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Applying best practices to designing patient education for patients with end-stage renal disease pursuing kidney transplant

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Abstract

Despite the known benefits of kidney transplant, less than 30% of the 615000 patients living with end-stage renal disease (ESRD) in the United States have received a transplant. More than 100000 people are presently on the transplant waiting list. Although the shortage of kidneys for transplant remains a critical factor in explaining lower transplant rates, another important and modifiable factor is patients' lack of comprehensive education about transplant. The purpose of this article is to provide an overview of known best practices from the broader literature that can be used as an evidence base to design improved education for ESRD patients pursuing a kidney transplant. Best practices in chronic disease education generally reveal that education that is individually tailored, understandable for patients with low health literacy, and culturally competent is most beneficial. Effective education helps patients navigate the complex health care process successfully. Recommendations for how to incorporate these best practices into transplant education design are described. Providing more ESRD patients with transplant education that encompasses these best practices may improve their ability to make informed health care decisions and increase the numbers of patients interested in pursuing transplant.

Kidney transplant is one of the treatment options for patients with end-stage renal disease (ESRD) who need renal replacement therapy (RRT). Compared with remaining on dialysis or receiving no therapy, kidney transplant is associated with decreased mortality and morbidity from ESRD¹ and enhanced quality of life.² Despite these benefits, less than 30% of the 615 000 patients living with ESRD in the United States have received a transplant.¹

More than 100 000 people are presently on the kidney transplant waiting list.³ In ESRD patients, a significant barrier to transplant is the shortage of donated kidneys for transplant. Each year, while more than 35 000 new patients are added to the transplant waiting list, only approximately 10 000 patients actually receive deceased donor kidney transplants.³ For this reason, many patients begin to consider another type of RRT, receiving a living donor kidney transplant (LDKT) from a family member, friend, or stranger. The advantage of the

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LDKT providing a better quality kidney more quickly⁴ is weighed against the future health risks to the potential living donors.⁵ Among these options, patients with ESRD choose the RRT that best fits their lifestyle.

An important problem situation that frequently occurs in the clinical setting is that patients with a new diagnosis of ESRD have very little time to decide which RRT they want to pursue and often do not receive sufficient information to make an informed decision.⁶ Although the US government mandates that all ESRD patients receive education about kidney transplant,⁷ current research suggests that at least 30% of dialysis patients are uninformed about this option.⁸ Further, research has shown that health care providers are often unable to educate patients about transplant because of their own lack of knowledge or time constraints.

Recently emerging studies indicate that higher quality transplant education may improve ESRD patients' access to transplant ^{10–12} and even increase transplant rates. ^{13–15} Health care professionals working in transplant centers, dialysis centers, and community nephrologists' practices currently educate ESRD patients about their RRT options. Yet, no consensus exists on the most effective ways to educate patients about kidney transplant. In order to facilitate research and clinical practice in caring for patients with ESRD, a clear understanding of "best practices" for transplant education is required.

Best practices for education are defined as "practices which lead to superior performance, achieving consistent quality in what is done." ^{16(p237)} To meet the requirements of best practice, transplant education needs to be clear, comprehensive, understandable, and motivating to facilitate patients successfully completing the clinical steps necessary to be evaluated for transplant. After a comprehensive literature review, relatively few research studies were found that define best practices in education specifically for ESRD patients. Thus, the narrative review was expanded to identify best practices in the broader literature including strategies and key recommendations that can be directly applied to designing education for ESRD patients pursuing kidney transplant.

A comprehensive review of the CINAHL and PubMed electronic databases was completed. Keywords included *kidney transplant, pretransplant education, end-stage renal disease treatment options, patient education, tailored education, low health literacy, cultural competence,* and *patient navigation*. This narrative review of literature includes research and expert opinion from the social work, psychology, health education, and nursing literature. A limitation of this review is that it excludes literature on the educational needs and recommendations for posttransplant patients.

Literature Review

From this review and synthesis of the broader literature, 4 strategies emerged as best practices for education for ESRD patients pursuing transplant: designing education that is (1) individually tailored, (2) understandable for patients with low health literacy, (3) culturally competent, and (4) helpful in showing patients how to navigate the complex health care process. For each strategy, a review of the broader literature and the benefits of the strategy in general and for ESRD patients pursuing transplant specifically are discussed.

The Table presents a summary of the strategies and key recommendations for best practices in education that can be translated to the education of ESRD patients pursuing transplant.

Individually Tailored Education

One educational strategy that is effective is individually tailoring materials on the basis of patients' specific knowledge levels, fears, or barriers regarding the desired behavior. ^{17,18} According to Kreuter and Skinner, ^{19(p5)} tailoring is "any combination of information or change strategies intended to reach one specific person, based on characteristics that are unique to that person, related to the outcome of interest, and have been derived from an individual assessment." To tailor educational efforts effectively, time must be taken to actively listen to the obstacles the patient is facing and to assess the patient's preferred learning styles (see Table).

A Review of the Broader Literature—A meta-analysis of 57 print interventions for health behavior change demonstrated that, across all studies, interventions with tailored health messages had a small, but significantly greater effect on health behaviors than did nontailored health messages (sample-size weighted effect size r = 0.074; 95% confidence interval, 0.066–0.082).²⁰ This meta-analysis included interventions in physical inactivity, diet, and tobacco use. Compared with large complex manuals of educational content, the types of tailoring materials that resulted in the greatest impact on health behavior change were shorter pamphlets, brochures, and newsletters. ²⁰ Giving smaller amounts of information across multiple sessions had a greater effect on behavior change than did other strategies.²⁰ Tailored materials also can be provided in many different learning formats, for example, through face-to-face, written, or video presentations, allowing material to be presented in the patient's preferred learning style. The use of pictures and graphics and overall attractiveness keep readers' attention, helping them retain information. Although tailored materials require more time in preparation, evolving technology provides greater ease and flexibility in creating and changing education materials to fit the unique characteristics of the population being seen in the clinic setting.¹⁸

Overall Benefits of Tailored Education—Tailoring education to the unique needs of an individual has been shown to be more effective than using a standardized one-size-fits-all educational approach. The benefits of tailoring seem to result from the patient's ability to better identify with the material, which increases thoughtful consideration, self-reflection, and self-assessment, thereby improving the patient's intent. Compared with a standard message condition, Campbell et al Treported that patients receiving messages tailored to their level of readiness to change were twice as likely to remember receiving the message, to read the information, and to make a significant change in health-promoting behaviors such as improving nutrition. Another important benefit of tailored education is an increase in the patient's self-confidence. For example, researchers in one study reported that including personalized feedback materials in a smoking cessation program improved self-confidence in quitting at twice the rate of groups receiving standard care. If the patient's name is printed on the pamphlets, the patient is more likely to read the materials, view the materials as being unique and specific to his/her situation, and reflect on the benefits of applying the information provided. Through tailoring, understanding of the materials is increased.

Potential Benefits of Tailored Education for ESRD Patients Pursuing

Transplant—A large amount of complex educational content is given to patients pursuing transplant that must be learned by the patient including information about surgical risks and benefits, a complex medication regimen, and details of follow-up care. Transplant education tailored to the patients' disease stage, 22 level of readiness to get a transplant, 23 or life circumstances 24 may more successfully assist ESRD patients in making an informed decision about their treatment. One study 24 compared the implementation of a home-based kidney transplant education program with the standard education provided at a transplant center. This study used a roundtable discussion that encouraged the patient and support persons to ask questions, tailored to their unique life circumstances. In this study, discussion of and knowledge about LDKT increased and the patients' concerns about transplant decreased significantly (r < 0.001). 24 Tailored programs with small amounts of education provided in different sessions may particularly help improve the education of ESRD patients who are living with mental fatigue and cloudiness that are associated with higher serum levels of creatinine. 25,26

Explore Transplant, a transplant education program based on the Transtheoretical Model of Behavior Change, was designed to provide information to patients tailored to their level of readiness to get a transplant.²³ Explore Transplant increased dialysis patients' knowledge of transplant, positive attitudes toward transplant, and the frequency with which they called a transplant center to begin transplant evaluation.²⁷ More research is needed to determine the type of tailored strategies and the number of sessions that are most effective in this specific population.

Understandable Education for Patients With Low Health Literacy

The Institute of Medicine defines health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." Health literacy entails more than a patient being able to read written instructions; it requires the ability to comprehend and apply the information ascertained. In 2003, the US Department of Education conducted a landmark study, the National Assessment of Adult Literacy, which measured the health literacy of English-speaking Americans ages 16 and older. According to this survey, only 12% of adults have sufficient health literacy. According to the American Medical Association, "poor health literacy is a stronger predictor of a person's health than age, income, employment status, education level, and race." Patients with low health literacy are often not able to understand and follow their health provider's care instructions appropriately, especially given the time constraint providers have to spend in discussion with any one patient, stressing the need for simple, easy-to-understand health education (see Table). According to the special patients with low health literacy are often not able to understand and follow their health providers have to spend in discussion with any one patient, stressing the need for simple, easy-to-understand health education (see Table).

A Review of the Broader Literature—Populations at highest risk for low health literacy are older adults, immigrants, minorities, and low-income individuals.²⁹ A systematic review of health literacy research conducted by the Agency for Health Care Research and Quality showed that lower health literacy is associated with increased use of the emergency department, increased number of hospitalizations, and less use of preventive screenings like

mammography. In addition, those with low health literacy often have poorer control of their disease process.³² Published reports illustrate many recommendations for the design of educational interventions to improve or accommodate low health literacy. Those interventions include creative approaches to communication such as designing brochures with large font including easy to understand pictures or graphs, developing culturally competent video materials, presenting only information that will directly help patients with their immediate problem while eliminating background information, and writing materials at a sixth-seventh grade reading level. 31,32 Another strategy is to infuse the patient into the message by using active voice and pictures of people similar to or identifiable by the patient in age or race.³² At times, specialized medical terms related to specific health diseases must be identified and defined for patients. The photonovela, a comic book that uses photographs combined with easy-to-read captions to tell an educational story, is gaining popularity among health education programs. The story and photos can be tailored to the setting and culture of the population, aiding the patient to identify with the informational message provided.³³ Affecting a patient's understanding and comprehension of health education has been associated with patients' overall health status and outcomes, including reduced hospitalizations, disease severity, and mortality.³²

Overall Benefits of Understandable Education for Low Health Literacy—If educational materials are written at an understandable level, patients may be more likely to read the material. Increasing the exposure the patient has to the material may increase the patient's knowledge. With knowledge, the patient is better able to problem solve specific symptoms they are having or contact the appropriate health care professional for assistance, thus reducing unnecessary emergency department visits, hospitalizations, and mortality.³² Another benefit may be increased health prevention screenings.³² Finally, communicating health information in a more understandable way may be more cost-effective, reducing potentially unnecessary use of health care (eg, extra hospital visits).³¹

Potential Benefits of Understandable Education For Low Health Literacy in ESRD Patients Pursuing Transplant—The health literacy studies conducted with the ESRD population revealed that the rate of low health literacy in kidney patients is similar to the rate in the US population. ^{34,35} Green et al ³⁶ reported that ESRD patients with low health literacy were more likely to miss dialysis treatments, to use the emergency department, and to be hospitalized as a result of inadequate disease management. This situation can affect a patient's pursuit of transplant evaluation in many ways. Patients who have poorer control of their ESRD, in addition to low health literacy, are less likely to pursue transplant. ^{37,38} Another example is the ESRD patient who decides to pursue transplant but cannot read or write. These patients are less likely to complete and return the packet of forms to begin the evaluation process, which in reality may block them from ever receiving a transplant. ³⁹

Despite recommendations for multimedia education, a recent review showed that most transplant centers in the United States use only written transplant educational materials. 40 Use of many different learning formats such as brochures, videos, and patient stories may enhance comprehension. 32 This increase in comprehension may aid ESRD patients pursuing transplant in making informed decisions about whether transplant fits their lifestyle. Further

research is needed in this population to see how well an educational program for patients with low health literacy affects completing the transplant evaluation process.

Culturally Competent Education

With the passage of health care reform in the United States, cultural competence is receiving more attention and is being seen as an important tool to reduce health care disparities. ⁴¹ Cultural competence is defined as "the ability to understand and work effectively with patients whose beliefs, values, and histories differ from one's own."^{42(p299)} Patients who are at risk for health care inequalities are of lower economic status, a minority race, noninsured, or of lower health literacy. ⁴³ A lack of culturally competent care and education is associated with alienation, inadequate treatment, ⁴¹ misdiagnosis, increased malpractice, and decreased patient satisfaction, which are also linked with health care disparities. ⁴⁴ There are high costs associated with health care disparities. These costs are a result of prolonged hospitalizations, ⁴⁵ improper utilization of services, ^{46–48} and medical errors. ^{49–51} Proper utilization of culturally competent education may help reduce cost while improving health care outcomes. ⁵²

In order to provide patients with culturally competent education, the health care provider must be educated and trained in several skills. These skills include the ability to actively listen, and the capacity to be flexibile in the treatment plan, as well as taking the time to assess if the plan is acceptable and understandable to the patient.⁵² Therefore, cultural competent education comes from delivering care, instructions, and materials that are congruent with the patient's beliefs, values, and experiences⁵² (see Table).

A Review of the Broader Literature—Evidence indicates that training in how best to deliver culturally competent care advances professionals' skills in asking patients questions about beliefs concerning their illness and provides strategies to bridge differing communication styles, leading to greater satisfaction of patients with their overall health care. 42,53 However, research also has shown that care must be taken when delivering cultural competence training, not to merely teach a list of traits or a set of categories that could lead to cultural stereotyping. 42–53 Culture is fluid, not static; therefore, the overall aim of this type of training is for health care providers to have an open mind and treat patients as individuals.

DeRosa and Kochurka⁵⁵ proposed 6 steps in the provision of culturally competent care. In the first step, the health care provider must develop attitudes associated with culturally competent care, such as caring, empathy, openness, and flexibility. Incorporating these behaviors in the fast-paced health care environment, with many health care providers presenting information quickly with minimal discussion and little time for questions, is challenging. Slowing down, asking patients what they expect from the treatment, and taking time to ask patients what questions they have are vital to being open and flexible to patients' needs. The second step is for the health care provider to assess how values and health care beliefs influence each person's health differently.⁵⁵ Some health care decisions require family discussion, while others are individual decisions.

The third step is for the health care provider to obtain information about the patient's preferences regarding communication, both in how it should be done and in what type of environment and time frame. Some patients may need more time at home with family and friends to process health information and may require additional visits to the health care provider to ensure comprehension. The fourth step is for the health care provider to complete a cultural assessment to learn patients' native language and health beliefs about, for example, medications. Patients who speak English as a second language may overestimate their ability to comprehend English fluently, which leads to misunderstandings of instructions often leading to medication errors.

The fifth step is for the health care provider to apply the preserve-accommodate-restructure framework.⁵⁵ This framework is based on preserving and accommodating the cultural aspects that improve health care outcomes while restructuring those practices that may interfere with treatment. This type of partnership is a win-win situation: the patient becomes an active member in his/her health care by collaborating with the health care provider to devise a plan that honors the patient's own beliefs while promoting good outcomes.

The sixth and final step is for the health care provider to avoid being defensive and to apologize for mistakes.⁵⁵ When meeting a person whose culture is different from one's own, a provider may make mistakes like invading personal space. Health care providers should take ownership and apologize. These 6 steps may help produce a culturally competent and individualized plan of care that respects the patient as an individual and increases the patient's sense of well-being.

Overall Benefits of Culturally Competent Education—Most studies of culturally competent education have focused on outcomes such as improving providers' sensitivity, knowledge, or communication skills, not on patients' outcomes. ⁵⁶ A few studies demonstrated increased patient satisfaction, ⁵⁷ trustworthiness, empathy, and respect ^{42,56} when culturally competent education was provided. Increases in patient satisfaction and trust may reduce dropping out, thereby giving the health care provider additional opportunities to educate patients.

Potential Benefits of Culturally Competent Education for ESRD Patients

Pursuing Transplant—Developing culturally competent education is an important step in reducing disparities in the pursuit and rates of transplant for minorities. Racial disparities have been associated with delaying referrals to the kidney transplant center, slowing the transplant evaluation process, and in some cases preventing access to transplant. Research suggests that the demographic disparities in kidney transplant may be getting worse because of physicians' bias in referring patients to the transplant center and patients' misconceptions about their eligibility for transplant. A review of transplant centers throughout the United States showed that a majority of centers rely on interpreters to communicate with non—English-speaking patients (78%) and that a minority of centers have bicultural staff (43%) or provide cultural competency training (34%). Another national analysis revealed that black patients with ESRD may not be benefiting from transplant education as much as white patients with ESRD benefit. Research has focused on ways to address this problem, with

one important recommendation being to improve health care providers' ability to deliver culturally competent education and care. 61,62

Among extant culturally competent transplant educational interventions, a good example is the Talking About Live Donation (TALK) intervention.⁶³ This intervention is a culturally competent educational program that has not only helped pre-ESRD patients and their family members consider LDKT⁶⁴ but is also equally acceptable to black and white patients.⁶⁵ A second intervention that provided transplant education to patients and their families in the home setting demonstrated a greater effect in black patients than in whites, while increasing the ability of patients of both races to discuss LDKT with potential donors.¹³ Educational interventions like these that engage family members, friends, or others are promising approaches to increase LDKTs, because they may help recipients find potential living donors. Clinical trials are needed to explore interventions that facilitate discussions about living donation and asking for a donation.²³

Navigation of the Health Care Process

Health care systems and processes are very complex especially for those who have limited experience with health care or have low health literacy. Patients may have difficulty understanding when and where to seek medical help or information. ⁶⁶ Patients who are confused or disempowered may appear to be noncompliant or make unintentional errors by misunderstanding instructions related to medical advice. Health care systems use a number of ways to assist patients in navigating: automated phone call appointment reminders, mailing of maps and forms before the first appointment, and concierge service. ⁶⁷ Even with these approaches, a heavy burden is still placed on the patient to understand and follow complex health care recommendations (see Table).

A Review of the Broader Literature—The use of patient navigators is gaining more attention as health care systems are trying to be seen as more user-friendly.⁶⁷ These navigators are either peers or educated professionals who assist patients in moving through the health care process. Koh et al⁶⁸ studied the use of a patient navigation system in cancer patients. Their study showed that more than 71% of the barriers to care such as fear, lack of financial resources, transportation, and child care were resolved at the first treatment visit thanks to interventions by patient navigators.⁶⁸

Overall Benefits of Being Able to Navigate the Health Care Process—The benefits of helping the patient through the health care process include increased attendance at scheduled appointments, increased ability to ask specific questions related to individual barriers to care, and decreased feelings of fear. An added health-related benefit is decreased loss to follow-up, which offers the health care provider more opportunities for assessment, management, and education. 69

Potential Benefits of Being Able to Navigate the Complex Transplant Evaluation Process for ESRD Patients Pursuing Transplant—Several barriers were identified that slow or prevent the patient from completing the transplant evaluation, including lack of financial resources, lack of knowledge about transplant, fear of medical

tests, and fear of surgery.^{39,70} For example, if patients do not understand medical terminology, they are unlikely to be able to navigate through the multistep transplant evaluation process well. Sullivan et al⁷¹ conducted a randomized control trial to test the impact of a tailored patient navigator on dialysis patients' completion of 8 steps toward receiving a kidney transplant (eg, deemed suitable for transplant, expresses interest in transplant) with the 8th, ultimate step being receipt of a kidney transplant. Patients who received the patient navigator completed significantly more steps toward transplant than patients in the control condition (3.5 vs 1.6; 95% confidence interval, 1.3–2.5).⁷¹ Additional efficacy and effectiveness trials examining the impact of patient navigators are greatly needed.

Patient navigators or other approaches to deliver patient education may be particularly effective if coupled with education sessions occurring at multiple time points throughout a patient's path from dialysis to transplant receipt.⁷² Several studies of transplant education suggest that educating patients early, either in dialysis centers or community nephrologists' practices,^{73–75} then again at transplant centers,¹¹ may be critical to providing the information most essential to patients at each point along their path to transplant. Comparative effectiveness trials that test the optimal number of educational intervention sessions as well as when the sessions should be given are needed.

Conclusion

Kidney transplants have been performed since the 1950s. Since that time, many research studies have demonstrated transplant benefits over dialysis, yet the rates of transplant remain low. Although the shortage of kidneys for transplant remains a critical factor in explaining lower transplant rates, another important and modifiable factor is patients' lack of comprehensive education about transplant. ¹⁴ The current practice of educating ESRD patients pursing transplant often consists of delivering the same educational packet to each patient, sometimes before ever meeting the patient in the clinic setting. For the most part, due to time constraints and a weak research base, tailored education is often not considered and the patient's health literacy, cultural beliefs, and navigational skills are often not assessed in a systematic way. For changes to occur in the education process, resources must be allocated in the form of materials and culturally competent staff to guide the ESRD patient through the process, beginning from the patient's initial request for information. More user-friendly, precise, and unbiased assessments of health literacy^{76,77} will enable transplant educators to understand which of their patients have low health literacy and therefore are at higher risk for adverse outcomes. Theoretically consistent practice, adequate educational preparation, and a guide to help navigate through the initial process may facilitate patients' understanding of the process, as well as information on expected outcomes after transplant.

Finally, although strategies from the broader literature about education can be applied to this population to try to reduce barriers and improve the rate of transplant, more evidence-based practice projects and well-controlled research studies are needed to assess the efficacy of various education strategies for ESRD patients pursuing transplant. In the future, through research examining the efficacy of various educational approaches for patients with ESRD,

we can build a knowledge base of the best education practices for ESRD patients. For now, providing more ESRD patients with kidney transplant education that encompasses best practices may improve their ability to make informed health care decisions.

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TableApplying strategies and key recommendations to designing patient education on end-stage renal disease

Strategies to improve education	Key recommendations
Tailor education for individual patients	Fit the format to the preferred way of learning (eg, face-to-face, written, or video presentation)
	Acknowledge what is known and build on that knowledge
	Print the patient's name on the information
	Tailor videos, images, pictures, and stories that relate to patients' experiences
	Provide more information in areas in which patients show an interest
	Create individualized goals, discussing how the patient will meet them, and what the patient will do when faced with a problem situation
	Limit the length: newsletters, bullet points, short sentences, and paragraphs
	Use frequent contacts to lessen the amount of information presented at one time (eg, chunking)
Make education understandable for patients with low health literacy	Use of photonovela, comic book
	Use several teaching formats (eg, written, verbal, and teach back)
	Focus on immediate, practical topics and eliminate background information
	Introduce no more than 3 topics at once, with the most important topic first
	Explain complex issues in easy-to-understand language
	Use white space
	Use large font and easy-to-read font (eg, sans serif typeface)
Provide culturally competent education for patients	Show care and empathy: "walk in their shoes"
	Assess the patient's cultural needs, sources of strength, and communication norms (eg, personal space, touch, eye contact, and taboo subjects)
	Meet patients where they are in regard to treatment options, knowledge, and definition of health beliefs
	Assess the economic resources that are available to the patient through their community/family
	Acknowledge own biases (eg, stereotypes or assumptions related to a patient's weight, skin color, accent, alternative remedies, and appearance)
	Keep an open about each patient's thoughts, feelings decision making, and values
Help patients navigate the health care process	Use reminders for upcoming appointments (eg, post cards and phone calls)
	Use navigating headings on materials to orient the reader
	Mail maps and forms to be completed before appointments, asking only for essential information
	Use patient advocates to call and assist with any barriers to accessing health care (eg, a lack of transportation)