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Educating Prospective Kidney Transplant Recipients and Living Donors about Living Donation: Practical and Theoretical Recommendations for Increasing Living Donation Rates

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Abstract

A promising strategy for increasing living donor kidney transplant (LDKT) rates is improving education about living donation for both prospective kidney transplant recipients and living donors to help overcome the proven knowledge, psychological, and socioeconomic barriers to LDKT. A recent Consensus Conference on Best Practices in Live Kidney Donation recommended that comprehensive LDKT education be made available to patients at all stages of chronic kidney disease (CKD). However, in considering how to implement this recommendation across different healthcare learning environments, the current lack of available guidance regarding how to design, deliver, and measure the efficacy of LDKT education programs is notable. In the current article, we provide an overview of how one behavior change theory, the Transtheoretical Model of Behavior Change, can guide the delivery of LDKT education for patients at various stages of CKD and readiness for LDKT. We also discuss the importance of creating educational programs for both potential kidney transplant recipients and living donors, and identify key priorities for educational research to reduce racial disparities in LDKT and increase LDKT rates.

Keywords

Living donor transplant; Patient education; Racial disparities; Best practices

Introduction

Presently, more than 100,000 individuals are awaiting a kidney transplant in the USA with more being added daily [1]. Each year, nearly 30,000 patients receive kidney transplants, with 75–80 % receiving deceased donor kidneys [1] due to the generosity of donors and efficient facilitation of kidney transplants by staff at organ procurement organizations around the country. Living donor kidney transplants (LDKT) from family members, friends,

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Compliance with Ethical Standards

Conflict of Interest

Amy D. Waterman, Mark L. Robbins, and John D. Peipert declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent

This article does not contain any studies with human or animal subjects performed by any of the authors.

or others make up the remaining 20–25 % of kidney transplants in the USA, but LDKT rates have declined over the past decade, from 6600 LDKTs in 2004 to only 5500 in 2014 [1].

While the potential for increasing the number of deceased donors is limited in part by the number of people who die in such a way that they can donate organs, there is substantial potential for increasing the number of living donors. With 245 million adults in the USA [2], it is likely that there are at least 100,000 more individuals who might feel motivated to donate a kidney to someone with chronic kidney disease (CKD) or end-stage renal disease (ESRD) [3, 4], eliminating the current kidney waiting list. Of the 5500 living donors who donated their kidneys in 2014, only 28 % were Black, Hispanic, or Asian [1]. Thus, there is even more potential for reducing educational and other barriers among racial/ethnic minority communities. Innovative initiatives to reach, educate, and motivate minority patients with kidney failure and their social networks to consider LDKT and living donation are needed [5].

Education about living donation is complex in that it involves two learners—the potential recipient and potential living donor—and requires communicating complex medical information about the risks and benefits of transplant and living donation to both to them. Many potential kidney transplant recipients considering LDKT also report feeling uncomfortable asking others to donate [6, 7]. Since some potential recipients have concerns about future health problems for the living donor including the low, but possible risks for high blood pressure [8] and future kidney failure post-donation [9], especially for minorities [8, 10], some rule out the option of living donation even before they fully understand its advantages to their health [7]. In these instances, family members and friends may never learn that they might be able to donate a kidney and have an opportunity to decide whether these levels of risks are acceptable to them.

A recent American Society of Transplantation (AST) Consensus Conference on Best Practices in Live Kidney Donation recognized living donation as the optimal treatment option for most patients with kidney disease, with recommendations that both patients and their potential living donors be comprehensively educated about the benefits and risks of living donation [11, 12]. Among the highest priority recommendations were to insure that comprehensive LDKT education was available to patients at all stages of CKD as well as to their potential living donors, that LDKT education occur multiple times for individuals across the stages of CKD progression, and that distinct efforts be made to increase access to LDKT education for potential recipients and donors identifying as racial/ethnic minorities [11]. Emerging evidence suggests that patients at lower levels of readiness for LDKT include those who are earlier in their CKD progression and racial/ethnic minorities [13–15]. Lessons from health education research across many behaviors indicate that when a patient is not ready to take a particular health behavior, like pursuing LDKT, educational messages strongly promoting taking that behavior in the near future often fall on deaf or resistant ears [16].

The goal of this article is to provide practical, theoretical, and evidence-based guidance for clinical providers educating patients about LDKT in their own settings and researchers designing and testing the efficacy of LDKT education programs for potential recipients and

donors. Specifically, we will: (1) discuss the advantages of employing the Transtheoretical Model in tailoring LDKT education to suit individual patients' levels of readiness and capacities to pursue LDKT, including applications for potential living donors and (2) suggest next steps in research related to the development of education for potential living donors and for administering effective LDKT education to a diverse and socioeconomically disadvantaged audience.

Theoretically Guided LDKT Education: Design, Delivery, and Measurement

Designing LDKT Education

The design of health education should incorporate best practices guided by a theoretical framework so that important leverage points for positive health behavior change can be identified [17]. Indeed, there is strong evidence that health education resources and campaigns that utilize best practices taken from behavioral science theories are more effective than programs not grounded in theory [18]. Health education programs grounded in theory help patients clarify what is important to them, develop strategies to overcome challenges they may face in making health behavior change ahead of time, and increase their knowledge of the health behavior they plan to change. While there are many theoretical frameworks to choose from that can help guide the design of LDKT education programs, including the Health Belief Model, the Theory of Reasoned Action, the Theory of Planned Action, and the Precaution Adoption Process Model [17], here we will detail the ways LDKT education design can benefit from the application of the Transtheoretical Model (TTM) of Behavior Change [17].

Delivering LDKT Education

The foundational construct of the TTM, readiness, holds that individuals vary in how ready they are to make a health behavior change like pursuing LDKT, and that their individual readiness can change over time along one of five stages of readiness, also called Stages of Change. In order to know which stage of change a particular patient is in, a validated assessment of readiness should be first made by the provider delivering education, then appropriate educational messages should be delivered that are tailored for each patient's particular stage [16]. This approach is very different from a blunt, "one-size-fits-all" educational message that suggests all kidney patients begin taking actions to find potential donors immediately, a common recommendation. Tailoring communications to a patient's stage of readiness: (1) allows providers to engage the entire population of eligible kidney patients, particularly racial/ethnic minorities and at-risk patients who are less likely to have received transplant education [13] in the

LDKT decision process and (2) ensures that patients are not pressed to take actions before they are ready, reducing resistance. We recently validated a brief assessment of LDKT readiness measuring the following stages: "I am not considering taking actions in the next 6 months to pursue living donation" (Precontemplation); "I am considering taking actions in the next 6 months to pursue living donation" (Contemplation); "I am preparing to take actions in the next 30 days to pursue living donation" (Preparation); and "I am taking actions

to pursue living donation” (Action) [19•]. A Maintenance stage was not included, since after receiving LDKT, no stage regression could occur. After being assessed as to their readiness stage, patients also can rate when they have “Already done,” “Are planning to do,” or “Don’t plan to do” smaller behaviors relevant to pursuing LDKT. In previous validation analyses for the LDKT readiness measure, a series of χ^2 tests revealed that, compared to patients in earlier stages, patients in later stages of readiness were more likely to have done or were planning to take behaviors like asking another person directly to be evaluated as a donor candidate and accepting another’s offer to donate ($p < 0.05$) [19•].

TTM-based health education for LDKT, or any health behavior, does not aim to move all patients into taking actions immediately, particularly if they are in earlier readiness stages, such as Precontemplation or Contemplation [20]. Instead, the goal of any educational content and recommendations is to move patients forward one stage toward the later stages of change for a given health behavior [20]. Appropriately delivered TTM education may require several meetings with a patient, over weeks or months, to shift a patient who is in early stages of readiness into pursuing LDKT. Compared to action-oriented interventions, interventions using tailored communications have been shown in randomized controlled trials to be very effective in many health behaviors including smoking cessation, dietary change, and increased physical activity [21]. There is evidence that patients who receive educational messages tailored to their readiness stage have twice the chance of taking a health behavior in the following 6 months compared with patients receiving general health recommendations [22, 23]. While there are no published trials on the impact of LDKT education explicitly tailored to the readiness stage of individual patients, a novel trial is currently underway that uses computerized assessments of LDKT readiness to generate unique tailored educational messages appropriate for each individual [24].

Figure 1 demonstrates how best to orient discussions with patients in the four stages of LDKT readiness and suggests which small steps toward LDKT may be most appropriate to discuss with patients in each stage. After LDKT readiness is assessed in a clinical setting, providers can create a tailored plan of small steps with the patient and provide support for accomplishing those steps, increasing the likelihood that the patient will make progress eventually into action for pursuing LDKT. A previous study found that patients first presenting for evaluation who were in later stages of readiness for LDKT were 4.3 times more likely to receive a LDKT years later [13], with LDKT readiness at evaluation onset being the single strongest predictor of ultimate LDKT receipt among 24 other modifiable and non-modifiable patient characteristics.

There are other constructs employed by the TTM that elucidate how to support patients with kidney disease in moving forward in their readiness toward pursuing LDKT. Patients move from early to later stages of LDKT readiness as their Decisional Balance, or comparative value of the pros and cons of taking a health behavior, change [20]. Across more than 12 health behaviors, including pursuit of LDKT [19•] and deceased donor kidney transplant [25], as patients move from Precontemplation into Action, their perception of the pros of making a behavior change increases, while their perception of the cons decreases [20]. Conversations about what is uniquely important to a kidney patient, including the possibilities of getting off dialysis, being able to eat restricted types of food, or being able

to travel more, can help increase patients' perceptions of the pros to pursuing LDKT. Cons, or fears and concerns about pursuing LDKT, should also be addressed. Sometimes patients are extremely concerned about something that has a low probability of actually occurring, like dying under anesthesia or the living donor having health problems later. In these cases, accurate, but sensitive, information [9] that communicates the low, but not absent, risk of these negative outcomes is recommended. A second approach proven successful at increasing readiness to pursue LDKT is to increase patients' self-efficacy or confidence that they can pursue LDKT even if they must manage challenges like not having transportation to the transplant center or having a potential donor say "no" [26–28]. Increasing self-efficacy for LDKT, beginning once a patient has progressed to the Contemplation stage of readiness, may require brainstorming about strategies on how to handle common barriers, how to cope with individuals not wanting to be tested as donors, and reducing larger tasks like "finding a living donor" into smaller, more manageable pieces like, "making a list of your community" and "writing and sending an email about your need for a kidney transplant."

Finally, though not a TTM construct, there is also some evidence that increasing knowledge of transplantation may also help increase patients' readiness to pursue LDKT [15, 25]. Given the significant knowledge gaps faced by kidney patients, helping them learn more about the facts related to LDKT will better prepare them for undergoing evaluation, surgery, and recovering afterwards.

Measurement of Efficacy of LDKT Education Programs for Recipients

Expecting an education program to increase rates of LDKT for patients along the entire CKD continuum, who all have varying levels of knowledge and readiness for LDKT, may be unfeasible over a relatively short intervention time period. To measure the efficacy of LDKT educational programs, there are LDKT attitude, knowledge, decision-making, and behavioral metrics that may serve as interim measures indicating increases in pro-LDKT awareness and actions and that may be associated with eventual LDKT [13]. Validated measures of these intermediate outcomes include the aforementioned measure of LDKT readiness we recently developed [19•], which is coupled with validated, TTM-based scales of Decisional Balance (pros and cons) and self-efficacy [19•, 29]. Though their validation analyses are not fully detailed, Rodrigue and colleagues report good initial psychometric properties of scales of willingness to discuss LDKT with others, concerns about LDKT, and LDKT knowledge [30]. While a few validated scales focusing on general kidney disease and transplant knowledge have been published [31–32], the Rotterdam Renal Replacement Knowledge Test (R3K-T) features a well-validated subscale focusing on LDKT knowledge particularly [33]. O'Connor and colleagues' Decisional Conflict Scale [34] and Decisional Self-Efficacy Scale [35] have been employed in trials of educational programs to increase LDKT [36–37]. Other studies have assessed intermediate LDKT pursuit attitudes using measures for which no psychometric properties are reported [38].

Measurement of small LDKT behaviors over time can also show movement toward actual LDKT. Some trials testing the efficacy of transplant education programs have tended to focus most on earlier behaviors as endpoints, e.g., having discussions about LDKT with family members, initiating evaluation for LDKT [39•, 40–41]. The primary outcome of

Boulware and colleagues' TALK study was steps toward LDKT including discussion of LDKT with family members and physicians, initiating and completing evaluation for LDKT, and identification of living donor candidates [39•]. Such behaviors are important outcomes for transplant education trials. Yet, even for these interim behaviors, few patients in earlier stages of readiness for LDKT may take these actions until they become more ready, indicating a need to suggest an evolving set of behaviors leading up to receipt of LDKT as LDKT readiness increases.

A good example of the use of multiple interim measures in addition to final behavioral endpoints can be seen in House Calls trial results reported by Rodrigue and colleagues in 2014 [42•]. This trial enrolled Black patients presenting for trans-plant, many of whom were at earlier stages of readiness for LDKT at the start of the trial: 24–37 % (depending on educational condition of randomization) were assessed to be in Precontemplation, while another 31–33 % were assessed to be in Contemplation, such that approximately 55–70 % of patients were in early stages of readiness for LDKT. After a single, 60–90 min educational session in patients' homes, the House Calls program was able to substantially increase patients' stage of LDKT readiness (only 4 % of patients receiving home-based education were in Precontemplation or Contemplation for LDKT 6 weeks post-intervention), and also increase living donor inquiries and evaluations, although significant increases in LDKT were not found. It is likely that, given the extensive proportion of patients in lower stages of LDKT readiness at the trial's start, increasing LDKT after only one educational session was not feasible. Instead, this program should be credited highly with its ability to increase patients' readiness for LDKT and activate potential living donors to begin the donation process, noting that additional educational sessions might then increase LDKT for this patient population.

Educating both Potential Living Donors and Recipients

Inclusion of Potential Living Donors in LDKT Education

The recent AST Consensus Conference also recommended that we must “provide patients and their caregivers with training about how to identify and approach potential living donors” [11••] to help them learn strategies to be as successful as possible in discussing the option of LDKT with potential donors. However, even if a potential recipient is trained and is taking actions to find living donors, until a willing and appropriate living donor is found who meets the medical, psycho- logical, psychosocial, and financial criteria required by a transplant center, a LDKT is not possible.

Emerging evidence has shown that addressing potential living donors' poor knowledge of LDKT and their concerns, including medical mistrust, may increase their willingness to donate [43]. Thus, programs that include both transplant candidates and their potential living donors in new educational learning opportunities also may help reduce the burden on the kidney patient of having to directly ask [39•, 42•] and allow more potential living donors to have their unique questions answered. To date, the most successful LDKT educational programs are primarily focused on the recipient but also include potential donors, often identified through the potential recipient's social network, in educational sessions and provide additional education afterwards for the potential living donors [39•, 42•, 44•].

Four key examples of how recipient-centered LDKT educational programs have involved potential living donors are the “House Calls” program [42• 45], a Dutch adaptation of the “House Calls” approach named Kidney Team at Home [44•], the Talking About Live Kidney Donation (TALK) [39•] program, and the Explore Transplant program [46]. Each of these programs aims to help the potential recipient identify individuals from their social network who may or may not be potential donors, and include these individuals in educational sessions about LDKT with the potential recipient. A common thread is a focus on supporting and guiding productive communication between the potential recipient and members of his or her social network related to LDKT, often in the presence of a transplant medical expert to answer questions and concerns for both parties. At least one of the programs, Kidney Team at Home, engages in direct discussions with members of the social network about their willingness to donate [44•]. Educational materials written for both transplant candidates and potential donors are available (e.g., brochures, DVDs) through these programs as well.

A recent publication stemming from the AST Consensus Conference outlines specific content recommendations for any program educating living donor candidates, particularly in covering the risks and benefits of donation, and recommends a nationally available, standardized source of education, which would be hosted by a neutral party [47••]. A focus on specialized content for potential living donors is warranted, as it is possible that knowledge gaps and specific concerns about LDKT differ between potential kidney transplant recipients and donors. For example, evidence suggests that a central concern about LDKT for potential recipients regards discomfort asking, harming the relationship with the donor, or worry about the donor's health [6• 7]. In contrast, potential living donors have expressed more concerns about their own surgery and recovery [43]. Both potential recipients and donors share concerns about costs [48• 49]. Recent developments in education aimed specifically at potential living donors seem to respond to these concerns. Tailored educational resources for potential donors, including a website for altruistic donors to learn more (www.livingdonationcalifornia) and a website in Spanish have recently been made available [50]. However, more work is still needed to help potential donors understand the complexities of participating in incompatible and compatible paired exchange programs.

Efficacy Testing of LDKT Education Programs for Donors and Next Steps

To date, most studies testing the impact of LDKT educational programs have focused on outcomes related to the potential recipient, with less being measured about how much the recipient's social network increased in their knowledge of LDKT, decreased in concerns about living donation, or made plans to be tested as living donors. Only the Kidney Team at Home study reported educational outcomes for members of the potential recipients' social network, and increases in LDKT knowledge, LDKT attitudes, and readiness to donate were demonstrated, indicating promise for this approach [44•].

Further, though readiness to donate has been assessed in observational studies with donors [43], assessing readiness when a potential donor presents for evaluation or in the context of LDKT education delivery must occur to help guide clinicians in determining which potential donors are most likely to donate. Knowing which patients are in early stages of readiness may also help support more ethical engagement with potential living donors, inviting them

to learn more vs. assuming that they are ready to complete all the donor evaluation tests and donate within 3 months. To our knowledge, there are presently no validated TTM-based measures of readiness, Decisional Balance, or self-efficacy available for potential living donors.

Educating a Racially/Ethnically and Socioeconomically Diverse Patient Population

The AST Consensus Conference also recommended that we “[p]rovide more culturally-tailored LDKT education to racial/ ethnic minority patients [...]” [11••]. This recommendation reflects evidence that racial/ethnic minorities pursuing trans-plant are less likely to receive LDKT than Whites at every transplant center in the USA [51] and are less likely to have received education about transplant previously [13]. Acknowledging that increasing educational efforts aimed at racial/ethnic minorities is one important way to reduce disparities, culturally competent, tailored LDKT education programs are being designed [52–55]. These approaches have been very successful in engaging kidney patients who are racial or ethnic minorities in education about LDKT and in helping to identify potential living donors, with gains realized in increased LDKT pursuit among the TALK and Explore Transplant Programs [39• 46], as well as increased LDKT in the “House Calls” program [56]. Further, culturally tailored and language- appropriate transplant evaluation clinics and online resources have been effective in increasing Hispanic patients’ knowledge about and interest in LDKT [50• 57].

Wherever possible, culturally competent LDKT education should address the core causes of racial/ethnic disparities in LDKT access. However, to date, the research explaining the causes for racial disparities in LDKT (and in transplant generally) is conflicting and requires further development. Taking cues from evidence that medical mistrust is a barrier to LDKT for racial minorities [58• 59], current culturally competent interventions have focused on addressing mistrust directly [60] and creating more trusting environments, usually away from the transplant center itself [42•• 61]. While this is certainly appropriate, a major gap in knowledge exists regarding the extent to which racial disparities in pursuit and receipt of

LDKT might also be driven by lower readiness for LDKT, fears and concerns regarding LDKT, and knowledge of LDKT among racial and ethnic minorities pursuing transplant, although these factors represent the primary targets of many educational resources and interventions. Initial evidence suggests that racial and ethnic minority patients may disproportionately begin the transplant process in early stages of LDKT readiness [42•] and that controlling for LDKT readiness and other, similar psychosocial constructs (e.g., knowledge of transplant) may play an important role in explaining the ultimate racial disparity in LDKT [13]. Finally, investigations of whether accounting for the low socioeconomic status (SES) of some racial/ethnic minority ESRD and transplant patients fully explains the racial disparity in access to transplant and LDKT have reached conflicting conclusions [62• 63]. Clarifying the impact of SES in LDKT will help inform attention to financial support resources within education programs. The AST Consensus Conference also duly recommended that future research must still occur to understand how modifying different possible causes for racial disparities affects pursuit of LDKT among different racial/ethnic minority groups [64••]. For example, past LDKT educational programs

targeting Black and/or Hispanic kidney patients have aimed to increase knowledge or address fears by providing improved educational materials and longer educational conversations [37], supporting patients in completing small steps toward LDKT [24], providing individually guided navigation services [40], and assisting patients in obtaining financial resources to address socioeconomic barriers [36]. For donor candidates, there is now a debate as to whether they should be compensated some amount for the uncovered costs associated with the evaluation and donation processes to work toward a goal of financial neutrality [11••]. A financial toolkit for living donors is being prepared to provide guidance and information on available resources to assist in mitigating donation-related costs [47••]. It is critical to compare the relative importance of different factors that may be potentially causing disparities in LDKT access so that appropriate choices can be made about how best to focus LDKT education and funds.

Conclusion

High-quality education can effectively increase transplant pursuit [65] and LDKT [45]. Some educational strategies and programs have evidenced success in educating patients at various stages of CKD and ESRD treatment, including in community nephrology clinics [39•], dialysis centers [40• 46], and transplant centers [42• 56]. We have outlined a key theoretical approach and research findings relevant to effectively providing LDKT education to patients of varying levels of readiness along the CKD trajectory and to their support network who may become living donors.

In the next decade, we must continue to answer many open questions related to LDKT education. First, although there is agreement of the importance of providing LDKT education at multiple timepoints through-out the course of a patient's CKD/ESRD experience, it is unclear what the actual educational “dose” should be in terms of how much time and educational content should be provided at each timepoint. It is also unclear whether the dose should vary over time for patients who have been educated about LDKT multiple times, and to what extent and on which factors the educational interventions should be tailored. A second, equally critical vein of LDKT education research regards the best ways to cost-effectively increase access to LDKT education for the hundreds of thousands CKD and ESRD patients and their family members and friends. Technology-based solutions may provide significant efficiencies [12••]. Yet, little research is available to demonstrate whether e-learning-, telehealth-, or telephone-based LDKT education programs are as effective as programs that deliver education in person with a clinician or other educator. Comparative- and cost-effectiveness analyses must be performed to determine which educational strategies can provide effective education with lower resource investment. Further, dissemination and implementation studies of currently evidence-based programs [37• 42• 45• 46• 66] are needed to determine if their effects are maintained when the programs are scaled to reach many thousands of patients, and to identify additional or unexpected barriers that may arise with large-scale implementation.

In summary, educational messages to better communicate the potential benefits and risks of LDKT and to encourage LDKT for appropriate patients will be most effective when education is tailored to individual patients' readiness, content increases their knowledge

about and preparation for LDKT and living donation, and messages are delivered and repeated over time in different clinical, community, and home-based settings. Going forward, LDKT education research must determine which techniques work best, and how effective strategies can be made accessible to the entire population of CKD and ESRD patients and their family members and friends. Accomplishing this objective will make access to LDKT education more equitable so that kidney patients and potential living donors of every racial/ethnic group and socioeconomic level can seek, learn about, and become involved in LDKT.

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Abbreviations

AST	American Society of Transplantation CKD Chronic kidney disease
ESRD	End-stage renal disease
LDKT	Living donor kidney transplant
OPTN	Organ Procurement and Transplantation Network
SES	Socioeconomic status
TALK	Talking About Live Kidney Donation
TTM	Transtheoretical Model of Behavior Change

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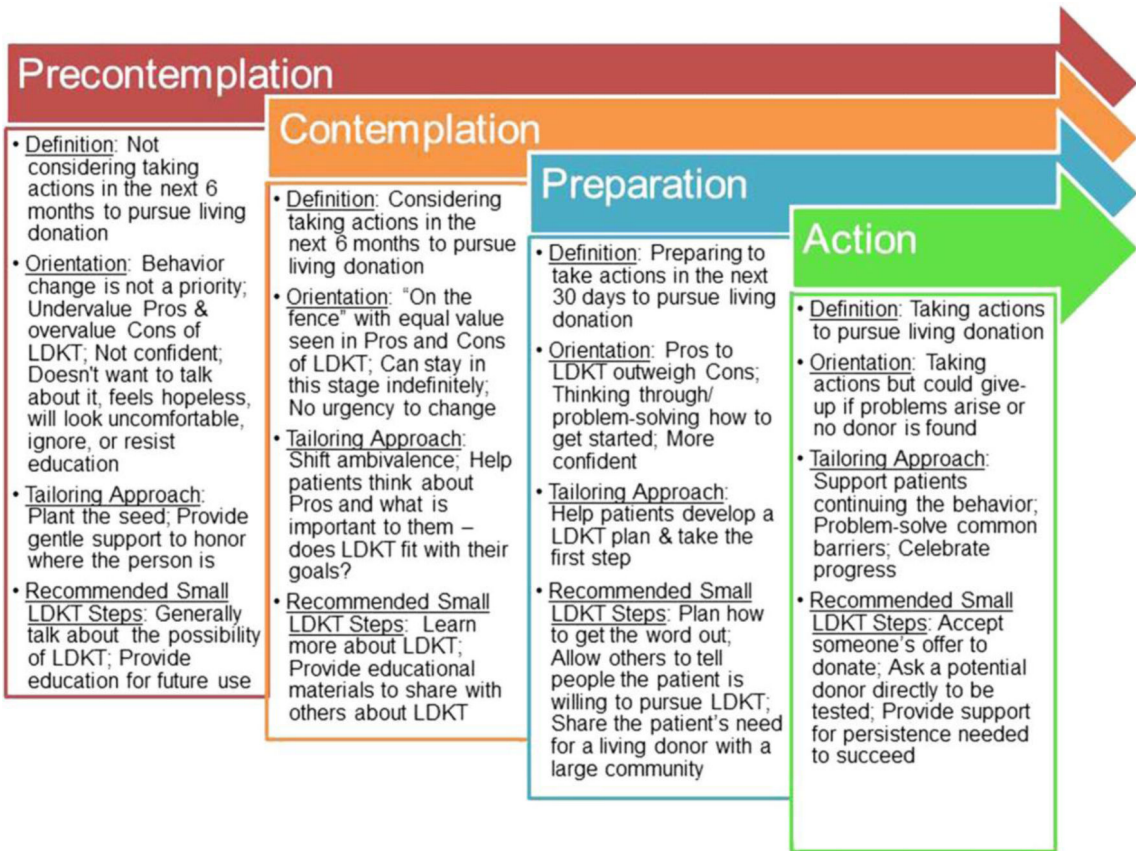


Fig. 1. TTM tailored educational recommendations for increasing readiness to pursue living donor kidney transplant. *LDKT* living donor kidney transplant, *TTM* transtheoretical model of behavior change