




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

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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.

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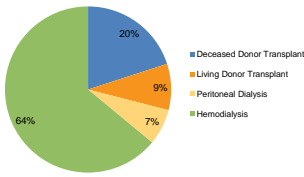
our agenda



- Need for better transplant education
- Theory and research that support transplant education best practices
- Apply theory & best practices to transplant discussions
- A family of transplant education programs

ESRD patient treatment options

678,000 patients with kidney failure in the US

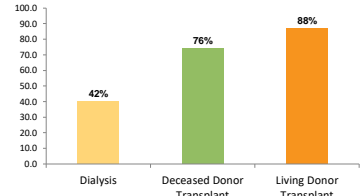


| Treatment Option | Percentage |
|---------------------------|------------|
| Deceased Donor Transplant | 20% |
| Living Donor Transplant | 9% |
| Peritoneal Dialysis | 7% |
| Hemodialysis | 64% |

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USRDS Annual Report 2017

5-year life benefits: Dialysis vs. transplant



| Treatment Option | 5-year Life Benefit (%) |
|---------------------------|-------------------------|
| Dialysis | 42% |
| Deceased Donor Transplant | 76% |
| Living Donor Transplant | 88% |

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USRDS Annual Report 2017

Transplant benefits: Live longer

| Patient age | # of years expected to live on dialysis | # of years expected to live with a transplant | Years of life gained with a transplant |
|-------------|---|---|--|
| 45-49 | 9 | 24 | 15 or more |
| 50-54 | 8 | 21 | 13 or more |
| 55-59 | 7 | 18 | 11 or more |
| 60-64 | 6 | 15 | 9 or more |
| 65-69 | 5 | 12 | 7 or more |
| 70-74 | 4 | 10 | 6 or more |
| 75-79 | 3 | 8 | 5 or more |

Barriers to transplant on many levels



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"

Low health literacy leads to poor health



Worse overall health status



More emergency room visits



More hospitalizations



Higher mortality rates

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




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Rudow, et al (2015); Waterman, et al (2015)

Better education about deceased (DDKT) and living (LDKT) transplants leads to better outcomes

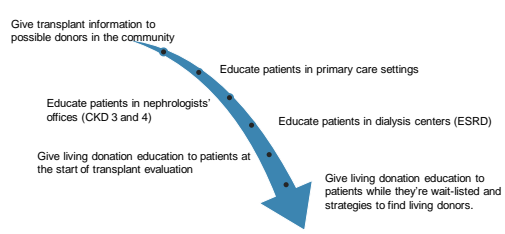
- High-quality transplant education leads to:
 - 36–49% higher transplant wait-listing rates¹
 - 25% higher donor evaluations and 22% higher LDKTs²
 - lower racial disparities in access to transplant
- Patients who start transplant evaluation feeling more ready to pursue LDKT are 4.3 times more likely to have an LDKT³
- Patients with greater knowledge are 1.2 times more likely to have an LDKT³



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Kucika, et al (2012);¹ Rodriguez, et al (2007);² Waterman, et al (2013)

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)

Educate patients in dialysis centers (ESRD)


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

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

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But does providing transplant education work?

A group randomized-controlled trial of 20 dialysis centers (N=253 patients) found that patients who received ET education ...



- Were more likely to increase in stage of readiness for LDKT (odds ratio=2.5)
- Had a greater increase in transplant knowledge
- Were more likely to restart or begin transplant evaluation

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Waterman & Peipert 2018

What we've learned

- Patients presenting for transplant haven't learned much about transplant beforehand
- Many have socio-economic challenges that may distract them from completing evaluation
- They may not trust us
- Patients who are racial/ethnic minorities may need additional educational support

Improving education increases completion of transplant evaluation and receipt of LDKTs.

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Educational foundation

- 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.

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Theoretical foundation

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

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The 5 stages of readiness to take a health behavior

- Precontemplation
- Contemplation
- Preparation
- Action
- Maintenance

Precontemplation

I won't do this

I am not going to do this

- Precontemplation
- Contemplation
- Preparation
- Action
- Maintenance

Contemplation

I may do this in the next 6 months

I am thinking about it

- Precontemplation
- Contemplation
- Preparation
- Action
- Maintenance


Preparation

I will do this in one month


I am planning how to do this

- Precontemplation
- Contemplation
- Preparation
- Action
- Maintenance

Action




I am currently doing this




Precontemplation Contemplation Preparation Action Maintenance

Maintenance



I'm already doing this (for over 6 months)



Precontemplation Contemplation Preparation Action Maintenance

Group activity: Stages of Change

How ready are you to exercise 5 times a week for 30 minutes a day?



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Recommend by U.S. Department of Health and Human Services, 2008

How ready are you to exercise 5 times a week for 30 minutes a day?

What stage are you in?

| | |
|------------------|-------------------------------|
| Precontemplation | I am not going to do this. |
| Contemplation | I am thinking about it. |
| Preparation | I am planning how to do this. |
| Action | I am currently doing this. |
| Maintenance | I am already doing this. |

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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

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Tailor education by patients' stage

- Motivate patients to move one stage only, not into action
- Recommend small changes vs. one big change



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Apply Stages of Change to transplant education

- Deceased and living donation are 2 **different** health behaviors
- Patients may be in different stages for deceased and living donation

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Readiness to pursue transplant

Among transplant-eligible dialysis patients:

Deceased Donation
(N=293)

Living Donation
(N=293)

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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

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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

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Pros and cons by Stage of Change

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Common transplant myths

I am not transplant-eligible

If I got a transplant, I would have to take 100 pills a day

If I get a transplant and it fails, I will die

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Tailor education to patient's readiness


| | | |
|---------------------------|--------------------------|--|
| Precontemplation | Plant the idea | Gently introduce the option of transplant & living donation |
| Contemplation | Shift their ambivalence | <ul style="list-style-type: none"> Provide education materials and recommend learning more Discuss success of DDKT and LDKT options Help them think about if LDKT could help them get a transplant sooner |
| Preparation | Help them begin | Plan small steps to tell community that they would be open to DDKT or LDKT |
| Action/Maintenance | Support not dropping out | Celebrate small actions and support the to keep looking for matching donor |

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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



Know the facts about transplant



Break a large task into small steps



Brainstorm about how to overcome barriers

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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

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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

H L M | EXPLORE Transplant & Living Donation | Williams, 2014, Journal of Health Psychology

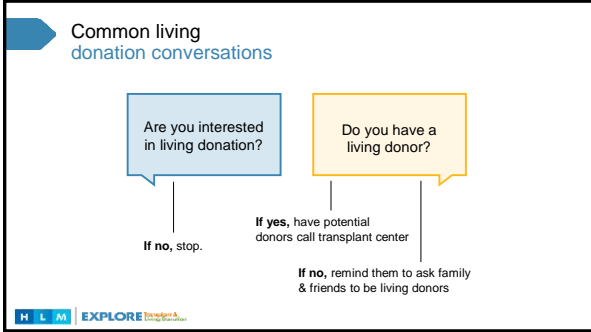
Change your living donor questions

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.)?

H L M | EXPLORE Transplant & Living Donation | Williams, 2014, Journal of Health Psychology



Small LDKT steps

| Actions | PreC | Cont. | Prep | Act |
|--|----------------------------------|-------|------|-----|
| | % Planning to do or already done | | | |
| Accept someone's offer to donate | 54% | 96% | 92% | 98% |
| Let others tell people that I would be open to living donation | 51% | 93% | 92% | 85% |
| Share education materials about living donation | 51% | 93% | 92% | 88% |
| Talk to people about my interest in transplant | 49% | 95% | 96% | 83% |
| Share my need for a living donor with a large community | 51% | 93% | 92% | 88% |
| Directly ask a potential donor to be tested | 28% | 58% | 83% | 70% |

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All tests significant at p<0.001

Words matter

- Present education as an invitation to learn instead of "you should's"
- Support patient in taking actions that are right for them
- Replace the word "ask" with "learn more"

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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

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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

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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"

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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

H L M | EXPLORE Transplant & Living Donation | Waterman, et al (2015) Clin J Am Soc Nephrol

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

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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

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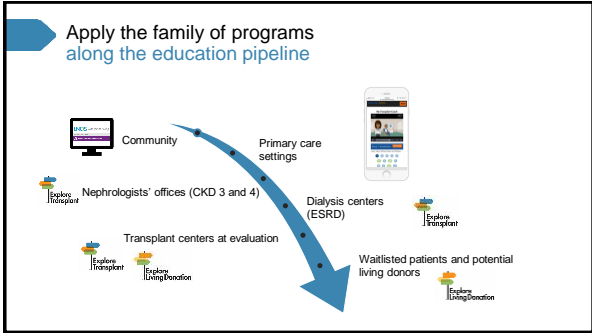


Health Literacy Transplant Educational Resources

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

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Explore Transplant Components

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Explore Living Donation Components

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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 informed options are available, so they can make informed decisions that are right for them.

mytransplantcoach.org

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<https://youtu.be/SARQdM7Dx6k>

My Transplant Coach Animated smartphone/tablet app

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My Transplant Coach feedback

1 year on waiting list

Goal 1: Patients who are on the waiting list for 1 year are still on the waiting list for 1 year. **80%**

3 years on waiting list

Goal 2: Patients who are on the waiting list for 3 years are still on the waiting list for 3 years. **95%**

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My Transplant Coach feedback report

My Transplant Coach Report: Current LUL/OLSR

This report contains educational information about access to living transplantation. These data represent national information representative of the My Transplant Coach website. We have used the information of your website to give you your website team. These data, along with your website and our other your transplant website.

Age: 65
Gender: Male
Race: White
Insurance: Medicare
Transplant: Kidney

After you use the My Transplant Coach website, you received the following information:

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The Transplant Process

The first step in 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 a 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 added onto the waiting list. In general, the longer you wait, the more likely you are to receive a transplant.

- Will be waiting for a kidney transplant (longer)
- Have had a living kidney donor transplant (shorter)

After waiting for 1 year

After waiting for 3 years

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 limit access to transplantation.



UNOS transplantliving.org/kidney

The UNOS Kidney Transplant Learning Center Purpose:

- Build a national online transplant education repository
- Establish a clearinghouse of educational resources about transplant and living donation for patients, living donors, and the interested public
- Combat barriers that limit access to transplants:
 - Ensure informed transplant and living donation decision-making
 - Provide equal access to quality information
 - Give access to trusted education to:
 - 650,000 people currently living with end-stage renal disease
 - More than 100,000 people awaiting a kidney transplant
 - Prospective living donors
 - The interested public

The UNOS Kidney Transplant Learning Center: Project Timeline

Summer 2016



Amy Waterman was invited to speak at the White House Organ Donation Summit

Fall 2016



HLM curates educational content from each of the 8 Blue Ribbon partners and conducts complete health literate review; plan website

Spring-Summer 2017



501 Creative applies revised health literate educational content onto website

Fall 2017



Education and Strategic partners, providers and patients provide feedback

January 2018



English language version of the UNOS KTLC is launched

Partners & Sponsors



「Questions?」

「Thank you!」

Contact me



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