

Readability, content analysis, and racial/ethnic diversity of online living kidney donation information

James R. Rodrigue^{1,2}  | Mario Feranil¹ | Jenna Lang¹ | Aaron Fleishman¹

¹Center for Transplant Outcomes and Quality Improvement, Transplant Institute, Beth Israel Deaconess Medical Center, Boston, MA, USA

²Departments of Surgery and Psychiatry, Harvard Medical School, Boston, MA, USA

Correspondence

James R. Rodrigue, PhD, The Transplant Institute, Beth Israel Deaconess Medical Center, Boston, MA, USA.
Email: jrrodrig@bidmc.harvard.edu

Funding information

National Institute of Diabetes and Digestive and Kidney Diseases, Grant/Award Number: R01DK085185; Julie Henry Research Fund; Center for Transplant Outcomes and Quality Improvement; Surgical Outcomes Analysis & Research (SOAR); Beth Israel Deaconess Medical Center

Abstract

More than three-fourths of adults in the USA use the Internet to access health-related information. Adults exploring the possibility of living donation should have access to online content that is readable and comprehensive. We simulated a search of online information about living kidney donation and evaluated readability, topics covered, and racial/ethnic diversity of 21 websites meeting inclusion criteria (eg, hosted by a nonprofit or patient advocacy organization, English content, based in USA). Using standard readability metrics, 62% of sites were classified as “Difficult to read” and none achieved the recommended reading level of sixth grade. On average, websites covered 18.5 (62%) of 30 recommended information topics (range: 7 to 28) and only 2.1 (23%) of 9 racial/ethnic diversity items (range: 0 to 6). Overall, the most common nonprofit or patient advocacy organization websites do not meet the readability standards established by the National Institutes of Health and the American Medical Association, many lack fundamental information about living kidney donation, and most are not racially/ethnically diverse. We encourage the transplant community to consider playing a more active role in improving the overall quality of online information disseminated to the general public. Further, there is a need to more critically examine the accuracy of online living donation content in future investigations.

KEYWORDS

kidney donation, living donation, living donors, online, websites

1 | INTRODUCTION

Live donor kidney transplantation (LDKT) is the best treatment for patients with end-stage renal disease (ESRD), providing superior outcomes compared to dialysis and deceased donor transplantation.¹ However, LDKT is made possible only by participation of a willing, altruistic, informed, healthy, and otherwise medically eligible living kidney donor (LKD). Transplant-eligible patients are encouraged by their transplant providers to identify potential LKDs and ask them to consider undergoing evaluation. Innovative educational programs have been developed to help patients identify potential LKDs, all with the goal of increasing the likelihood of LDKT.^{2–7} Some education campaigns are now focused on the general public to increase the number of nondirected LKDs.^{8,9}

Adults who may consider living kidney donation often begin their own self-educational process prior to contacting the transplant center by seeking information online. There are many websites for such individuals to visit, and some have called for a single online clearinghouse of information for potential LKDs.^{10,11} Certainly, those exploring the possibility of living donation should have access to accurate, up-to-date information to facilitate informed decision-making about whether to pursue evaluation. If confronted with insufficient, unreliable, or inaccurate information online, otherwise willing adults may decide not to pursue evaluation or, perhaps worse, their decision to pursue evaluation may be misguided.

More than three-fourths of adults in the United States (USA) use the internet to access health-related information.¹² Consequently, guidelines exist for website developers seeking to disseminate

health-related information to a diverse general public.¹³ However, numerous analyses have shown that most websites fall short of readability and quality standards.^{14–17} In an earlier analysis of living donation websites, Moody et al.¹⁸ found that while most of the 86 national and international websites they reviewed provided accurate information, the majority were written above the 10th grade level (sixth grade is recommended) and there was considerable variability in the range of recommended content covered. Each website, on average, covered only about one-third of the recommended information about living donation and fewer than half covered potential long-term medical and psychological risks, expected benefits to the donor, or the voluntary nature of donation. Similarly, in an evaluation of 20 Spanish-language online resources about living kidney donation, Gordon et al.¹⁹ found that average readability was at the 9th grade level and none of the websites addressed 7 of the 12 topics evaluated.

Considering the Moody et al.¹⁸ study was conducted more than a decade ago and the Gordon et al.¹⁹ study focused exclusively on Spanish-language sites, we sought to update and expand the readability and content analysis of living donation websites. Regulations pertaining to LKD evaluation and follow-up processes in the United States (USA) have changed since the Moody et al.¹⁸ study and new findings about the long-term outcomes of LKDs have recently emerged.^{20–23} Additionally, we wanted to examine the racial/ethnic diversity of living donation websites. This is an important analysis considering the known racial disparities in LDKT, the declining rate of living donation in certain minority populations, and emerging evidence that some long-term medical outcomes following donation are disproportionately worse for certain minorities.^{21,24–29}

2 | METHODS

2.1 | Website Identification

Most people use a general search engine for health information, vs sites that specialize in health information.¹² Therefore, on June 27, 2016, we searched Google using the terms “kidney donation,” “living kidney donation,” and “how to be a kidney donor.” Google was selected for identifying websites because it is the search engine used for 81% and 96% of online desktop and mobile device searches, respectively.³⁰ Location, cookies, and user account information were disabled to reduce bias in websites identified by the search engines. For inclusion in our analysis, websites had to (i) be hosted by a nonprofit or patient advocacy organization, (ii) be focused on the United States population, (iii) contain information pertinent to living kidney donation, and (iv) have English content. We excluded websites that were identified by search engines as sponsored sites, transplant program-specific websites, media reports (eg, news articles), scientific publications, personal narrative websites, and non-U.S. websites. Transplant program websites were excluded because programs vary in donor policies and practices, may focus more specifically on their own program practices and experiences, and the general public often prefers websites that are independent.¹² Also, some transplant programs have paid fees for prime placement on search engines. Non-U.S. websites were

identified by the uniform resource locator, hosting country, address/country provided on the website, or specific mention of the country targeted. Scientific publications were excluded because they are written for a professional audience (eg, researchers, clinicians), narrowly focused, and not for transplant candidates and/or potential living donors. Also, scientific articles focus on one or two specific aims and, therefore, are narrowly focused. We made an a priori decision to include in our analysis the first 10 websites from each of the three Google searches that met inclusion/exclusion criteria. Once we identified these 10 websites, we stopped the online search process for that search term and went on to the next search term.

To ensure the websites we identified by Google search were representative of the websites recommended and/or frequently encountered by the transplant community, we asked six participants (two nephrologists, one surgeon, one nurse, one social worker, one living donor) from the 2014 Consensus Conference on Live Kidney Donation¹¹ to review the list and supplement it with any other websites they felt were important to include in our analysis. Each website meeting inclusion criteria was examined for popularity using the Widexl.com Link Popularity Check (<http://www.widexl.com/>), which identifies the number of websites with embedded links to the target website under evaluation.

2.2 | Readability

All written information about living kidney donation within a single click of the homepage was copied and downloaded into a Microsoft Windows text file for each website. All words, regardless of length or complexity, were retained and unchanged. Readability assessment was completed using the Readability Studio Professional Edition (Oleander Software, Ltd, Vandalia, OH). Six different readability tests (FRE index, Flesch–Kincaid Grade Level, Fry Graph, Gunning Fog Index, Raygor Readability Estimate, and SMOG Formula) using unique formulas that consider word length, sentence length, word complexity, and/or word familiarity were examined. We conducted readability assessments for all information combined across websites and for each individual website.

2.3 | Living kidney donation content

We developed a checklist of informational content considered important by regulatory agencies and members of the transplant community to disclose to potential LKDs to facilitate informed decision making, for example, living donation evaluation processes, donation eligibility criteria, risks and benefits of donation for the LKD, and benefits of LDKT for the transplant patients.^{10,11,18–20,31,32} We asked five transplant professionals (two nephrologists, one surgeon, one nurse, and one social worker) who participated in the Consensus Conference on Best Practices in Living Kidney Donation¹¹ to review the checklist for completeness, redundancy, and accuracy. Based on their feedback, we added items and made other modifications, resulting in a checklist with 30 items. For some checklist items, in addition to determining whether it was mentioned on the website, we documented the

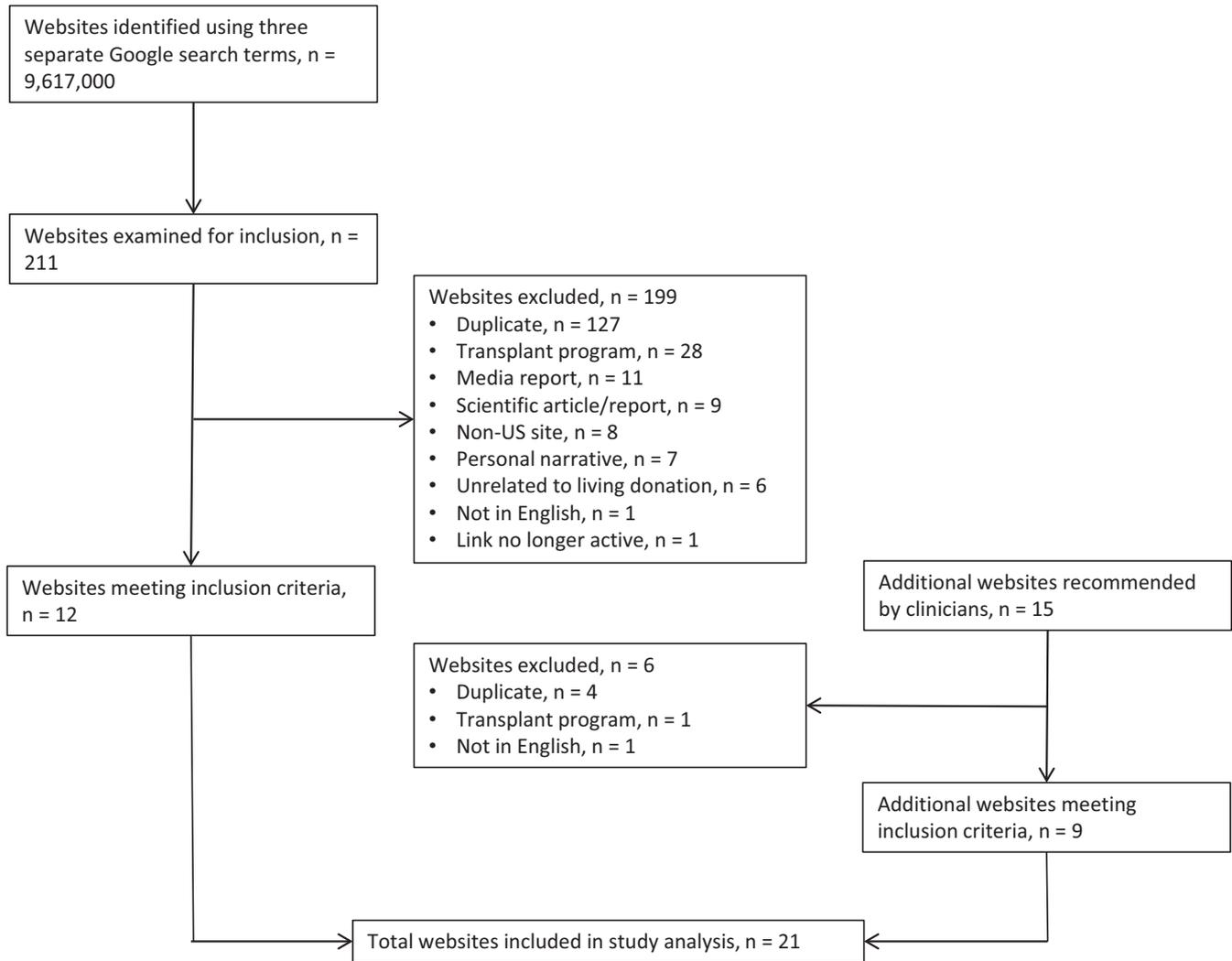


FIGURE 1 Website selection

presence of any specific content that led the item to be scored favorably. For instance, a website could be credited with having information about the medical risks of living donation, whether it identified one medical risk or several medical risks. Therefore, we recorded each of the medical risks identified on the website.

Two nonclinician raters independently examined the living kidney donation content of each website for the presence of these informational topics. Nonclinicians were used to best reflect the end-users of the websites, that is, potential LKDs. They limited their review to website content only, that is, did not click through to external links. Kappa coefficient was 0.87, indicating good agreement between raters. Disagreements were discussed until consensus was reached or, if consensus was not reached, by an independent arbiter who reviewed the sites in question.

2.4 | Racial/Ethnic diversity

In the absence of any existing measures, we developed a checklist to assess each website's racial/ethnic diversity. Items were generated based on literature addressing racial disparities in living kidney

donation and LDKT and website elements that were thought to be important by the minority LKDs (n=2), transplant candidate (n=1), and LKD nurse coordinator (n=1) we consulted. The final checklist comprised nine items, focusing on whether the website mentioned race or ethnicity, provided information and video vignettes in a language other than English, had images and videos in which racial minorities were represented, mentioned differences in living donation rates and outcomes based on race, noted racial disparities in LDKT, and provided links to other websites for specific minority populations. The same two raters independently reviewed the websites and coded the presence of these nine items. High agreement was achieved (kappa coefficient=0.78), and disagreements again were resolved as noted above.

3 | RESULTS

3.1 | Website popularity and readability

Our Google searches resulted in 9 617 000 hits (536 000 for "kidney donation," 381 000 for "living kidney donation," and 8 700 000 for "how to be a kidney donor") (Figure 1). For each search, we examined

TABLE 1 Living kidney donation websites accessed

Website	Organization	Popularity ^a
livingkidneydonorsnetwork.org	Living Kidney Donors Network	2900
kidney.org	National Kidney Foundation	2600
kidneyregistry.org	National Kidney Registry	2000
paireddonation.org	Alliance for Paired Kidney Donation	1600
livingdonationcalifornia.org	Living Donation California	1100
Informate.org		778
unos.org	United Network for Organ Sharing	512
helplivingdonorssavelives.org	American Living Organ Donor Network	445
transplantliving.org	United Network for Organ Sharing	426
livingdonorsonline.org	International Association of Living Organ Donors	350
kidneylink.org	PKD Foundation	279
americantransplantfoundation.org	American Transplant Foundation	261
livingdonor101.com	LivingDonor101	165
nationalkidneycenter.org	National Kidney Center	100
waitlistzero.org	Waitlist Zero	37
donatelifenet.net	Donate Life America	32
livingbank.org	The Living Bank	3
wikihow.com	wikiHow	1
myast.org	American Society of Transplantation	0
donors1.org	Gift of Life Donor Program	0
Johnbrockingtonfoundation.org	John Brockington Foundation	0

^aNumber of websites that link to the target website.

all websites identified until we reached 10 sites that met inclusion/exclusion criteria. After excluding duplicates and sites that did not meet inclusion criteria, we had 12 websites that were eligible for study inclusion. Our clinician panel identified an additional 15 websites, and nine met inclusion criteria. In total, 21 websites were included for analysis in the study.

Table 1 lists the 21 websites we identified for analysis and popularity. Most of the websites (n=16, 76%) were not part of the Moody et al.¹⁸ study and, therefore, are reviewed for the first time here. Five (24%) websites had >1000 links to their website from external

sites—livingkidneydonorsnetwork.org, (2900), kidney.org (2600), kidneyregistry.org (2000), paireddonation.org (1600), and livingdonationcalifornia.org (1100). None of the remaining websites exceeded 800 external links and eight (38%) had ≤100 links. Most websites (n=15, 71%) reported a copyright date or date of last revision. Ten sites were reportedly updated in 2016, three in 2015, one in 2014, and one in 2011. Eight (38%) and 14 (67%) websites had videos or images, respectively, featuring LKDs and/or LDKT recipients.

We copied and downloaded a total of 132 pages for evaluation and, collectively, they had an overall average reading level of 10.9. Further analysis of these 132 pages was performed. The six readability tests yielded very similar findings; therefore, we present results from the Flesch Reading Ease (FRE) test, which is more commonly used and easily interpreted. The FRE yields a score ranging from 0 to 100 (0=hardest to read, 100=easiest to read). The average score for the 21 websites combined was 50.0, which is classified by the FRE analysis as “Difficult to read.” Individual website FRE scores ranged from 38 (“Difficult to read”; nationalkidneycenter.org) to 63 (“Plain English—Easily understood”; informate.org) (Figure 2). Thirteen (62%) websites had FRE scores in the “Difficult to read” category, six (28%) in the “Fairly difficult to read” category, and two (10%) were classified as “Plain English—Easily understood.” We also calculated specific readability test scores for each website and, across all readability metrics, none of the websites achieved an average reading grade level below 9th grade.

3.2 | Living kidney donation content

Table 2 shows the number and percentage of informational topics covered on each website we accessed. On average, websites covered 18.5 (62%) of the 30 recommended informational elements, ranging from 7 (23%; johnbrockingtonfoundation.org) to 28 (93%; transplantliving.org) topics covered.

Table 3 summarizes the number and percentage of websites that covered each of the living kidney donation topics, from most to least common. The majority of websites covered the various risks associated with living kidney donation (financial, 90%; surgical, 86%; medical, 71%; social, 62%; psychological, 57%), although coverage of specific risks within each risk category was uneven. For instance, while surgical risks such as death (n=15, 71%), infection (n=16, 76%), and pain/discomfort (n=16, 76%) were covered by the majority of websites, only half or fewer mentioned the risk of injury to surrounding tissues/organs (n=11, 52%) or hernia (n=10, 48%). Similarly, specific medical and psychological risks were not identified by a majority of sites (eg, <50% of websites noted risk of permanent loss of kidney function, proteinuria, pregnancy complications, fatigue, regret, or depression). However, most websites described that personal expenses related to donation may not be reimbursed (n=16, 76%) and that LKDs may incur lost wages/income as a result of donation (n=17, 81%). More than half (n=13, 62%) indicated that resources may be available for LKDs to defray some donation-related costs.

Most websites covered kidney paired donation (86%), living kidney donation eligibility (82%), and the evaluation process (82%), the

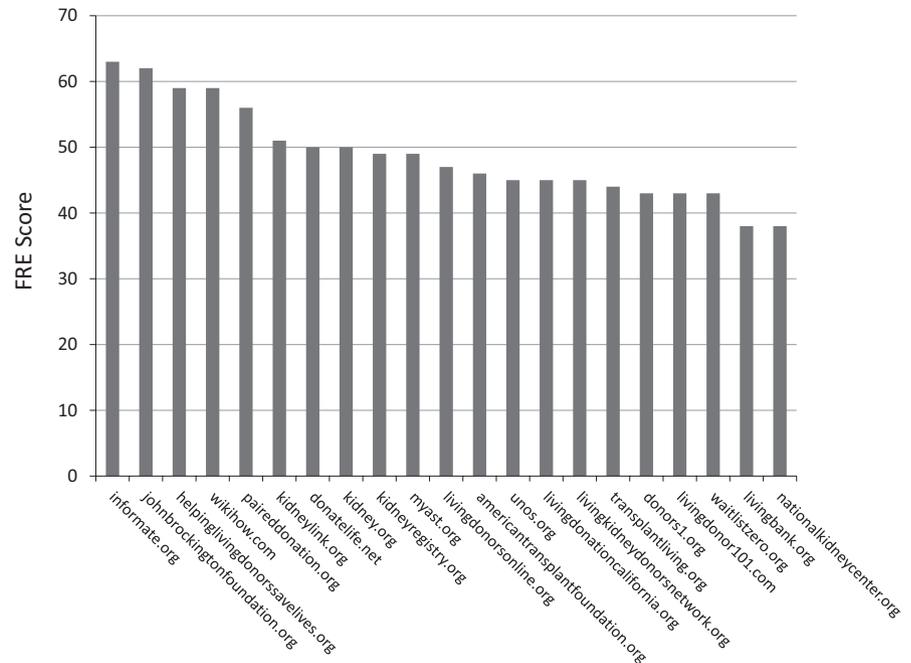


FIGURE 2 Flesch Reading Ease (FRE) score by website accessed. Higher scores reflect content that is easier to read

TABLE 2 Number (%) of living kidney donation informational topics covered on each website accessed

Website	Living Donation Topics Covered ^a
	n (%)
transplantliving.org	28 (93)
livingdonationcalifornia.org	27 (90)
unos.org	26 (87)
Informate.org	25 (83)
kidney.org	24 (80)
livingdonorsonline.org	24 (80)
waitlistzero.org	22 (73)
americantransplantfoundation.org	21 (70)
livingkidneydonorsnetwork.org	21 (70)
livingdonor101.com	20 (67)
paireddonation.org	18 (60)
myast.org	18 (60)
donors1.org	18 (60)
wikihow.com	17 (57)
livingbank.org	15 (50)
kidneylink.org	14 (47)
kidneyregistry.org	12 (40)
nationalkidneycenter.org	12 (40)
donatelife.net	11 (37)
helplivingdonorssavelives.org	9 (30)
Johnbrockingtonfoundation.org	7 (23)

^aRange=0-30.

requirement that donation be voluntary and free from inducement (82%), medical costs associated with donation evaluation and surgery are covered by the recipient's health insurance (76%), typical length of hospitalization (71%) and recovery (71%), possible benefits of living donation for the donor (67%), the annual number of LKDs in the USA (62%), living donation exclusion criteria (62%), and the acquisition or transfer of a human organ for anything of value (ie, cash, property, and vacations) is illegal (62%). Also, most websites described the alternative procedures or treatments available to the transplant candidate (86%), the benefits of the transplant candidate having a LDKT vs alternative procedures or treatments (86%), and the large number of patients on the kidney transplant waiting list (71%).

In contrast, half or fewer of the websites indicated that donation eligibility criteria may vary across transplant programs (48%), the availability of the independent living donor advocate (43%), LKDs are given priority if they need a kidney transplant in the future (38%), health information obtained during LKD evaluation is confidential and private (33%), the typical waiting times for transplant candidates on the deceased donor waiting list (33%), the required two-year follow-up of LKDs by programs (33%), the benefits of pre-emptive LDKT for the transplant candidate (19%), and the potential LKD is evaluated by a different team of professionals than those for the transplant candidate (14%).

3.3 | Racial/Ethnic diversity

On average, websites covered 2.1 (23%) of the nine diversity checklist items, ranging from 0 (donatelife.net; nationalkidneycenter.org; wikihow.com) to 6 (informate.org). Nearly two-thirds (n=13, 62%) of websites included racial minorities in still images; however, only eight

**TABLE 3** Number (%) of websites that covered each living kidney donation topic

Living Kidney Donation Topic	n (%)
1. Financial risks of donation	19 (90)
Donor lost wages/income	17 (81)
Personal expenses (eg, travel, lodging, etc.) related to donation may not be covered	16 (76)
Caregiver or companion lost wages/income	2 (10)
2. Alternative procedures or treatments available to the transplant patient	18 (86)
3. Benefits of LDKT vs alternative treatments for the transplant patient	18 (86)
Improved quality of life	12 (57)
Planned surgery	12 (57)
Shorter waiting time for transplant	10 (48)
Reduced risk of delayed graft function	9 (43)
Longer graft survival	8 (38)
Limited or no dialysis exposure	8 (38)
Planned desensitization, if necessary	8 (38)
Reduced risk of rejection	8 (38)
Longer patient survival	6 (29)
More cost-effective	3 (14)
Transplant performed at time of optimal health	2 (10)
Shorter hospitalization	1 (5)
4. Surgical risks of donation	18 (86)
Pain and discomfort	16 (76)
Infection	16 (76)
Death	15 (71)
Bleeding (blood loss)	14 (67)
Injury to surrounding tissues/organs	11 (52)
Hernia	10 (48)
5. Kidney paired donation (kidney exchanges)	18 (86)
6. Donor evaluation process	17 (82)
7. Donation eligibility criteria	17 (82)
8. Donation decision must be voluntary and/or free from coercion/inducement	17 (82)
9. Donor evaluation and surgery costs are covered by the transplant center or transplant patient's insurance	16 (76)
10. Number of patients on the deceased donor transplant waiting list	15 (71)
11. Medical risks of donation	15 (71)
High blood pressure (hypertension)	12 (57)
Future kidney failure may be higher compared to nondonors	12 (57)
Permanent loss of kidney function	9 (43)
Proteinuria	9 (43)
Pregnancy complications	8 (38)
Fatigue	8 (38)
12. Typical length of hospital stay for donor	15 (71)
13. Typical recovery time after donation	15 (71)
14. Process for anonymous (nondirected) donation	14 (67)
15. Benefits of living donation for donor	14 (67)
16. Number of annual living kidney donors in USA	13 (62)
17. Financial resources may be available to donor	13 (62)
National Living Donor Assistance Center	12 (57)
American Kidney Fund	5 (24)

(Continues)

TABLE 3 (Continued)

Living Kidney Donation Topic	n (%)
American Transplant Foundation	4 (19)
Other(s)	10 (48)
18. Acquisition or transfer of human organ for anything of value is illegal	13 (62)
19. Common donation exclusion criteria	13 (62)
20. Social risks of donation	13 (62)
Impact on ability to obtain, maintain, or afford health insurance	11 (52)
Impact on ability to obtain, maintain, or afford life insurance	11 (52)
Future health problems may not be covered by recipient's insurance	9 (43)
Changes in relationship with recipient	5 (24)
Changes in family dynamics or other relationships	5 (24)
21. Psychological risks of donation	12 (57)
Feelings of regret	10 (48)
Depression	10 (48)
Anxiety	10 (48)
Body image changes	6 (29)
Lifestyle changes	3 (14)
22. Donor candidate can confidentially decline donation at any time during evaluation process	11 (52)
23. Eligibility criteria may vary across transplant programs	10 (48)
24. Donor candidate will be assigned an independent living donor advocate (role described)	9 (43)
25. Donors receive priority on waiting list if kidney transplant needed in future	8 (38)
26. Donor health information obtained during evaluation is confidential and private	7 (33)
27. Typical waiting times for transplant patients on the deceased donor transplant list	7 (33)
28. Importance of follow-up at specified intervals for 2 y after donation (programs required to submit follow-up data)	7 (33)
29. Benefits of pre-emptive transplant for the transplant patient	4 (19)
30. Donor candidate is evaluated by a different team than that for the transplant patient	3 (14)

(38%) had videos depicting minorities. Few websites mentioned race or ethnicity at all (n=6, 29%), provided text information (n=5, 24%), or videos (n=2, 10%) in another language in addition to English, mentioned differences in living donation (n=2, 10%) or LDKT (n=2, 10%) rates by race, provided links to other websites for specific minority populations (n=4, 19%), or mentioned differences in living donation outcomes based on race (n=2, 10%).

4 | DISCUSSION

There are many circumstances when an adult may seek information about living donation online. For instance, one may turn to the internet to gather information (i) when considering whether to initiate donation evaluation on behalf of a known individual (family member, friend, co-worker, etc.) in need of transplantation, (ii) when examining the possibility of nondirected donation, or (iii) to supplement information provided by a living donor nurse or physician after initiating screening or evaluation. Importantly, as noted by others,¹⁸ websites may be the only source of information for individuals who decide not to pursue living donation evaluation. Thus, it is essential that the general public has access to understandable, accurate, comprehensive,

and current information about the most essential aspects of living donation to facilitate informed decision making. Individuals who visit websites that do not meet these minimal standards may make decisions about living donation evaluation based on incomplete or inaccurate information.

In the current study, we found that all living donation websites we reviewed fail to meet the widely accepted recommendation that health-related information be presented at the 6th grade reading level or lower.³³ Our finding of an average readability at or above the 11th grade level mirrors that of Moody et al.¹⁸ a decade ago, suggesting little to no progress in improving the readability of online living kidney donation information. Nearly half of all adults in the USA have literacy problems that make it difficult to fully comprehend health-related information.^{34,35} This large segment of the U.S. adult population is unlikely to fully comprehend information on living donation websites as currently written at the 11th grade level. We recommend that existing and future websites providing living kidney donation information consider the rapidly expanding literature on health literacy and numeracy to implement strategies that make information more accessible to a broader population.³⁶ Table 4 presents some common strategies to improve website readability, particularly for those with low literacy. Additionally, website developers should conduct usability testing with

TABLE 4 Strategies to improve the readability, comprehension, and cultural relevancy of living donation websites

Use shorter sentences and paragraphs
Use an active (vs passive) voice
Use bullet points to better cluster certain types of information
Use headings and subheadings to make it easier for readers to scan the website and understand what information is being presented
Use question-based headings
Use videos and other media to facilitate faster processing of information
Visually emphasize key points (eg, bold, underline, different color)
Use alternative strategies to present mathematical concepts such as probability and risk
Provide information specific to populations with known disparities in living kidney donation rates and outcomes (eg, racial/ethnic minorities)
Include adults in images and videos that are representative of the diversity of potential LKDs
Provide non-English content and videos
Engage a cultural specialist to help guide the development of culturally relevant content
Conduct usability testing with adults that are representative of the potential LKD population

adults that are representative of the diversity of the potential LKD population. Strategies such as the “teach-back” method may help to ensure that the information presented is not only readable but understandable to the general consumer.³⁷

Our findings also underscore the degree to which most living donation websites do not reflect racial/ethnic diversity. Some websites with personal images and video testimonials included racial/ethnic minorities. However, very few websites directly mentioned race/ethnicity, its relevance in living donation and LDKT, or made content available in a language in addition to English. These findings are surprising considering the sharp decline in living kidney donation among blacks, known racial disparities in LDKT rates, differences in long-term outcomes by race, and the rapidly growing population of adults in the USA for whom English is not the primary language.^{21,26,27,38} Gordon et al.¹⁹ found relatively few websites targeting Hispanics in the USA and those that did were found to have readability levels that were too high. Also, very few attended to cultural beliefs, which have been found to be important determinants of living donation willingness in the Hispanic population.^{19,39–41} Websites that do not consider racial/ethnic diversity or cultural relevance in the development process risk exacerbating existing disparities by disseminating information that may not be considered trustworthy because of its inattention to these issues.

While federal regulations require transplant programs to provide specific information to potential LKDs, no such regulations or minimum standards exist for websites. In addition to known variability in the quality and accuracy of online information, we found that several informational topics that transplant programs are required to communicate to potential LKDs are either not covered at all or presented in insufficient detail by many websites (eg, independence of the donor

evaluation team, confidentiality of the evaluation and its findings, required two-year follow-up of LKDs). Also, while most of the websites mention the various risks of living kidney donation, there is considerable variability in the specificity of these risks.

Transplant providers are best positioned to discuss with potential LKDs the requirements and inherent complexities of donation (eg, the evaluation process, eligibility criteria, surgery, potential risks and benefits for both the donor and recipient, and long-term outcomes) as well as the emergence of new information that may impact decision-making. Unlike a website, the provider is also able to place this information in both the broader contexts of donation and transplantation and the specific circumstances of an individual potential LKD's unique risk assessment. Ideally, these websites would supplement the more detailed information that potential LKDs receive as part of their evaluation. However, as noted by Gordon et al.,⁴² variability in educational processes at transplant programs may be contributing to findings that many LKDs express dissatisfaction with information about some aspects of the donation process and may not have a full understanding of donation risks. This is supported by Thiessen et al.,³¹ who found that many of 148 written informed consent forms for LKD evaluation they reviewed did not include educational elements required by CMS and/or OPTN (eg, only 48% contained information about the potential for decreased kidney function following donation). In a study of former LKDs, Valpour et al.⁴³ found that only 52% and 32% stated that they understood the long-term medical and financial risks of donation, respectively. Thus, these deficiencies regarding the education of potential LKDs exist at both the program level and online. Importantly, Waterman et al.¹⁰ have proposed a theoretical framework for designing and delivering living kidney donation information to both transplant candidates and potential LKDs, and emphasized the need to provide more culturally tailored education about donation.

In recent years, innovative programs have been implemented to increase both the awareness and number of LKDs.^{2–7} Such programs, if successful, are likely to increase the number of individuals who will seek more information online about living donation. In our view, the expansion of such programs to promote directed living donation, along with targeted media reports to raise general awareness of nondirected donation, obligates the transplant community to guide the provision of both accurate and sufficient information online to facilitate the initial education and decision-making of adults considering living kidney donation. While some have suggested the creation of an authoritative online clearinghouse for living donation information,^{10,11} this will not stop the development of websites by individuals and various organizations trying to meet the needs of their constituents. An alternative strategy for increasing the overall quality of all living donation websites, which may facilitate more rapid improvement in available information online, is for one of the professional transplant societies (eg, American Society of Transplantation's Live Donor Community of Practice) to adopt a proactive role in reviewing living donation websites and providing a seal of approval only if they meet minimum predefined readability, racial/ethnic diversity, and content standards. Specific feedback could be given to website hosts that do not receive the seal of approval, which may help them to eventually achieve the minimum standards.

In addition to the information we coded, we were surprised how difficult it was to navigate many of the websites and to identify the informational topics we were coding. Also, while we did not focus on the accuracy of the information provided, there were clear instances of inaccurate statements (eg, claims of no data on pregnancy complications, upper donor age limit of 60 years old) or data that were no longer current (eg, links to data last updated in 2006, no known evidence of long-term risk of renal failure in LKDs). Most websites did not provide source citations or references for data provided, nor did they provide other information considered important by the NIH in evaluating health information online (eg, who pays for the website, who verified information before being posted on the website, whether the website has a linking policy, etc.).⁴⁴ Future investigations might consider evaluation of these additional metrics. Also, transplant providers should evaluate the accuracy of living donation websites and timeliness of the information provided—both those we reviewed and those we did not—before recommending them to transplant and living donor candidates.

This study has several notable strengths: the inclusion of the most common nonprofit or patient advocacy organization websites, reproducible measures of evaluation, use of data collection methods that minimized bias and subjectivity, and an assessment of racial/ethnic diversity. However, our findings should be considered in the context of several important limitations. First, we excluded living donation websites developed by transplant programs, personal websites, and websites hosted outside the USA, which may have different levels of readability and comprehensiveness. Moody et al.,¹⁸ however, did not find any differences in these characteristics based on website type or source. Nevertheless, our findings are not applicable to these other website types and should not be generalized beyond those we evaluated. Also, our method for selecting websites to review may not reflect the manner in which individuals search for information about living donation. Second, we recognize that there are other sites not reviewed in this study that potential LKDs may be accessing and these warrant similar levels of scrutiny. Third, while we gathered information about the racial/ethnic diversity of websites, we did not focus on the broader construct of cultural relevancy, which includes a deeper examination of cultural beliefs and misconceptions about donation, perceived community support for donation, and religious beliefs and concerns, among others. Gordon et al.¹⁹ provide an example of how a broader assessment of cultural relevancy could be undertaken in future studies. Fourth, we excluded websites for which English was not the primary language, thus perhaps biasing our evaluation toward websites that may have lower racial/ethnic diversity. Fifth, we did not evaluate the accuracy of the content provided nor the aesthetic quality of the websites. Future assessment of content accuracy is warranted, but will require careful consideration of center-specific and regional variations in practice and policies, as well as agreement by the transplant community regarding what constitutes an accurate statement. Sixth, our study did not examine which types of and how much information is necessary for potential donors to feel informed enough to pursue evaluation, which is an important question for future study. Finally, while our development of the content checklist was informed by the work of others^{11,18,19} and included additional items that reflect new policies

and regulations²⁰ that did not exist at the time of the Moody et al.,¹⁸ the measure has not been validated. We considered using the widely used DISCERN measure,⁴⁵ but it was created to help users of consumer health information judge the quality of information about their treatment choices rather than to assess the content of online sources. Also, our review focused on readability, content inclusion, and racial/ethnic diversity, not website quality or the accuracy of information presented.

In conclusion, many adults turn to the Internet for basic information that may help them consolidate their thinking about whether to consider living kidney donation. However, our evaluation of living kidney donation websites hosted by patient or nonprofit organizations echoes the findings initially reported by Moody et al.¹⁸ a decade ago—namely, some websites lack fundamental information considered important to disseminate to those considering living kidney donation, most websites lack racial/ethnic diversity, and all websites have readability levels that are too advanced. We encourage the transplant community to consider playing a more active role in improving the overall quality of online information disseminated to the general public.

ACKNOWLEDGMENTS

This research is supported by Award Number R01DK085185 from the National Institute of Diabetes and Digestive and Kidney Diseases. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute of Diabetes and Digestive and Kidney Diseases or the National Institutes of Health. This research was also supported, in part, by the Julie Henry Research Fund, the Center for Transplant Outcomes and Quality Improvement, and Surgical Outcomes Analysis & Research (SOAR), Beth Israel Deaconess Medical Center, Boston, MA.

CONFLICTS OF INTEREST

There are no conflicts of interest to report.

REFERENCES

- Hart A, Smith JM, Skeans MA, et al. OPTN/SRTR Annual Data Report 2014: kidney. *Am J Transplant*. 2016;16(S2):11-46.
- Schweitzer EJ, Yoon S, Hart J, et al. Increased living donor volunteer rates with a formal recipient family education program. *Am J Kidney Dis*. 1997;29:739-745.
- Rodrigue JR, Cornell DL, Lin JK, Kaplan B, Howard RJ. Increasing live donor kidney transplantation: a randomized evaluation of a home-based educational intervention. *Am J Transplant*. 2007;7:394-401.
- Marlow NM, Kazley AS, Chavin KD, Simpson KN, Balliet W, Baliga PK. A patient navigator and education program for increasing potential living donors: a comparative observational study. *Clin Transplant*. 2016;30:619-627.
- Garonzik-Wang JM, Berger JC, Ros RL, et al. Live donor champion: finding live kidney donors by separating the advocate from the patient. *Transplantation*. 2012;93:1147-1150.
- Pradel FG, Suwannaprom P, Mullins CD, Sadler J, Bartlett ST. Short-term impact of an educational program promoting live donor kidney transplantation in dialysis centers. *Prog Transplant*. 2008;18:263-272.
- 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;61:476-486.
8. Gordon E. Living donors can save lives—and have the greatest potential to combat our organ shortage. Pacific Standard. <https://psmag.com/living-donors-can-save-lives-and-have-the-greatest-potential-to-combat-our-organ-shortage-d8d117024176#.y1x3bj7l2> Accessed November 14, 2014.
 9. Donate Life America and UPMC utilize social media to educate about living donation and help end waiting list deaths. <http://www.prnewswire.com/news-releases/donate-life-america-and-upmc-utilize-social-media-to-educate-about-living-donation-and-help-end-waiting-list-deaths-300283144.html>. Accessed October 1, 2016.
 10. 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;3:1-9.
 11. LaPointe Rudow D, Hays R, Baliga P, et al. Consensus Conference on Best Practices in Live Kidney Donation: Recommendations to optimize education, access, and care. *Am J Transplant* 2015;15:914-922.
 12. Fox S, Duggan M. Health online-2013. <http://www.pewinternet.org/2013/01/15/health-online-2013/>. Accessed October 6, 2016.
 13. Winker MA, Flanagin A, Chi-Lum B, et al. Guidelines for medical and health information sites on the internet: principles governing AMA web sites. American Medical Association. *JAMA.* 2000;283:1600-1606.
 14. Prabhu AV, Hansberry DR, Agarwal N, Clump DA, Heron DE. Radiation oncology and online patient education materials: deviating from NIH and AMA recommendations. *Int J Radiat Oncol Biol Phys.* 2016;96:521-528.
 15. Storino A, Castillo-Angeles M, Watkins AA, et al. Assessing the accuracy and readability of online health information for patients with pancreatic cancer. *JAMA Surg.* 2016;151:831-837.
 16. Ibrahim AM, Vargas CR, Koolen PG, Chuang DJ, Lin SJ, Lee BT. Readability of online patient resources for melanoma. *Melanoma Res.* 2016;26:58-65.
 17. Lutz ER, Costello KL, Jo M, et al. A systematic evaluation of web-sites offering information on chronic kidney disease. *Nephrol Nurs J.* 2014;41:355-363;364.
 18. Moody EM, Clemens KK, Storsley L, Waterman A, Parikh CR, Garg AX; Donor Nephrectomy Outcomes Research (Donor) Network. Improving on-line information for potential living kidney donors. *Kidney Int.* 2007;71:1062-1070.
 19. Gordon EJ, Rodde J, Gil S, Caicedo JC. Quality of Internet education about living kidney donation for Hispanics. *Prog Transplant.* 2012;22:294-303.
 20. OPTN (Organ Procurement and Transplantation Network)/UNOS (United Network for Organ Sharing). OPTN Policies, Policy 14: Living Donation. http://optn.transplant.hrsa.gov/ContentDocuments/OPTN_Policies.pdf. Accessed October 1, 2016.
 21. Muzaale AD, Massie AB, Wang MC, et al. Risk of end-stage renal disease following live kidney donation. *JAMA.* 2014;311:579-586.
 22. Grams ME, Sang Y, Levey AS, et al. Kidney failure risk projection for the living kidney donor candidate. *N Engl J Med.* 2016;374:411-421.
 23. Mjoen G, Hallan S, Hartmann A, et al. Long-term risks for kidney donors. *Kidney Int.* 2014;86:162-167.
 24. Taber DJ, Gebregziabher M, Hunt KJ, et al. Twenty years of evolving trends in racial disparities for adult kidney transplant recipients. *Kidney Int.* 2016;90:878-887.
 25. Rodrigue JR, Kazley AS, Mandelbrot DA, Hays R, LaPointe Rudow D, Baliga P. Living donor kidney transplantation: overcoming disparities in live kidney donation in the US—Recommendations from a Consensus Conference. *Clin J Am Soc Nephrol.* 2015;10:1687-1695.
 26. Gill J, Dong J, Rose C, Johnston O, Landsberg D, Gill J. The effect of race and income on living kidney donation in the United States. *J Am Soc Nephrol.* 2013;24:1872-1879.
 27. Rodrigue JR, Schold JD, Mandelbrot DA. The decline in living kidney donation in the United States: random variation or cause for concern? *Transplantation.* 2013;96:767-773.
 28. Lentine KL, Schnitzler MA, Xiao H, et al. Racial variation in medical outcomes among living kidney donors. *N Engl J Med.* 2010;363:724-732.
 29. Lentine KL, Segev DL. Health outcomes among non-Caucasian living kidney donors: knowns and unknowns. *Transpl Int.* 2013;26:853-864.
 30. Net Market Share. <https://www.netmarketshare.com/search-engine-market-share.aspx?qprid=4&qpcustomd=0> Accessed November 17, 2016.
 31. Thiessen C, Kim YA, Formica R, Bia M, Kulkarni S. Written informed consent for living kidney donors: practices and compliance with CMS and OPTN requirements. *Am J Transplant.* 2013;13:2713-2721.
 32. Tan JC, Gordon EJ, Dew MA, et al. Living donor kidney transplantation: facilitating education about live kidney donation—Recommendations from a Consensus Conference. *Clin J Am Soc Nephrol.* 2015;10:1670-1677.
 33. Weiss BD. *Health literacy: a manual for clinicians.* Chicago, IL: American Medical Association Foundation and American Medical Association; 2003.
 34. Safeer RS, Keenan J. Health literacy: the gap between physicians and patients. *Am Fam Physician.* 2005;72:463-468.
 35. Mackert M, Mabry-Flynn A, Champlin S, Donovan EE, Pounders K. Health literacy and health information technology adoption: the potential for a new digital divide. *J Med Internet Res.* 2016;18:e264.
 36. How to write easy-to-read health materials. Available at: <http://www.nlm.nih.gov/medlineplus/etr.html> Accessed October 2, 2016.
 37. Rider BB, Lier SC, Johnson TK, Hu DJ. Interactive web-based learning: translating health policy into improved diabetes care. *Am J Prev Med.* 2016;50:122-128.
 38. Passel JS, Cohn D. U.S. Population Projections: 2005-2050. Pew Research Center. <http://www.pewhispanic.org/2008/02/11/us-population-projections-2005-2050/>. Accessed October 2, 2016.
 39. Siegel JT, O'Brien EK, Alvaro EM, Poulsen JA. Barriers to living donation among low-resource Hispanics. *Qual Health Res.* 2014;24:1360-1367.
 40. Alvaro EM, Siegel JT, Turcotte D, Lisha N, Crano WD, Dominick A. Living kidney donation among Hispanics: a qualitative examination of barriers and opportunities. *Prog Transplant.* 2008;18:243-250.
 41. 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;100:1149-1160.
 42. Gordon EJ. Informed consent for living donation: a review of key empirical studies, ethical challenges and future research. *Am J Transplant.* 2012;12:2273-2280.
 43. Valapour M, Kahn JP, Bailey RF, Matas AJ. Assessing elements of informed consent among living donors. *Clin Transplant.* 2011;25:185-190.
 44. National Institutes of Health, Office of Dietary Supplements. How to evaluate health information on the internet: questions and answers. https://ods.od.nih.gov/Health_Information/How_To_Evaluate_Health_Information_on_the_Internet_Questions_and_Answers.aspx. Accessed January 13, 2017.
 45. Charnock D, Shepperd S, Needham G, Gann R. DISCERN: an instrument for judging the quality of written consumer health information on treatment choices. *J Epidemiol Community Health.* 1999;53:105-111.

How to cite this article: 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. <https://doi.org/10.1111/ctr.13039>