors progressed to actual donation as compared with non-traditional donors (27.3% vs. 10.6%, p = 0.008).</b>	Yes
<sup>b</sup> Tan <i>et al.</i> 2014 [43] Social media's role in engaging donors USA	Potential donors- N/A Narrative report	To determine if live donor nephrectomy broadcast on a live Twitter feed increases awareness. One week after this broadcast, 19 people contacted their center about donation, and one person successfully donated. <b>60 days after broadcast, the number of individuals interested in evaluation increased by 27.6%.</b>	Yes
<sup>b</sup> Braun <i>et al.</i> 2016 [31] Web-based program to expedite screening USA	2306 potential donors Screening questionnaire	To compare the demographics between potential kidney and potential liver donors who passed the online screening process from 2013 to 2015. <b>Only 1% (23) of kidney donors who went on to successfully donate met through social media.</b>	No

**Table 2.** Continued.

Study and IT intervention	Target population/ Type of study	Study aims and findings	Can potentially link donor and patient?
<sup>b</sup> Gamston <i>et al.</i> 2017 [35] Social media role in engaging donors UK	Potential donors- N/A Narrative	This was a narrative analysis of a mother who posted on Facebook about her son needing a kidney donor. The son received an altruistic donation three years later.	Yes
<sup>b</sup> Gareau <i>et al.</i> 2019 [36] Social media's role in engaging donors Canada	Potential donors- N/A Narrative	This is a narrative about a patient's spouse who posted the need for a kidney donor on social media. The transplant program received 170 inquiries, and patient received an altruistic donation.	Yes
<sup>a</sup> Kumar <i>et al.</i> 2016 [26] Social media based application- 'Donor' USA	54 transplant candidates developed the donor facing intervention Single Center case control study	To develop a smartphone application (Donor) in order to help patients share their stories with family and friends to facilitate the identification of potential live donors 12/2014 to 12/2015. Study participants were more likely to identify a live donor. <b>27.5% of Kidney transplant candidates had donor contact the transplant center. Overall, compared with matched controls, participants were 6.61 times more likely to have a donor come forward on their behalf (p &lt; 0.001).</b>	Yes
<sup>b</sup> Zuidema <i>et al.</i> 2015 [45] Interactive website Netherlands	20 potential donors Prospective study	To launch a website to register interest in donation and determine if there was an increase in LDKT and compared donor petitioned via Facebook. <b>They found that 90% of donors identified through Facebook do not pass screening, whereas 75% of potential donors solicited by the website underwent screening (either at the study center or at an outside center).</b>	Yes
<sup>b</sup> Ruelas <i>et al.</i> 2012 [40] Web-based portal -' BREEZE-MedSleuth Inc' to identify potential donors USA	55 potential donors Prospective study	To determine if using a web-based patient portal captures donor medical histories and facilitates the identification of a donor. They found that this web-based effectively identified eligible donors and can help with expediting evaluation and reducing costs.	Not studied
<sup>b</sup> Slaats <i>et al.</i> 2015 [42] Web-based portal to engage potential donors Netherlands	Potential donors Prospective study	To determine if the online portal can raise awareness of LDKT and shared patients' and donors' personal stories with the aim of having them interact with each other for possible donation. Data were collected over 3 months. Most donors were "unspecified" (n = 17), of whom there was 1 donation, 1 patient listed for nephrectomy, and 5 undergoing donor evaluation.	Yes
<sup>a</sup> Chang <i>et al.</i> 2013 [32] social media's role to engage donors USA	91 Facebook pages Analysis of Facebook posts	To determine how Facebook posts by kidney transplant candidates can increase the number of potential donors being tested based on a single day Facebook search. They found the pages that shared more recipient information reported higher number of donors being tested	Yes



**Table 2.** Continued.

Study and IT intervention	Target population/ Type of study	Study aims and findings	Can potentially link donor and patient?
<sup>a</sup> Kazley <i>et al.</i> [37] Social media's role to engage donors USA	199 patients (transplanted and ESKD) Cross sectional study	To determine the patterns of social media usage among kidney transplant recipients and candidates from 5/2015 to 9/2015. Facebook, Twitter, and Instagram were the three most commonly used social media platforms. <b>23 (11.6%) patients had used social media to post about needing a kidney donor.</b>	Yes
<sup>a</sup> Moore <i>et al.</i> 2013 [38] Web based application to engage/identify donors USA	266 Potential donors Pre/post-implementation	To develop, evaluate and implement a unique web-based application for screening potential donors. <b>Over 3 months, there was a 90% increased per month of self-referrals after the implementation of the web-based application.</b> They also noted increased numbers of living donor evaluations and transplants.	Yes

The bold text highlights the percentage of transplant candidates who were connected with potential donors.

<sup>a</sup>Published as a manuscript.

<sup>b</sup>abstract.

by Braun *et al.*, found that social media, although effective in generating interest, failed to attract donors who successfully donated [31].

TBI interventions were also helpful for screening donors. For instance, Zuidema *et al.*, found that 90% of donors identified through Facebook do not pass screening, whereas 75% of potential donors solicited by their interactive website underwent screening (either at the study center or at an outside center) [45]. Another screening portal developed by Moore *et al.* showed a 90% increase in self referrals after implementation of a website-based screening portal [38].

Like the candidate-facing interventions, the quality of the studies presented was disparate, and the risk of bias was difficult to ascertain. The study least affected by bias risk was by Moore *et al.*, which showed that TBI is well suited to expedite screening of donor candidates but did not demonstrate increase in the linkage of donors with transplant candidates [38] (Appendix S2).

### Interactive websites

All website-based interventions simultaneously targeted both potential transplant candidates and donors [47–51]. Only, one intervention may possibly increase the likelihood of linking donors with transplant candidates but no formal evaluation of this endpoint was

conducted [48]. The “KidneyTIME” interactive website allowed patients to share animated videos via social media, text, or email (i.e., a transplant candidate can share information with his/her potential donor) [48]. Gordon *et al.* described the use of a social media campaign that increased public traffic to the “*Informate*” website [47]. Moody *et al.*, Rodrigue *et al.*, and Valizadeh-Haghi and Ramitzadeh evaluated the quality and accessibility of websites on living donation and transplant; they found that inaccurate and invalidated information was prevalent on the internet, and this may impact patients’ and donors’ decisions about pursuing LDKT (Table 3) [49–51].

Although effectiveness in improved engagement was demonstrated by interactive websites, most of the studies evaluated did not meet minimal criteria needed to assess for bias, and a formal bias assessment was not done. Furthermore, caution should be exercised when using some interactive websites that present inaccurate information. (Appendix S2).

### Discussion

This review of available TBI tools describes strategies that aim to increase living donation for kidney transplantation, a crucial and life-saving endeavor in many individuals living with kidney disease. If a TBI strategy

**Table 3.** Web-based TBI.

Study and IT intervention	Target Population/ Type of study	Study Aims and Findings	Can potentially link donor and patient?
*Kayler et al, 2020 [48] Interactive website- KidneyTIME USA	116 potential donors, potential recipients, and recipients Qualitative analysis	Developed animated videos that are web-based to educate potential recipients and donors. Information can be shared between a patient and donor using text, social media or email. This was a qualitative analysis	Yes
*†Gordon et al, 2016 [47] www.informate.org USA	Targeting Hispanic community (donor and patients)	Describes the utilization of a mass media and social media campaign targeting the Hispanic community to use the 'Informate' website to learn about LDKT.	Not studied
*†Moody et al, 2007 [49] USA/Canada	Potential donors and recipients	Evaluated the quality of websites discussing living donation; only 38% of websites covered recommended information. The most visited websites were not the best for information.	Not studied
*†Rodrigue et al, 2017 [50] USA	Potential donors and recipients	Evaluated the readability and content of living donation websites. They found that the non-profit organizations did not meet the national readability standards. Also, many websites lacked fundamental information about LDKT and were not culturally sensitive.	Not studied
*†Valizadeh-Haghi and Rahmatizadeh, 2018 [51] Iran	Potential donors and recipients	Evaluated the accessibility of websites about kidney transplantation. They found that several websites were not accessible to most people. Government and educational health websites had better performance.	Not studied

\*Published as a manuscript.

†Study design did not involve human subjects.

is identified that can successfully increase linkage between living donors and candidates regardless of their access to specialty services, it can be scaled on a national level to help lessen disparities in access to LDKT experienced by racial and ethnic minorities in the US. Our review demonstrates that TBI-based education leads to increased awareness of LDKT, especially among racial/ethnic minorities [21,25,28]. Our analysis

takes this finding one step further by asking if TBI tools can link potential donors and recipients and ultimately to increase LDKT rates. We found that both transplant candidate-facing and donor-facing TBI hold potential to increase LDKT. Although this sets the foundation for future successful strategies, our study did not demonstrate superiority of one TBI over another for linking potential donors and transplant candidates.

The decreasing rates of LDKT in African American patients is a concerning trend and can be attributed to lack of self-efficacy and knowledge about strategies to engage potential donors, misunderstanding of living donor selection criteria, mistrust of the medical system, high prevalence of comorbid conditions in their social network pool, and financial disincentives for donation [8–12]. In the Hispanic population, lack of awareness and fear contribute to lower LDKT rates but studies show that Hispanic patients are also reluctant to ask for a living donation because this request may place undue pressure on a loved one who may feel obligated to help [52]. The most modifiable barrier to kidney donation among racial/ethnic minorities is lack of necessary skills to request kidney donation from family and friends [12].

Of the 30 studies, we evaluated only three were RCTs (all transplant-candidate facing) [25,28]. Waterman *et al.*, developed the YPT program to coach and educate transplant candidates, and found that this strategy increases “readiness” for LDKT as compared with usual techniques used by transplant centers for this purpose [30]. The iChoose Kidney decision tool showed a trend toward improved access to LDKT but this was not statistically significant [28]. Gordon *et al.* showed that group exposed to *Informaté* had higher same day and sustained (3 weeks) knowledge scores as compared with the usual care group. Other less rigorously designed studies showed success in achieving process outcomes such as increasing interest or willingness to move forward among donors and candidates.

The *Informaté* website and the LOVED application specifically focused on promoting LDKT in Hispanic and African American patients, respectively. Although the *Informaté* website did not study its impact on transplantation outcomes and linkage between potential donors and recipients, it holds potential as a strategy to increase engagement of Hispanic patients in the process of LDKT. The LOVED application demonstrated high acceptability and increased awareness in African American patients and enhanced their ability to approach potential donors about transplant.

The use of TBI to improve LDKT among transplant candidates is feasible. Most patients with ESKD own smartphones and use TBI to gain knowledge about their disease. Hussein *et al.*, evaluated utilization of smartphones in 949 dialysis patients and found that 81% of patients owned smartphones or internet capable devices, and 70% had a high proficiency in using their mobile devices [16]. However, proficiency was lower in patients who were Hispanic/Latinx and those who had less than a college education [16]. Similarly, Lockwood *et al.*,

demonstrated a high usage of smartphone technology in pre-transplant and post-transplant African American patients [15]. The way in which African American and Hispanic CKD/ESKD patients use smartphone technology also needs to be studied to better understand the types of TBI (texting, social media posts, or website portals) that would best meet the needs of these populations.

Successful TBI to increase knowledge of, and interest in, living donation have several features in common; they include easy accessibility, ability to enhance education, and are culturally sensitivity with options for non-English speaking populations [53]. In our study social media platforms played a larger role in donor-facing interventions as compared with transplant candidate-facing interventions. Web-based and mobile applications for transplant candidates were more effective in enhancing knowledge and starting the conversation with friends and family about living donation. Web-based tools developed by a transplant institution also facilitated the screening of donors and helped to expedite the path to successful LDKT [38,40,44,45].

Our study has several limitations. It is possible that our review missed some relevant studies due to the broad search strategy utilized (used broad categories to define TBI). We also excluded non-English studies. Formal meta-analysis was not possible because of the quality, rigor, and heterogeneity of the studies limiting the inferences drawn. Strategies being used in non-English speaking countries may not have been reported in the English literature. Most of our studies were published abstracts and non-RCTs, which increased the risk of bias. We also limited our included studies to those that used TBI as a platform to increase LDKT knowledge, patient engagement, and potential identification of a donor or recipient.

Although we did not find any single TBI strategy to effectively increase rates of LDKT and link potential donors and recipients, our results show that TBI can encompass powerful and efficient tools to achieve these goals. Future design of TBI should include ease of use, easy accessibility, culturally sensitive websites or applications that present the option to include a personal narrative from the prospective candidate. This review showed that TBI were accepted, feasible, and hold great potential for increasing LDKT rates across the transplant candidate and donor populations.

## Authorship

Dr. Priya P. Deshpande: participated in conceptualization, research design, data analysis and writing. Dr. Sunit Jariwala: participated at the third author to

resolve any disputes during the title, abstract and article screening process. Lily Martin: performed the initial search of all papers and abstracts related to this topic. Dr. Ladan Golestaneh: participated in conceptualization, research design, data analysis and writing.

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## Conflict of interest

The authors declare no conflicts of interest.

## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

**Appendix S1.** Key words and Search strategy used for this scoping review.

**Appendix S2.** Quality evaluation of the included studies for the primary analysis using the Newcastle-Ottawa scale (NOS).

## REFERENCES

- Hunsicker LG. A survival advantage for renal transplantation. *N Engl J Med* 1999; **341**: 1762.
- Mange KC, Joffe MM, Feldman HI. Effect of the use or nonuse of long-term dialysis on the subsequent survival of renal transplants from living donors. *N Engl J Med* 2001; **344**: 726.
- Meier-Kriesche HU, Kaplan B. Waiting time on dialysis as the strongest modifiable risk factor for renal transplant outcomes: a paired donor kidney analysis. *Transplantation* 2002; **74**: 1377.
- Gill JS, Tonelli M, Johnson N, Kiberd B, Landsberg D, Pereira BJ. The impact of waiting time and comorbid conditions on the survival benefit of kidney transplantation. *Kidney Int* 2005; **68**: 2345.
- Purnell TS, Luo X, Cooper LA, et al. Association of race and ethnicity with live donor kidney transplantation in the United States From 1995 to 2014. *JAMA* 2018; **319**: 49.
- Reed RD, Sawinski D, Shelton BA, et al. Population health, ethnicity, and rate of living donor kidney transplantation. *Transplantation* 2018; **102**: 2080.
- UNOS. Kidney Allocation system status update. <https://unos.org/news/kidney-allocation-system-status-update/>. Published 2014.
- Vilme H, Davenport CA, Pendergast J, Boulware LE. Trends in African Americans' attitudes and behaviors about living donor kidney transplantation. *Prog Transplant* 2018; **28**: 354.
- Lunsford SL, Simpson KS, Chavin KD, et al. Racial disparities in living kidney donation: is there a lack of willing donors or an excess of medically unsuitable candidates? *Transplantation* 2006; **82**: 876.
- Purnell TS, Hall YN, Boulware LE. Understanding and overcoming barriers to living kidney donation among racial and ethnic minorities in the United States. *Adv Chronic Kidney Dis* 2012; **19**: 244.
- Boulware LE, Hill-Briggs F, Kraus ES, et al. Identifying and addressing barriers to African American and non-African American families' discussions about preemptive living related kidney transplantation. *Prog Transplant* 2011; **21**: 97. quiz 105.
- Lentine KL, Mandelbrot D. Addressing disparities in living donor kidney transplantation: a call to action. *Clin J Am Soc Nephrol* 2018; **13**: 1909.
- Waterman AD, Robbins ML, Peipert JD. Educating prospective kidney transplant recipients and living donors about living donation: practical and theoretical recommendations for increasing living donation rates. *Curr Transplant Rep* 2016; **3**: 1.
- Boulware LE, Hill-Briggs F, Kraus ES, et al. Effectiveness of educational and social worker interventions to activate patients' discussion and pursuit of preemptive living donor kidney transplantation: a randomized controlled trial. *Am J Kidney Dis* 2013; **61**: 476.
- Lockwood MB, Saunders MR, Lee CS, Becker YT, Josephson MA, Chon WJ. Kidney transplant and the digital divide: is information and communication technology a barrier or a bridge to transplant for African Americans? *Prog Transplant* 2013; **23**: 302.
- Hussein WF, Bennett PN, Pace S, et al. The mobile health readiness of people receiving in-center hemodialysis and home dialysis. *Clin J Am Soc Nephrol* 2020; **16**: 98.
- Barnieh L, Collister D, Manns B, et al. A scoping review for strategies to increase living kidney donation. *Clin J Am Soc Nephrol* 2017; **12**: 1518.
- Munn Z, Peters MDJ, Stern C, Tufanaru C, McArthur A, Aromataris E. Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC Med Res Methodol* 2018; **18**: 143.
- Moher D, Liberati A, Tetzlaff J, Altman DG, Group P. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med* 2009; **6**: e1000097.
- Wells GASB, O'Connell D, et al. The Newcastle-Ottawa Scale (NOS) for assessing the quality of nonrandomised studies in meta-analysis.
- Axelrod DA, Kynard-Amerson CS, Wojciechowski D, et al. Cultural competency of a mobile, customized patient education tool for improving potential kidney transplant recipients' knowledge and decision-making. *Clin Transplant* 2017; **31**: e12944.
- Cabacungan AN, Diamantidis CJ, St Clair Russell J, et al. Development of a telehealth intervention to improve access to live donor kidney transplantation. *Transplant Proc* 2019; **51**: 665.
- Cameron A. Use of social media to facilitate identification of potential living donors. *Am J Transplant* 2016; **16** (Suppl 1): 18.

24. Gordon EJ, Feinglass J, Carney P, *et al.* An interactive, bilingual, culturally targeted website about living kidney donation and transplantation for hispanics: development and formative evaluation. *JMIR Res Protoc* 2015; **4**: e42.
25. Gordon EJ, Feinglass J, Carney P, *et al.* A culturally targeted website for hispanics/Latinos about living kidney donation and transplantation: a randomized controlled trial of increased knowledge. *Transplantation* 2016; **100**: 1149.
26. Kumar K, King EA, Muzaale AD, *et al.* A smartphone app for increasing live organ donation. *Am J Transplant* 2016; **16**: 3548.
27. Lee CT, Cheng CY, Yu TM, *et al.* Shared decision making increases living kidney transplantation and peritoneal dialysis. *Transplant Proc* 2019; **51**: 1321.
28. Patzer RE, McPherson L, Basu M, *et al.* Effect of the iChoose Kidney decision aid in improving knowledge about treatment options among transplant candidates: A randomized controlled trial. *Am J Transplant* 2018; **18**: 1954.
29. Sieverdes JC, Treiber FA, Mueller M, *et al.* Living organ video educated donors program for kidney transplant-eligible African Americans to approach potential donors: a proof of concept. *Transplant Direct* 2018; **4**: e357.
30. Waterman ACY, Peipert JD, Beaumont JL, Anderson CS, Paiva AL, Robbins ML. Your path to transplant education increases patients' transplant attitudes, knowledge, informed decision-making and pursuit: an randomized control trial. *Am J Transplant* 2019; **19**: 420.
31. Braun H, Feiner J, Roll G. Where do living donors come from? A comparison of potential living liver and kidney donors at a high-volume US center. *Transplantation* 2016; **100**: S179.
32. Chang A, Anderson EE, Turner HT, Shoham D, Hou SH, Grams M. Identifying potential kidney donors using social networking web sites. *Clin Transplant* 2013; **27**: E320.
33. Dreher A, Moore D. How are potential living kidney donors recruited? *Am J Transplant* 2016; **16**.
34. Dubray BS, Shawar S, Rega S, *et al.* The impact of social media on self-referral patterns for living kidney donation: characteristics of respondents. *Am J Transplant* 2020; **20**: 43.
35. Gamston F. Directed altruistic kidney donation- A single centre experience. *Pediatric Transplant* 2017; **21**: 91.
36. Gareau AJ, Khan F, Stamm L, Berka N. Public solicitation for a living kidney donor: Effects on the transplant waiting list and HLA laboratory workload. *Hum Immunol* 2019; **80**: 45.
37. Kazley AS, Hamidi B, Balliet W, Baliga P. Social media use among living kidney donors and recipients: survey on current practice and potential. *J Med Int Res* 2016; **18**: 1.
38. Moore DR, Feurer ID, Zavala EY, *et al.* A web-based application for initial screening of living kidney donors: development, implementation and evaluation. *Am J Transplant* 2013; **13**: 450.
39. Moore D, Zavala I, Feurer H, *et al.* Preliminary evaluation of a web-based application for initial screening of living kidney donors. *Am J Transplant* 2012; **12**: 59.
40. Ruelas M, Peele A, Webber AB, Lee B, Hirose R, Roberts JP. Living kidney donor candidate triage using web-based patient portal. *Am J Transplant* 2012; **12**: 79.
41. Simpson MA, Morin DS, Akoad MI, Pomposelli JJ, Pomfret EA. Non-traditional living donors. *Am J Transplant* 2012; **12**: 433.
42. Slaats D, Zuidema W, van de Wetering J, Hesselink D, Terkivatan T, Betjes M. Closing the knowledge gap: the successful launch of an interactive website dedicated to information on living kidney donor transplantation [abstract]. *Am J Transplant* 2015; **15** (Suppl. 3). <https://atcmeetingabstracts.com/abstract/closing-the-knowledge-gap-the-successful-launch-of-an-interactive-website-dedicated-to-information-on-living-kidney-donor-transplantation/>.
43. Tan M, Mulloy M, Pollinger H, Gibney E. Impact of social media on living kidney donation awareness. *Am J Transplant* 2014; **14**: 836.
44. Webber A, Hirose R, Lee B, Peele A, Light C, Roberts JP. Successful use of an interactive web-based patient portal to directly evaluate potential living kidney donors. *Am J Transplant* 2012; **12**: 58.
45. Zuidema W, van de Wetering J, Weimar W, *et al.* Living kidney donors triggered by social media: do they donate? *Transpl Int* 2015; **28**: 475.
46. Dreher A, Moore D. How are potential living kidney donors recruited? *Am J Transplant* 2016; **16**(Suppl. 1): 29.
47. Gordon EJ, Shand J, Black A. Google analytics of a pilot mass and social media campaign targeting Hispanics about living kidney donation. *Internet Interv* 2016; **6**: 40.
48. Kayler LK, Dolph B, Seibert R, Keller M, Cadzow R, Feeley TH. Development of the living donation and kidney transplantation information made easy (KidneyTIME) educational animations. *Clin Transplant* 2020; **34**: e13830.
49. Moody EM, Clemens KK, Storsley L, *et al.* Improving on-line information for potential living kidney donors. *Kidney Int* 2007; **71**: 1062.
50. Rodrigue JR, Feranil M, Lang J, Fleishman A. Readability, content analysis, and racial/ethnic diversity of online living kidney donation information. *Clin Transplant* 2017; **31**: e13039.
51. Valizadeh-Haghi S, Rahmatizadeh S. Evaluation of the quality and accessibility of available websites on kidney transplantation. *Urol J* 2018; **15**: 261.
52. Gordon EJ, Rodde J, Gil S, Caicedo JC. Quality of Internet education about living kidney donation for Hispanics. *Prog Transplant* 2012; **22**: 294.
53. Singh K. Mobile health in dialysis: the best engagement medium is the one that's with patients. *Clin J Am Soc Nephrol* 2020; **16**: 12.