Applying Best Practices and Theory to Improving Transplant Discussions

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Explore Transplant Training
co-founder & lead trainer

Christina Goalby, MSW
Manager of transplant initiatives – Health Literacy Media

- Served as a consultant for Dr. Waterman’s Research Lab at UCLA
- Co-Creator of the Explore Transplant Dialysis Provider Training
- Taught over 100 Explore Transplant trainings in the US and Canada
- Used Explore Transplant directly with over 300 patients
- Previously Divisional Lead Social Worker at DaVita
- Nephrology social worker since 1996
- Past Co-chair of CNSW of Eastern MO & Metro East
About Health Literacy Media

Health Literacy Media (HLM) is a St. Louis-based health communications nonprofit. We partner with health care organizations, providers, and advocates to promote clear, patient-friendly health messaging and education.

Explore Transplant (ET) & Explore Living Donation (ELD) are our 2 kidney transplant education programs, which work to further improve the lives of kidney patients and their families, and guide the providers who care for them.
Need for better transplant education

1. Theory and research that support transplant education best practices
2. Apply theory & best practices to transplant discussions
3. A family of transplant education programs
ESRD patient treatment options

678,000 patients with kidney failure in the US

- 64% Hemodialysis
- 20% Deceased Donor Transplant
- 9% Living Donor Transplant
- 7% Peritoneal Dialysis
5-year life benefits: Dialysis vs. transplant

- Dialysis: 42%
- Deceased Donor Transplant: 76%
- Living Donor Transplant: 88%
Transplant benefits:
Live longer

<table>
<thead>
<tr>
<th>Patient age</th>
<th># of years expected to live on dialysis</th>
<th># of years expected to live with a transplant</th>
<th>Years of life gained with a transplant</th>
</tr>
</thead>
<tbody>
<tr>
<td>45-49</td>
<td>9</td>
<td>24</td>
<td>15 or more</td>
</tr>
<tr>
<td>50-54</td>
<td>8</td>
<td>21</td>
<td>13 or more</td>
</tr>
<tr>
<td>55-59</td>
<td>7</td>
<td>18</td>
<td>11 or more</td>
</tr>
<tr>
<td>60-64</td>
<td>6</td>
<td>15</td>
<td>9 or more</td>
</tr>
<tr>
<td>65-69</td>
<td>5</td>
<td>12</td>
<td>7 or more</td>
</tr>
<tr>
<td>70-74</td>
<td>4</td>
<td>10</td>
<td>6 or more</td>
</tr>
<tr>
<td>75-79</td>
<td>3</td>
<td>8</td>
<td>5 or more</td>
</tr>
</tbody>
</table>
Barriers to transplant on many levels

- Patient barriers
- Provider barriers
- Friends and family barriers
- Healthcare system and public policy barriers
Skills mismatch

Education materials are written beyond most people’s ability to understand.

Health care providers often use medical jargon that’s unfamiliar to most people.
Low health literacy is a big problem

93 million American adults lack the health literacy skills to understand and use health information

1 in 5 adults have health literacy skills considered to be “below basic”

NAAL, 2003
Low health literacy leads to poor health

- Worse overall health status
- More emergency room visits
- More hospitalizations
- Higher mortality rates

NAAL, 2003; Griffey et al., 2014; Mitchel et al., 2012; Baker et al., 2007
Some populations are more vulnerable

These populations are more vulnerable to low health literacy:

- The elderly
- People with lower income levels
- People with lower education levels
- People with limited English proficiency
- People with serious mental illness
American Society of Transplantation (AST) Consensus Conference recommendations

Create simple, validated, engaging educational tools to raise rates of living donor kidney transplant (LDKT):

- Repeat LDKT education at many points as kidney disease progresses
- Build patients’ and potential living donors’ knowledge, readiness, and actions to take small steps towards LDKT over time
- Distribute education tools widely

Better Education May Help Promote Better Outcomes Across Living and Deceased Donation

- Improving education and transplant knowledge may increase completion of a transplant evaluation and receipt of a deceased or living donor kidney transplant.¹

- The American Society of Transplantation (AST) recommend the following for kidney transplant:²
  - Simple, validated, engaging educational tools be created
  - Repeated education at many points as kidney disease progresses
  - Education tools distributed widely in a modular way

This led to the development of Explore Transplant educational resources

Build a pipeline for delivering transplant education

Give transplant information to possible donors in the community

Educate patients in primary care settings

Educate patients in nephrologists’ offices (CKD 3 and 4)

Give living donation education to patients at the start of transplant evaluation

Educate patients in dialysis centers (ESRD)

Give living donation education to patients while they’re wait-listed and strategies to find living donors.
our agenda

1. Need for better transplant education
2. Theory and research that support transplant education best practices
3. Apply theory & best practices to transplant discussions
4. A family of transplant education programs
All patients have the right to make an informed choice about their treatment.

Each patient is unique and has to decide what is best for them.

We can work together to lower inequalities in access to the best treatment options for our patients.
Prochaska’s Transtheoretical Model of Behavioral Change (TTM):

- It has successfully motivated patients to take 55 health behaviors
- National Institutes of Health (NIH) recommends its use to reduce racial disparities in health
The 5 stages of readiness to take a health behavior

- Precontemplation
- Contemplation
- Preparation
- Action
- Maintenance
Focuses on the decision-making of the individual and is a model of intentional change.

Operates on the assumption that people do not change behaviors quickly.

TTM-tailored communication is effective in producing significant behavior changes.

<table>
<thead>
<tr>
<th>TTM 5 Stages of Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Precontemplation (Not ready)</td>
</tr>
<tr>
<td>I won’t do this</td>
</tr>
<tr>
<td>I am not going to do this</td>
</tr>
<tr>
<td>Contemplation (Getting Ready)</td>
</tr>
<tr>
<td>I may do this in the next 6 months</td>
</tr>
<tr>
<td>I am thinking about it</td>
</tr>
<tr>
<td>Preparation (Ready)</td>
</tr>
<tr>
<td>I will do this in 1 month</td>
</tr>
<tr>
<td>I am planning how to do this</td>
</tr>
<tr>
<td>Action</td>
</tr>
<tr>
<td>I am currently doing this</td>
</tr>
<tr>
<td>Maintenance</td>
</tr>
<tr>
<td>I am already doing this (for over 4 months)</td>
</tr>
</tbody>
</table>

About the theory:
**Stages of Change**

People are in different stages of readiness to take a behavior
- Many people are not yet ready to start
- People change stages over time
- People can move both ways and get more or less ready
Tailor education by patients’ stage

- Motivate patients to move one stage only, not into action
- Recommend small changes vs. one big change
Deceased and living donation are 2 different health behaviors.

Patients may be in different stages for deceased and living donation.
Among transplant-eligible dialysis patients:

Deceased Donation (N=293):
- Precontemplation: 17%
- Contemplation: 23%
- Preparation: 13%
- Action: 29%
- Maintenance: 18%

Living Donation (N=293):
- Precontemplation: 9%
- Contemplation: 14%
- Preparation: 74%
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When do patients pursue transplant?

When they see many **pros** to transplant, such as:

- Getting a degree
- Watching their kids grow up
- Travel more freely
Pros and cons by Stage of Change
When do patients pursue transplant?

When they have a chance to talk about their transplant fears and cons.

When talking to patients:

- Normalize worry when a patient express emotions
- Correct myths to help a patient learn
- Brainstorm about barriers and ways to overcome them
When do patients pursue transplant?

When they are confident that they can successfully overcome any barrier to getting a transplant.

**Confidence goes up when patients:**

- Have someone who is rooting for them
- Break a large task into small steps
- Know the facts about transplant
- Brainstorm about how to overcome barriers
Review: When do patients pursue transplant?

- Education is **tailored** to their level of readiness
- Their **pros** to transplant go up
- They talk about their **cons** to transplant
- Their **confidence** about getting a transplant goes up
## Tailor education to patient’s readiness

<table>
<thead>
<tr>
<th>Stage</th>
<th>Action</th>
<th>Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Precontemplation</td>
<td>Plant the idea</td>
<td>Gently introduce the option of transplant &amp; living donation</td>
</tr>
<tr>
<td>Contemplation</td>
<td>Shift their ambivalence</td>
<td>Provide education materials and recommend learning more</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Discuss success of DDKT and LDKT options</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Help them think about if LDKT could help them get a transplant sooner</td>
</tr>
<tr>
<td>Preparation</td>
<td>Help them begin</td>
<td>Plan small steps to tell community that they would be open to DDKT or LDKT</td>
</tr>
<tr>
<td>Action/Maintenance</td>
<td>Support not dropping out</td>
<td>Celebrate small actions and support the to keep looking for matching donor</td>
</tr>
</tbody>
</table>
**Change your transplant question**

**Q1:** How willing are you to learn more about transplant?

**Q2:** Which of these actions would you be willing to do?

- Read information/watch videos about getting on the deceased donor waiting list
- Share educational materials about deceased donation with people in your life
- Generally talk to people you trust about whether to get a deceased donor transplant
- Call the transplant center to pursue evaluation
- Complete and mail back the transplant center’s new patient medical forms
- Invite someone to come to evaluation with you
- Come to the transplant center to complete medical tests
- Follow-up with transplant coordinator until transplant evaluation is complete
Change your living donor questions

Q1: How willing are you to learn more about living donation?

Q2: Which of these actions would you be willing to do?

▪ Read information/watch videos about getting a living donor transplant
▪ Share education materials about living donation with people in your life
▪ Generally talk to people you trust about whether to get a living donor transplant
▪ Make a list of people who might be a living donor for you
▪ Ask another person to tell others about your need for a living donor transplant
▪ Ask potential donors to be tested
▪ Give potential living donors the transplant center phone number
▪ Share my need for a living donor with a large community (e.g., Facebook, Twitter, etc.)?
## Small LDKT steps

<table>
<thead>
<tr>
<th>Actions</th>
<th>PreC</th>
<th>Cont.</th>
<th>Prep</th>
<th>Act</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accept someone’s offer to donate</td>
<td>54%</td>
<td>98%</td>
<td>92%</td>
<td>98%</td>
</tr>
<tr>
<td>Let others tell people that I would be open to living donation</td>
<td>51%</td>
<td>93%</td>
<td>92%</td>
<td>85%</td>
</tr>
<tr>
<td>Share education materials about living donation</td>
<td>51%</td>
<td>93%</td>
<td>92%</td>
<td>88%</td>
</tr>
<tr>
<td>Talk to people about my interest in transplant</td>
<td>49%</td>
<td>95%</td>
<td>96%</td>
<td>83%</td>
</tr>
<tr>
<td>Share my need for a living donor with a large community</td>
<td>51%</td>
<td>93%</td>
<td>92%</td>
<td>88%</td>
</tr>
<tr>
<td>Directly ask a potential donor to be tested</td>
<td>28%</td>
<td>58%</td>
<td>83%</td>
<td>70%</td>
</tr>
</tbody>
</table>

All tests significant at $p<0.001$
Words matter

Present education as an invitation to learn instead of “you shoulds”

Support patient in taking actions that are right for them

Replace the word “ask” with “learn more”
Varied and adequate education

- Use education that shows real stories of recipients and living donors
- Be sure to educate patients on both the benefits and risks (pros and cons)
- Based on health disparity research, remember that certain patients may need additional educational support
Revisit options & involve a support system

Don’t assume a patient will be a “no” just because they were a year ago

Revisit the idea of living donation with patients who are on the waiting list

Be sure to include family and friends
Take small steps & address misconceptions

- If a patient resists, take a step back
- Move patients 1 stage at a time
- Help debunk myths, such as “I’m too old”
Which Dialysis Centers were able to Increase Wait-Listing Rates?

Centers that provide 3 or more of these practices have higher wait-listing rates:

- Make appropriate referrals
- Give transplant center phone numbers
- Provide education for potential living donors
- Take time to educate
- Provide administrative support
- Providers who know more about transplant
- Providers who have detailed discussions about transplant and living donation
Living donation decision making

- More patients are in early stages for living donation
  - Provide information
  - Learn with family members

- Living donation decision-making often occurs after patients present for transplant
General transplant knowledge

You don’t have to be a transplant expert!

Call your local Transplant Representative if:
- Your patient has a very complex medical history
- Your patient has financial or insurance questions
- You want to learn about resources or programs offered by that transplant center
our agenda

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Health Literacy Transplant Educational Resources

Our programs help kidney transplant patients and living donors make informed treatment choices that includes:

- Print brochures & videos
- Animated web applications
- Online web resources
- Video storytelling applications
- Training on how to find living donors
- Available in English and Spanish
- Reaches variety of populations
- Access to peer mentors, recipients and donors who share their experiences

A result of the collaboration of numerous thought leaders, educators, researchers, and experts, that started with the partnership between Amy Waterman, PhD, and Health Literacy Media
Explore Living Donation

Components

Welcome

Basics of living kidney donation

How to find a living kidney donor

How to help a loved one with kidney disease

Resources to learn more

Explore Living Donation

Components
Other transplant education initiatives:

My Transplant Coach

My Transplant Coach is an interactive decision aid to help kidney patients learn about and understand their condition, and assist them in making healthcare decisions.

This online, video-based decision aid uses animated videos and personalized graphs to help patients understand what treatment options are available, so they can make informed decisions that are right for them.

https://youtu.be/SA8QyM7dzwk

https://mytransplantcoach.org
My Transplant Coach

Animated smartphone/tablet app

Your Information

Please share the information below. We'll use what you share to give you customized information about treatment options for kidney disease.

We will not store or share the information you provide. If you leave the site before you finish the program, you will need to enter this information again.

- Height: [ ] Feet [ ] Inches
- Weight: [ ] Pounds
- Age: [ ] Years
- Gender:
  - [ ] Male
  - [ ] Female
- Race:
  - [ ] Hispanic/Latino
  - [ ] Asian
  - [ ] African
  - [ ] White
  - [ ] Others
  - [ ] Don’t know
- Blood Type:
- Time on Dialysis: [ ] Years [ ] Months
- Check if you have diabetes: [ ]
- Check if you have high blood pressure: [ ]
- Check if you have had a previous transplant: [ ]

Please select closest center to your location:

Explore
difference in
treatment
courses

take the
test
take the
test

Entire United States

My Transplant Coach

Graph 1: Patients with your characteristics

This graph demonstrates the percentage of patients with your characteristics who are alive in 5 years if they chose to remain on dialysis, are placed on a local waiting list and possibly receive a deceased donor kidney transplant, or who receive a living donor transplant.
My Transplant Coach feedback

1 year on waiting list

3 years on waiting list

These graphs demonstrate what happens to patients who remain on the waiting list in your region. As you can see, every year some patients receive a transplant, some patients pass away waiting, and some die prior to the operation.
My Transplant Coach:

Feedback Report

My Transplant Coach Report: Created 1/11/2018

This report contains educational information about options for kidney transplantation. These data were based on health information you provided on the My Transplant Coach website. We hope that this information will prove helpful to you and your medical team. Share this information with your doctor and ask about your treatment options.

While visiting the My Transplant Coach website, you entered the following information:

Age: 54
Race: White
Gender: Male
Years on dialysis: 1y. 0m
Transplant center: MOSL - Saint Louis University Hospital

Helping you decide what treatment option is right for you

Kidney failure can be a frightening event for many patients. Fortunately, patients have a variety of different options which can help you live longer despite kidney failure. Among these options, patients need to choose between dialysis and kidney transplant. The graphs below show how many people like you expect to living after 5 years, based on the treatment they chose. This graph compares the average results for patients who stay on dialysis, wait for and receive a deceased donor kidney transplant in the area you pointed, or have a living donor kidney transplant in the next few months.

It is important to remember these things about this graph. First, not everyone who waits for a deceased donor transplant will receive a transplant in the first 5 years. In some areas of the country, many patients are transplanted in five years, while in others, most patients wait 7-8 years. Second, these results are for average patients with your characteristics. You and your doctor can work together to look at your own health and determine if these estimates are right for you. Third, treatments with higher numbers are expected to help patients like you live longer.

The Transplant Process

The first step to getting a transplant is to get referred to a transplant center. There, you will meet the transplant team and they will help you to determine if transplant is right for you. Once you have been evaluated and found to be a good candidate for transplant, you can either have a living donor transplant (if you have someone who will give you a kidney) or be entered onto the waiting list. In general, the longer you wait, the more likely you are to receive a transplant.

The next chart shows you what happens to people like you who choose to wait for a kidney from a deceased donor in your area. You’ll see 100 people on the graphs, and the different colors show how many people are:

- Still waiting for a kidney transplant (orange)
- Have received a deceased donor kidney transplant (green)
- Have died before being able to receive a kidney (blue)

We’ve included the graphs for 1 year and 5 years. That means these graphs show how many people like you are expected to still be waiting, to have received a kidney, or died after 1 year the waiting list and after 5 years on the waiting list. Unfortunately, some patients die prior to receiving a transplant from the list.

After waiting for 1 year: 46
After waiting for 5 years: 2
Other transplant education initiatives:
transplantliving.org/kidney

UNOS Kidney Transplant Learning Center

The UNOS Kidney Transplant Learning Center (KTLC) is an online, national, clearinghouse of public educational resources about transplant and living donation for end-stage renal disease patients, potential living donors, and the interested public.

This site, accessible by computer, tablet, or phone, was developed to ensure informed transplant and living donation decision-making and equity in access to quality education about transplant and living donation to combat barriers that research suggests limits access to transplantation.
Summary

- Kidney transplant improves survival outcomes compared with dialysis\(^1\)
- However, a number of barriers to transplant exist\(^2\)
- Better transplant education may lead to better patient outcomes\(^3\)
- Educational materials need to be tailored to each patient’s need and current stage of change\(^3\)
- Explore Transplant has created a family of educational resources tailored to help support transplant centers' patient educational programs\(^4\)

Questions?
Thank you!
Contact me

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