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Living kidney donors and their family caregivers: developing an evidence-based educational and social support website

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Abstract

Context—Although graft and patient survival rates for living kidney donation are improved, some healthcare providers question whether volunteer donors and their informal caregivers are fully informed of the donation process and the risks involved. Donors and their family caregivers have reported that they receive limited information about the predonation and donor recovery process. Offering web-based information and social support is one way to address this gap.

Strategy—Living kidney donor candidates and their family caregivers participating in the Living Donor Information Network for Caregiving (LINC) have access to a variety of online informational resources and a social support discussion forum throughout their living kidney donation experience. Strategies in the development and implementation of an online information and social-support resource are presented.

Conclusions—Use of the LINC website for information and support may assist health care providers in identifying potential barriers in the current donation process and provide direction for enhancing knowledge and confidence among donors and family caregivers.

In the past decade, living organ donation has dramatically changed the field of transplantation and the lives of those with end-stage organ disease. In 2010, there were 6276 living kidney donors in the United States (almost 96% of all living organ donors).¹ There is consensus within the transplant community that living organ donors must be “fully informed of the risks and benefits as a living donor, and fully informed of the risks, benefits, and alternative treatments available to the recipient.”² The care of these living kidney donors frequently falls to a family member or friend who serves as the caregiver during the postoperative recovery period.

The Living Donor Information Network for Caregiving (LINC) is a newly developed website offering information and social support for living kidney donors and their family caregivers throughout the living donation process. LINC offers (1) information modules and web links, and (2) a discussion board with other kidney donors as mentors. The long-term objective of LINC is to develop a model of online donor and family caregiver education and social support to be implemented at transplant centers nationally. The purpose of this article

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is to present approaches to facilitate participation and engagement in a web-based information and social support site for living kidney donors and caregivers. Areas to be discussed are development of a website guided by a conceptual framework, the development of an online discussion forum, including tracking of participation, and a variety of strategies used to promote website usage.

Background

Approximately 26 million adults, or 11% of the US population, have chronic/end-stage renal disease, with an annual health care cost of \$32.4 billion.³ Despite the many technological advances, 94949 patients with end-stage renal disease are currently on the waiting list for kidneys; the number of patients in need is increasing by 20% per year.^{3–6} Living kidney transplantation provides the best survival and quality of life outcomes for patients with end-stage renal disease.⁴

Inadequate education due to limited access to information for living kidney donors has been identified as a factor that may prevent or discourage potential donors from living organ donation.^{6–9} Web-based education has been noted to increase the healthcare participation of patients and family caregivers by equipping them with information that bolsters their confidence in interactions with their healthcare provider.^{10–14} Evidence from several studies of individuals with different types of diseases has indicated that patients, their spouses, and informal caregivers desire additional education, opportunities for information sharing, and social support.^{15–18}

Internet-based education programs may increase knowledge and benefit patients and caregivers when used in conjunction with traditional education methods.¹⁹ Brennan²⁰ suggests that online support systems and educational offerings may make meeting the demands of ever-changing home care goals and make recovery information more accessible and efficient for an individual patient and family. Taylor and McMullen²¹ report that living kidney donor candidates and their spouses experience a process of information gathering and decision making in which they feel confident and fully informed about the decision to donate. By using a variety of engaging and interactive methods, Internet-based resources can reach out to a more heterogeneous patient population, cross over generational barriers benefiting multiple learning styles.^{22,23} However, very few studies have prospectively examined the adequacy of education for living donors and their caregivers. In an exploratory study²⁴ of living kidney donors, fewer than 20 participants (20%) reported that they “felt well informed.” Researchers must invest more time in developing theory-based online interventions and modes of educational delivery.

Living Kidney Donors and Family Caregivers

Living kidney donors and their family caregivers have reported using the Internet for support and information regarding donation, especially throughout the donation process.^{22–24} Areas that have been acknowledged as inadequate include donor reports of unexpected financial hardships related to the donation,^{22–25} recovery from surgery being more painful than they had anticipated,^{23,24} and seeking further information regarding surgery from the Internet. This finding was consistent with results of studies of family caregivers across many types of illness.^{16,26–28}

“There is a need for health care professionals to take into account a range of situational and contextual factors that may affect the use of online support groups” and more robust research will guide the development of effective web-based interventions. Research has indicated that web-based informational resources can guide patients and caregivers in prioritizing relevant information.^{27–31} A better understanding of online resources in regards

to living kidney donation can aid in the establishment of best practice for information and social support delivery among this community of patients.

Development of the Living Donor Information Network for Caregiving (LINC)

Conceptual Framework: Donor and Caregiver Characteristics

The conceptual framework of the LINC website design was built upon the donor and family framework of informed decision making about healthcare³² (see Figure). This framework represents the interactive and dynamic nature of donor candidates' and family caregivers' needs for information and support. The characteristics of donor candidates and family caregivers (such as race, sex, education, and previous Internet use) as well as existing information and social support for living donation all influence donor and informal caregiver outcomes.^{33–35}

Data on racial differences in accessing the Internet for healthcare information are conflicting. In 1 national study, African Americans were more likely than whites to obtain health information from the Internet.³⁵ In this national study, use of the Internet increased for all racial and ethnic groups, with African Americans and Hispanics increasing faster than other groups. In contrast, Jackson et al³⁶ reported that racial differences in Internet access still exist. African Americans use the Internet less intensely than do other racial groups, even when access is not an issue and factors related to Internet use such as income and education are controlled for.^{34–37} The Pew Internet project reported that age and education influence Internet use for healthcare information, with younger and more highly educated persons using the Internet more for health information than older persons with less education.³⁷ They also found that regular Internet users were more likely to use this medium to seek information on healthcare. Jackson and colleagues³⁶ found that women were more likely to access the Internet for health information than were men. However, male spouses and caregivers of living donors had all accessed the Internet seeking information about living kidney donation.²¹

In conclusion, developing a model of health education that is sensitive to cultural, age, and gender differences, such as LINC, can enhance trust by encouraging consistent and unbiased information exchange between the transplant team, donor candidates, informal caregivers, and donor mentors.

Conceptual Framework: Adequacy of Information and Support

Few studies have prospectively examined the adequacy of education for living donors and their caregivers; further, these studies have been limited in terms of sample size and scope. In 2 studies^{21,38} of living kidney donors, donors reported unexpected financial hardships related to the donation. In another pilot study,²⁴ 35% (n=52) reported that recovery from surgery was more painful than they had anticipated. Family caregivers of kidney donors have also reported being inadequately prepared to care for the donor during the surgical recovery phase.^{21,39} Lost time from work and realistic time frames for full recovery after donation were areas reported as presented to donors and caregivers in an overly simplistic manner by the transplant team.^{21–24,38,39}

The implications of these findings are critical in the holistic assessment of donor candidates and caregiver factors that affect pre- and posttransplant perceived adequacy of information and overall reports of satisfaction with the donation process.^{21,38–41} LINC has substantial promise to deliver additional, consistent information and support via a variety of accessible

formats as well as minimize the gap in information provision for patients and family caregivers.^{42–46}

Conceptual Framework: Online Healthcare Information and Support

“The immediacy of information access, the day or night accessibility, continual updating of information and the wider range of information available positively distinguish the Internet from other forms of information.”⁴⁵(p1797) Discussion boards, frequently termed “support groups without walls” are highly accessible sources of information and are the next most used Internet resource for consumers seeking health information, second only to stagnant disease-focused web pages.^{43–47} Discussion board participants have reported that they feel valued “for the strength of their contributions rather than being evaluated on their physical appearance.”⁴⁷(p19)

The Wisdom of Patients: Health Care Meets Social Media,⁴¹ from the California Healthcare Foundation, reports that health consumers highly value the information they get through their social networks and that persons tend to trust “a person like me” more than an authority figure. Also, trust will be enhanced by the consistency of information and support shared by donor candidates, informal caregivers, and donor mentors. In the interactions with other donors on an online platform such as LINC, where all donor candidates and family caregivers have received the same information about donation, users may be more likely to believe that they are being treated fairly by transplant professionals and the transplant center.⁴¹ Overall, there is little information on the trust that those considering donation placed in transplantation professionals or whether they consult with physicians other than those on the transplant team. The online LINC discussion forum provides information that is easily accessible, and the donors and their caregivers can ask questions about donation or seek support without being concerned that the respondent is considering their race, age, sex, or educational status.

Insufficient education about living donation and inadequate support after donation surgery have been documented in studies; substantial numbers of publications have shown that spouses/caregivers contribute significantly to the well-being of their ill partners in a variety of illnesses. The evaluation of technology-mediated communication of information and support remains limited despite the ever-growing use of information technology resources globally. Theoretically developed Internet resources will advance the understanding of how online mechanisms influence patients’ and caregivers’ outcomes.

The Living Donor Information Network for Caregiving

Development and Design of Evidence-Based Education and Social Support Network

A “Google” search on living kidney donation produced more than 1 300 000 websites. Websites of universities performing living kidney donation surgeries within 400 miles of Johns Hopkins Hospital Comprehensive Transplant Center that were similar in patient characteristics and volume of transplants performed were selected. The first 100 disease-oriented web pages were also selected as a reference. Each site was examined in the 4 primary categories noted as priorities in the donation education literature: recipient resources, donor resources, family caregiver resources, and communication (Table 1). Of these, 15 sites offered key topics presented to all donor candidates such as pain, risk of infection, child care, medical care after donation, and financial burden.^{8,23,24,34,38–41} Only 4 (4%; n=100) met all topic criteria and had an online chat or discussion board link. Of these 4 sites, only 1 (National Kidney Foundation) currently offers an asynchronous discussion board with social support mechanisms for living kidney donors (Table 1), and none offered a support site for family caregivers of living kidney donors. Reliability of the website review was established with 4 transplant team members reviewing designated sites, with multiple

sites being reviewed by more than 1 team member. A checklist was created to help guide reviewers and to ensure accuracy and further establish fidelity in the website evaluation process.

Studies of caregivers of patients experiencing a variety of diseases report that electronic social support services, such as information and support discussion boards, may reduce stress and strain on caregivers.^{21,48–57} Drawing on their shared embodied expertise, participants confirm the medical character of their problem and its remedy, and they empower each other to search for physicians who will recognize and treat their condition accordingly.^{41,43} Our extensive Google search revealed an insufficient availability of discussion boards for living donor candidates and caregivers. By providing this resource for donor candidates and their caregivers, LINC can address this deficiency.

LINC Design

The user interface design for LINC was developed on the basis of the review of the sites in Table 1. All donor candidates and family caregivers have access to the same content. To date, users choose information resources according to their self-selected area of interest. The LINC website addresses education and support by providing the following links:

1. **Educational Resources.** Numerous educational strategies are used on the LINC. Five minute “How to Use the Web Site” videos help guide visitors to what is available on the LINC teaches them how to navigate through the site. A variety of educational web links, including online articles, and YouTube clips (with closed captioning) are posted. Each posted item has been reviewed and approved by the comprehensive transplant team at Johns Hopkins Hospital.⁵⁸ Additionally all hard copy materials provided to donor candidates during their face-to-face evaluation with transplant coordinators are also posted as PDF files.^{58–60}
2. **Discussion Forum.** An asynchronous discussion board was selected because it allows social interaction and requires relatively low technology and computer skills (typing proficiency).⁶¹ The initial 4 forums were developed on the basis of categories found in the literature (see Discussion Forum). The users can create other forums and subforums.

Donor Mentors for Support

The communication within peer networks establishes that social and group norms have a strong influence on health-related behavior.^{53,62,63} A number of living kidney donors serve as online mentors. Donor mentors visit the discussion board to answer questions and offer advice to the living kidney donor candidates and caregivers who posted. These mentors are donors who expressed an interest in working with those individuals considering donation. The mentors are diverse in sex and race and received formal training through this comprehensive transplant center’s donor mentor program sponsored by the transplant coordinators. This certified hospital training provided guidance for the advice that donor mentors offer to donor candidates and their family caregivers. If questions came up about user postings, each mentor was given direct access to the development team. Along with the mentors, the LINC development team monitors postings to ensure matters of medical urgency are addressed with the transplant team.

Preliminary Testing of LINC

A critical component of the LINC development was the team members’ and donor mentors’ navigation through the website as if they were users. Feedback was paramount with guiding the information technology department in the restructuring of various aspects of the LINC site to ensure ease of use for users with basic computer skills.⁶³

Discussion Forum: Topics

The initial discussion board threads were initiated by the transplant team and supported in the literature.^{7,8,12,21,38} These threads included (1) Caregiver forum, (2) Questions about the procedure, (3) How is the process moving for you?, and (4) Life after donation. These categories are grounded in prior work with spouses of living kidney donors.

To date the available literature of caregivers of living kidney donors is limited to spouses. Taylor and McMullen²¹ found that spouses of living kidney donors reported that information-seeking behaviors changed as they and their donor moved through the donation experience. First, immediately after the donor candidate's predonation evaluation, spouses had questions about the surgical procedure (Questions about the procedure). Next, spouses expressed the need to explore the hospitalization, the amount of time that passed from evaluation to actual donation, and length of time needed to stay home and care for the new donor (How is the process moving for you? and Life after donation). Donors and family caregivers have reported that having an experienced donor and caregiver to speak with regarding the donation both before and after donation would have been helpful.^{21,38–40} For example, the literature explains that donors and caregivers have expressed that the transplant team's presentation of time frames for full postoperative recovery and lost time from work (Life after donation) have been reported in the transplant literature as oversimplified and that getting the information from other donors and caregivers may have guided overall preparation.^{12,21,27}

Discussion Board Participation

The first page of the discussion forum includes a disclaimer and rules for proper participation in the discussion board. Donor candidates and their family caregivers are encouraged to post responses to the discussion board throughout their donation experience. Donors, family caregivers, and mentors are introduced to the discussion board disclaimer that reiterates that LINC is a venue to contact potential donors to discuss donation and the donation process but LINC does not offer medical advice.^{61,64} Additionally, rules for proper online etiquette, otherwise known as “netiquette,” are clearly stated in the first page of the discussion forum^{60–69} (Table 2).

Researchers in previous studies have observed that determination of the “dosage” of a web-based information and social support discussion board is problematic. The frequency of discussion board postings is likely to decrease within the first 3 weeks of initial participation. This dropoff is a common phenomenon among online support groups.^{27,70–76} Some users may sign on only to quickly look for new postings (lurk) and not leave a post.

In anticipation of decreased use, weekly text messages and e-mails have been designed that encourage participation. A simple text message includes: “Have You ‘LINCed’ in Today?” Additionally, a “push e-mail method” has been implemented. Push e-mail sends e-mail alerts to all users and donor mentors when a new post has been created. All donor mentors and users receive an e-mail message with each new post. New postings are “flagged” with a small flag graphic that reads “New” and stays on each post for 1 week. This process enables rapid identification among donors and family caregivers. These mechanisms serve as reminders for users and bolster participation throughout the study. An important feature, however, is the ability of participants to opt out of receiving texts, e-mails, or e-mail digests.

Scharer⁵⁶ has suggested that following the data and tracking the time of day and number of minutes for those visits that result in a posting, versus those visits that simply involve scanning for new posts, can help direct the establishment of a “dose” for further evaluation of the impact of online discussion board support and information. Further details should be

explored regarding the tracking of data, such as total number of hits on the website and time stamps indicating exactly when each page is visited.^{28,29}

Discussion Board Participation by Development Team

Discussion board developers must consider the overall outcome and impact of their involvement within the Internet community for risk of potentially confounding the dialogue and dynamic of the discussion board community. Gaiser and Shreiner⁶⁵ advise “the researcher to be intentional and thoughtful about when, where and how the researcher will choose to interact.” The intent in lurking should be to gather data strategically to communicate effectively with the users and not to deceive or violate trust. Nahm et al⁶¹ suggest that to enhance participation from “lurkers,” discussion board developers should make occasional posts to stimulate discussion especially when online communities are smaller such as at the beginning of a project. The LINC development team has decided to remain a “passive” user in the monitoring of donor and caregiver posts, to minimize any potential conflict with or influence on the users’ thoughts or concerns.

Researchers suggest that users be made aware that developers “lurk” not only to monitor postings, but to ensure accuracy of data. Yet prior researchers report very few instances in which users posted false or misleading information, and almost all inaccurate posts are corrected by other users within hours.⁶⁰ Any approach should be weighed carefully by the development team. The establishment of protocol in responding to postings that may be unethical or harmful to other users is critical.^{17,26–28,71}

Limitations

Currently, LINC is a single-center educational website. The limited diversity experienced in this single-center living donor candidate population has not necessitated a multilingual LINC site. Inclusion of a LINC website model in additional transplant centers offering living donation will elevate needs for greater racial and ethnic diversity. The same is true with LINC in regard to users with various disabilities.

The LINC website was designed on the basis of limited literature on the topic of online health education and social support for living kidney donation. LINC has the potential to add to the educational and social support resources for living donors and their caregivers. LINC is a currently ongoing program with active enrollment funded by the National Institutes of Health/National Institute of Nursing Research. Data analysis is anticipated for the near future, including the report of findings on user satisfaction of the education and social support provided by the LINC website.

Conclusion

Informatics initiatives, including Internet information sites and online discussion boards, increase the accessibility of healthcare information and can potentially increase the knowledge and effectiveness of patients and caregivers. Internet-based education programs increase knowledge and benefit patients, as do traditional education methods.⁷² Online support systems and educational offerings may allow for changing home care goals and make information more accessible and efficient for patients and their families. Combining high-quality health information with interactive components mediated by information technology can benefit patients. Web-based interventions offered at an institutional establishment may also affect the equity of Internet access and improve readability of the health information provided.^{74–78}

With close to 80% of Americans seeking health information on the Internet,³⁶ establishing an Internet community can potentially increase donor participation and satisfaction with the living donation process and make a significant contribution in the understanding of the role of family caregivers in the donation process. Internet-based education and social support surpasses other traditional educational strategies in terms of its reach (potentially global) and convenience to users.^{34,57,69}

The evaluation of technology-mediated information and support remains limited despite the ever-growing use of information technology resources throughout the United States and evidence that communication technologies are frequently used for informational and support purposes.³⁰ Questions about how donor candidate–family caregiver characteristics such as age, race, sex, ethnicity, education, and prior Internet use are related to intensity of use (dose), as well as the impact of Internet-based information and social support on satisfaction with the process of living kidney donation remain unanswered. LINC can address this gap.

Studies are needed that examine the impact of sites such as LINC on perceived information adequacy and social support of donors and their informal caregivers.^{33,37–39} Through the incorporation of a variety of informational and support resources, such as discussion boards and the use of donor mentors for patients and families experiencing living kidney donation, LINC and other innovative research methods using information technology hold great promise for improving both access to health information and health outcomes for a variety of populations and diseases.

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Figure.
Study framework.

Table 1

Living donor websites from regional hospital centers, including Johns Hopkins Hospital Transplant Center and University of Maryland Medical Center. Of the 15 sites, only 4 offered online discussion boards. None offered social support discussion boards for donor candidates and/or family caregivers.

Website name and web address	Discussion board	Recipient resources	Donor resources	Caregiver resources
Congressional Kidney Caucus http://mcdermott.house.gov		Answers to basic questions Lists of donation facts Kidney transplant legislation Links to online resources	Answers to basic questions	
Donate Life (Department of Health & Human Services) www.organdonor.gov		Transplant myths dispelled Frequently asked questions Donor/Recipient stories	Donor/Recipient stories	
Donate Life America http://donatelife.net/understanding-donation/living-donation		Answers to common questions Links to more information	Answers to common questions Links to more information	
Gift of Life Donors Program www.donors1.org		Transplant myths dispelled Archived newsletters and publications Links to online resources	Religious views on donation Archived newsletters and publications Links to online resources	
Johns Hopkins Comprehensive Transplant Center www.hopkinsmedicine.org/transplant		Conferences/Events to attend Description of the process Mentoring availability Frequently asked questions	Mentoring availability Description of the process Donors' stories Workup instructions	Conferences and events to attend Mentoring availability
Living Donors Online www.livingdonorsonline.org	☒	Links to online resources Tips on how to secure a donor Living donation stories	How to become a living donor Message board, including forum, prayer, news, seeking matches "Living Donor Buddies" program Living donation stories	This message board is for all living organ donors and message board-posting own stories and not looking for advice; Strictly moderators who post stories. Few comments or responses to stories, not many posts—lots of lurkers. Information and education board. Not updated.
MatchingDonors.Com www.matchingdonors.com	☒	Media quotes about donation Ability to post looking for a donor	Donation stories from the media Tips for potential donors Ability to post looking for recipient	Must be a registered user to post comments. This site is dedicated to helping individuals to match with others who are in need. Stories for recipients who need transplants.
Mayo Clinic Transplant Center http://www.mayoclinic.org/kidney-transplant		Brief piece on financing transplant Transplant stories, statistics Clinical research recruitment	Frequently asked questions Transplant stories	

Website name and web address	Discussion board	Recipient resources	Donor resources	Caregiver resources
National Living Organ Donors Foundation www.livingorgandonors.org	☒ On-line chat times	Research publications Media stories about donation Links to online resources Transplant stories Articles on variety of topics Downloadable brochures Common questions answered	Transplant stories Message boards, pen pals, listserv	Patient/Family kidney disease guide
National Kidney Foundation Serving the National Capital Area http://www.kidney.org/transplantation/livingDonors		Frequently asked questions Identification, financial resources Transplant myths dispelled Public policy issues Publications available	Frequently asked questions	
Rhode Island Hospital Donor Guide http://www.rhodeislandhospital.org/oth/Page.asp?PageID=OTHG58076		Donor guide, including choosing donors and what to expect, donor considerations, facts, process— including testing	Donor guide, including choosing donors and what to expect, donor considerations, facts, process— including testing	
Transplant Living www.transplantliving.org		Links to online resources Calendars to educational events Support group listings Transplant stories	Facts, information, testing, finances Common questions answered Donor/Recipient stories	
Transplant Recipients International www.triweb.org	☒	Links to online resources “Lend a Helping Ear” Matching Message board	“Lend a Helping Ear” matching Message board	Website creation to update others “Lend a Helping Ear” matching Recipient listserv
TransWeb http://www.transweb.org/stories/kidney_donors/index.shtml		Living kidney donors’ stories		
United Network for Organ Sharing www.unos.org		Data Links to online resources Newsroom for media releases	Links to online resources Donor evaluation guidelines	
United States Transplant www.sttr.org		Scientific registry of recipients Publications about transplant	Question and answer page, with video Donor testimonials	Question and answer page, with video
University of Maryland Transplant Center www.umm.edu/transplant		Question and answer page, with video (Live) monthly programming list Links to online resources Recipient testimonials News releases	Anatomy guide to nephrectomies Frequently asked questions	
University of Southern California Transplant Center www.surgery.usc.edu/divisions/kidney/index.html		Transplant Patient Guide Guide to medications Links to online resources	“The Decision to be a Donor” Description of the process	
Penn Transplant Institute http://www.pennmedicine.org/transplant/patient-care/transplant-programs/kidney		Current clinical trials		

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Website name and web address	Discussion board	Recipient resources	Donor resources	Caregiver resources
Washington Regional Transplant Community http://www.beadonor.org		Live support group meeting offer Links to online resources Outcomes data in graphs		
		Common questions Myths vs facts Seminars, events offered		

Table 2

Netiquette guidelines for the Living Donor Information Network for Caregiving

What is Netiquette?	The etiquette of online communication		
Practice good Netiquette	Remain cordial and courteous—words can be easily misinterpreted.	Don't use all CAPS: in the online world, it's the same as shouting!	Be forgiving – whether it is a spelling error or a question that you may think of as “stupid”—be kind about it.
After reading the posting	Get involved in the discussion—make meaningful contributions.	Share resources you have found helpful.	
Maintain privacy	Refrain from using your name or the names of your family members.		