Ethical Considerations in Palliative Care for Transplant Patients

TODAY'S PRESENTERS

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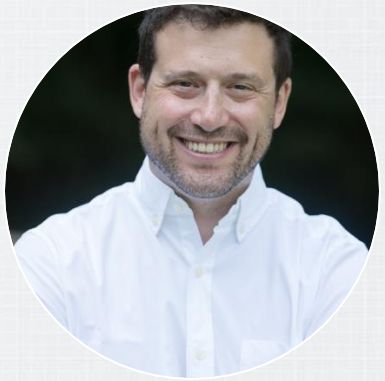

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THE Alliance | *Equipping a Modern Profession of Lifesavers in Organ Donation & Transplantation*

Tuesday, April 1, 2025, 3:00pm – 4:00pm ET

Continuing Education Information

Evaluations & Certificates

Nursing

The Organ Donation and Transplantation Alliance is offering **1.0 hours of continuing education credit** for this offering, approved by The California Board of Registered Nursing, Provider Number CEP17117. No partial credits will be awarded. CE credit will be issued upon request within 30 days post-webinar.

CEPTC

The Organ Donation and Transplantation Alliance will be offering **1.0 Category I CEPTC credits** from the American Board for Transplant Certification. Certified clinical transplant and procurement coordinators and certified clinical transplant nurses seeking CEPTC credit must complete the evaluation form within 30 days of the event.

Certificate of Attendance

Participants desiring CE's that are not being offered, should complete a certificate of attendance.

- Certificates should be claimed within 30 days of this webinar.
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- Group leaders, please share the follow-up email with all group participants who attended the webinar.

Deanna Fenton

Senior Manager, Program Development and Operations

THE Alliance

Need Assistance?

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Meet Our Moderator

Lecia Snell Kinen

MSN, RN, CCTC

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Quality and Compliance

Keck Hospital of USC

Keck Medicine of USC

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ETHICAL CONSIDERATIONS IN PALLIATIVE CARE FOR TRANSPLANT PATIENTS

JOSH LAKIN MD

RICHARD LEITER MD, MA

APRIL 1ST, 2025

ACKNOWLEDGMENT OF INEQUITY

Before we start, we pause to acknowledge that structural racism pervades the healthcare system in which we work, and particularly affects people with kidney disease. We are not experts in this realm; we invite anyone in this meeting to point out inaccuracies or insensitivities in our words today.

DISCLOSURES

We have no conflicts to interest

SPECIAL CONSIDERATIONS FOR TRANSPLANT CLINICIANS AROUND ETHICS AND PALLIATIVE CARE

- High-stakes decision-making
- Unique and complex medical and surgical considerations
- Layers of psychosocial needs
- Multiple teams of clinicians involved with varying points of view

Murakami et al, J Palliat Med, 2022

PALLIATIVE CARE: SCOPE OF PRACTICE

Psychosocial and Spiritual Support

Medical Decision-Making

Symptom Management

OBJECTIVES

1

Review helpful communication skills of balancing hope and worry in the pre-transplant period

2

Consider tensions around exploration and probing of patient's lives and how to document in the medical record in the pre-transplantation period

3

Discuss navigating the unique obligations patients, families, and clinicians hold in the post-transplant period related to organ transplantation

MS. J'S LIVER WAS POOR, AND WORSENING…

A 55 year old woman with a history of alcoholic cirrhosis and end-stage kidney disease. She has been sober for 3 years and has been activated for liver-kidney transplant. She is under general anesthesia, in the operating room for transplant, but the procedure is cancelled for donor organ reasons.

As she is waking up from anesthesia…with her anxious family around:

What do we say?

What could we have said before to make this any easier?

BALANCING HOPE AND CONCERN IN THE PRE-TRANSPLANT PERIOD

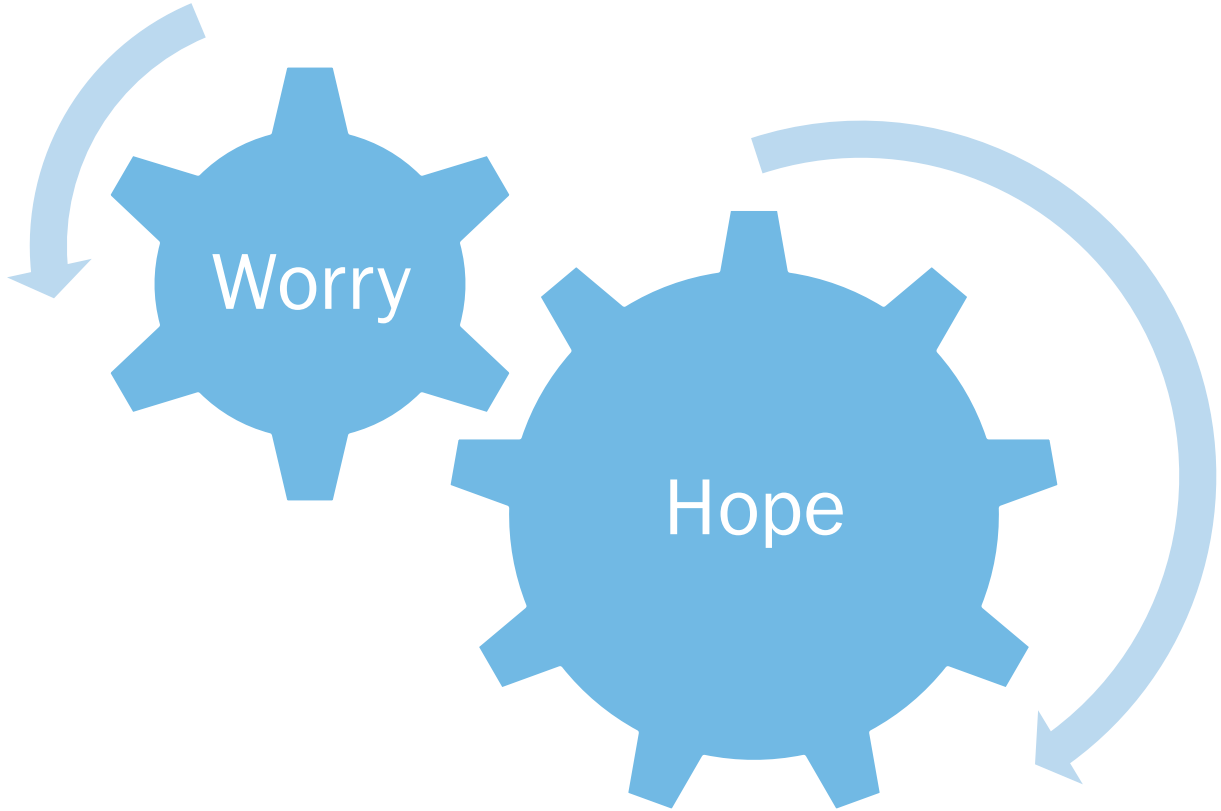
SPECIFIC COMMUNICATION TOOLS/SKILLS

Hope/worry

I wish…I wonder

Best case/Worst case

USE HOPE/WORRY TO ALIGN WITH PATIENT/CARE PARTNERS AND CONVEY DIFFICULT NEWS



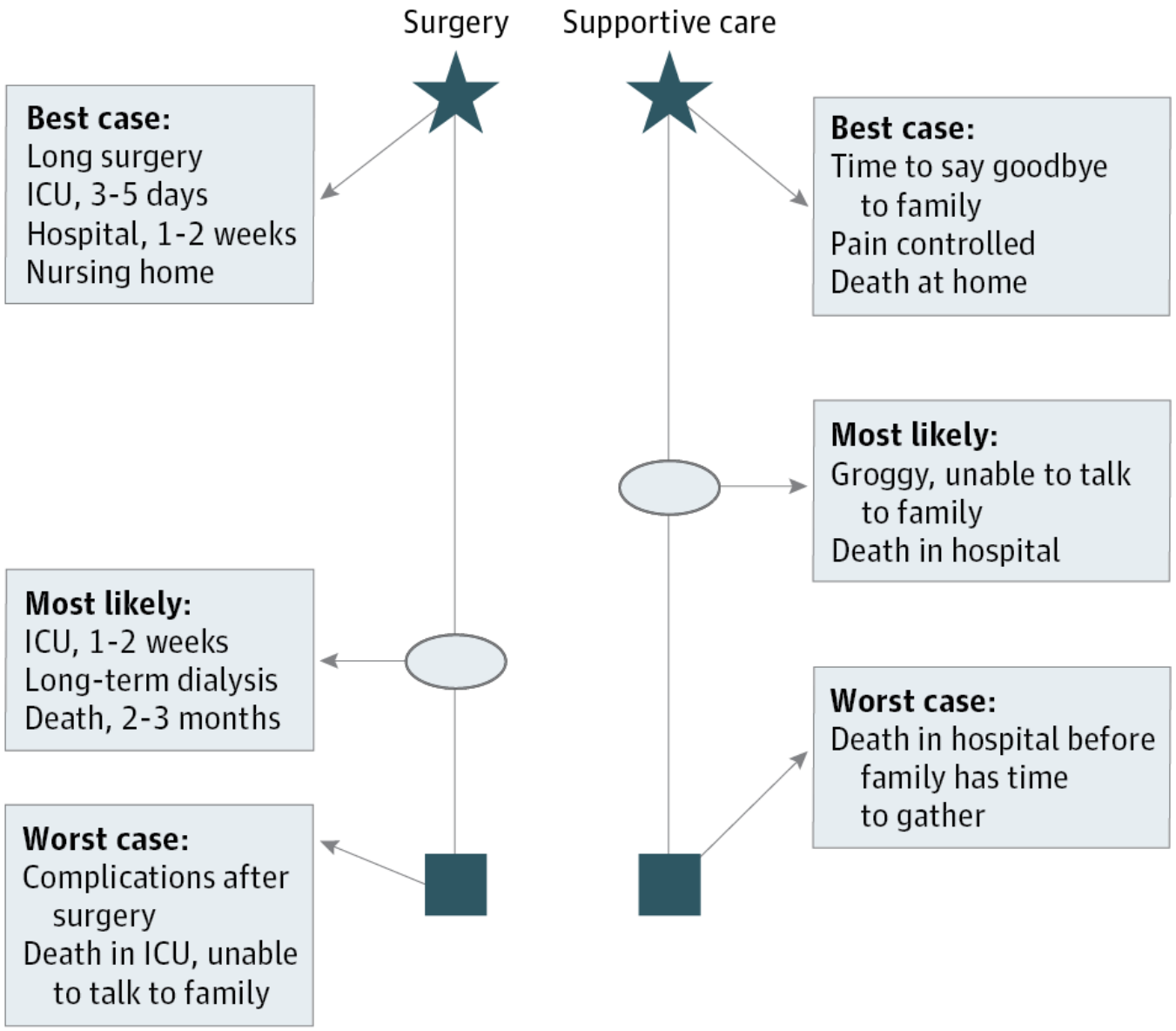
I WISH/I WONDER GENTLY ALLOWS PATIENTS TO CONSIDER HARD THOUGHTS

I wish

I wonder

BEST CASE/WORST CASE PROVIDES A FRAMEWORK TO DISCUSS COMPLEX DECISIONS

TAYLOR ET AL., JAMA SURGERY, 2017



EXAMPLE OF CHOICE FRAMING IN ADVANCED KIDNEY DISEASE: COMMON PARADIGM THAT IS NOT QUITE ACCURATE

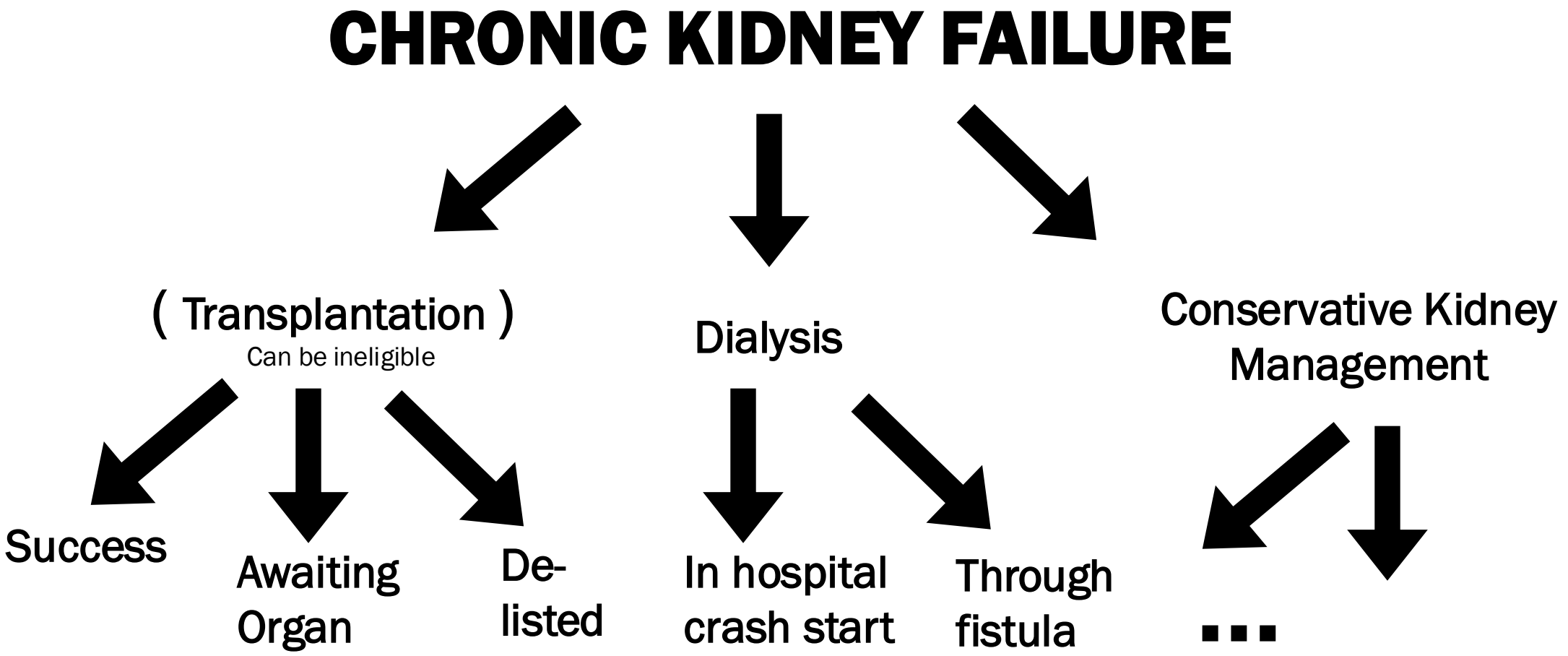
CHRONIC KIDNEY FAILURE

Transplantation

Dialysis

"Do nothing"
"No treatment"
"Giving up"

FOR THE LARGEST GROUP OF INCIDENT KIDNEY FAILURE PATIENTS (>75 YEARS OLD),
THERE ARE MANY BRANCH POINTS AND POSSIBLE COMPLEX OUTCOMES:

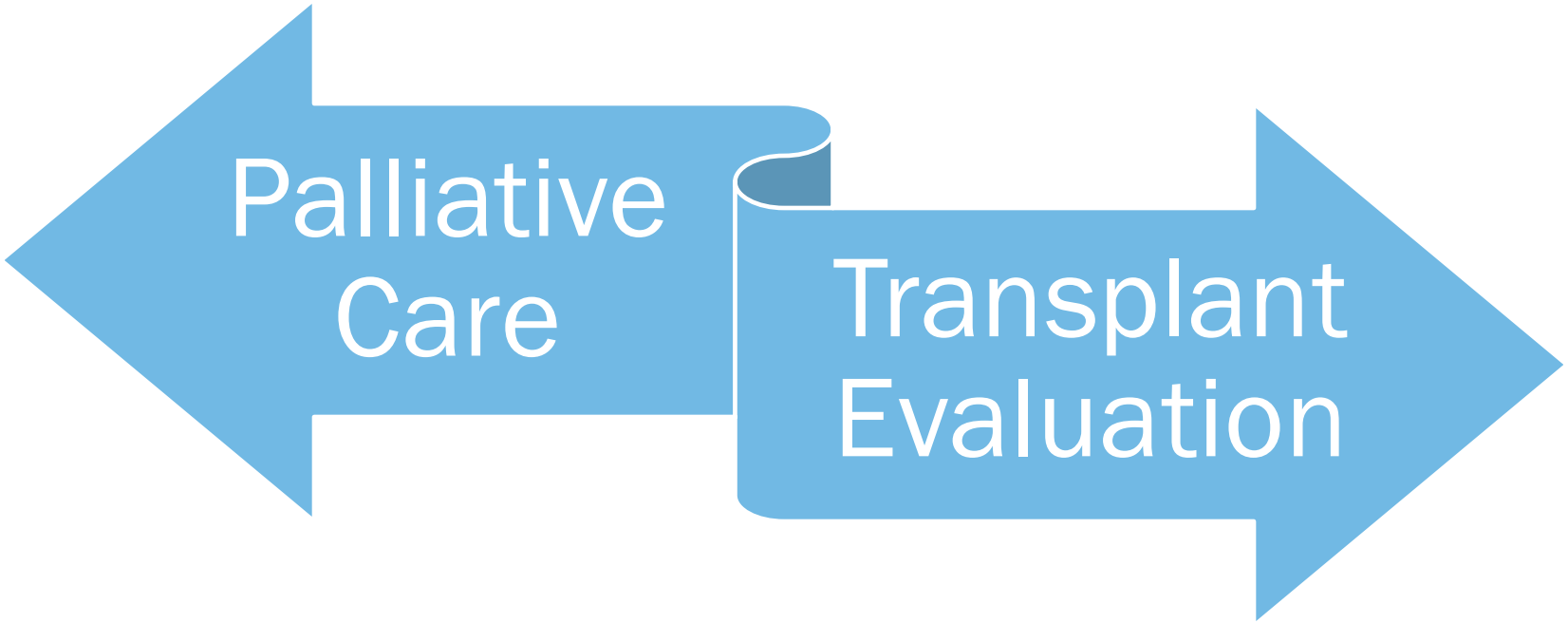


MS. J 1 YEAR LATER…

Ms. J continues along working with her transplant team and striving for transplant but it hasn't yet happened. She is exhausted, feeling unwell and talks with one of her clinicians saying "I don't want to live like this anymore." This is interpreted as suicidal ideation and documented in her medical record. As a result, she is de-listed from transplant. While awaiting psychiatric evaluation for this issue for re-listing, she decompensates and becomes too sick for the evaluation and dies on CMO in the hospital with family at bedside without being relisted.

DOCUMENTING DISCUSSIONS IN THE MEDICAL RECORD

What do you do when someone listed for transplant says “I can’t live like this anymore”?



UNDERSTAND WHAT IS REALLY GOING ON

“I don’t want to live like this anymore”

- NOT suicidal ideation
- Dissatisfaction with her quality of life
- Having a difficult day

DEPRESSION IS COMMON IN CKD AND ESKD

- 20-44% of patients with kidney failure have major depressive disorder

- Depression is associated with nearly twice the risk of death, hospitalization, or dialysis initiation in CKD patients

- Limited and mixed data on therapy
  - SSRI no better than placebo in CKD patients
  - SSRI slightly better than CBT in ESRD patients on dialysis

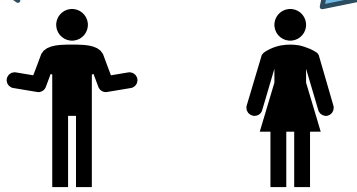
Exercise therapy for depression

Hedayati, JAMA, 2010; Hedayati, JAMA, 2017

WHAT TO SAY

I don’t want to live like this anymore!

-Tell me more
-People mean different things when they say this. How are you thinking about it?
-NURSES (these statements may be signals of emotional distress NOT suicidality)



CONTEXT MATTERS WHEN DOCUMENTING

Patient states “I don’t want to live like this anymore.”

Ms. J expressed disappointment and frustration with her current quality of life. She’s tired of being in pain and feels that she’s suffering.

SERIOUS ILLNESS COMMUNICATION IN TRANSPLANT IS NUANCED

Normalize talking about worries

Patients need to trust us

Communication outside of the EMR is critical

POST-TRANSPLANT OBLIGATIONS FOR PATIENTS

Caring for Yourself and Your Transplant

"Transplantation is an extraordinary journey that tests the limits of one's strength and courage In addition to commitment and faith, it requires strong mental and physical preparation as well as endurance. But you already know that. If you can endure transplantation, you can conquer anything that you set your mind to. The tough part is over. Now it's time to let your body heal so your inner radiance and spirit shines through again. Wishing you well as you continue on your own transplant journey."

-Diane Carnevale, artist and kidney transplant recipient (October 2018)

TRANSPLANT RECIPIENTS HAVE PRACTICAL, ETHICAL, AND EMOTIONAL OBLIGATIONS

POST-TRANSPLANT OBLIGATIONS FOR CLINICIANS

Looking beyond Mortality in Transplantation Outcomes

Daniela J. Lamas, M.D., Joshua R. Lakin, M.D., Anil J. Trindade, M.D., Andrew Courtwright, M.D., Ph.D., and Hilary Goldberg, M.D., M.P.H.

Consider three of our patients, nearly 1 year after lung transplantation.

Mr. S., who is 67 years old, underwent transplantation for pulmonary fibrosis. He is alive, but

would not, regardless of the quality of his life.

But people have priorities other than simply being alive. And yet despite an increasing emphasis on patient-centered outcomes in

goal is to prioritize urgency of need (rather than accrued time on the list), the prioritization of patients with the highest risk of death over the short term has meant that a disproportionate

POST-TRANSPLANT OBLIGATIONS

Can we approach goals of care and other serious illness communication peri- and post-transplant the same way we do for patients without a transplant?

ADVANCE CARE PLANNING IS COMPLICATED, BUT SHOULD IT BE?

The transplant imperative

Code status

Disability, chronic illness

Berkhout et al, J Liver Transplant, 2022

INFORMED CONSENT PRIOR TO TRANSPLANT IS COMPLICATED

What does it mean to provide informed consent before a transplant?

Can patients and their families truly understand what they might go through?

I. Threshold Elements (Preconditions)

1. Competence (to understand and decide)
2. Voluntariness (in deciding)

II. Information Elements

3. Disclosure (of material information)
4. Recommendation (of a plan)
5. Understanding (of 3. and 4.)

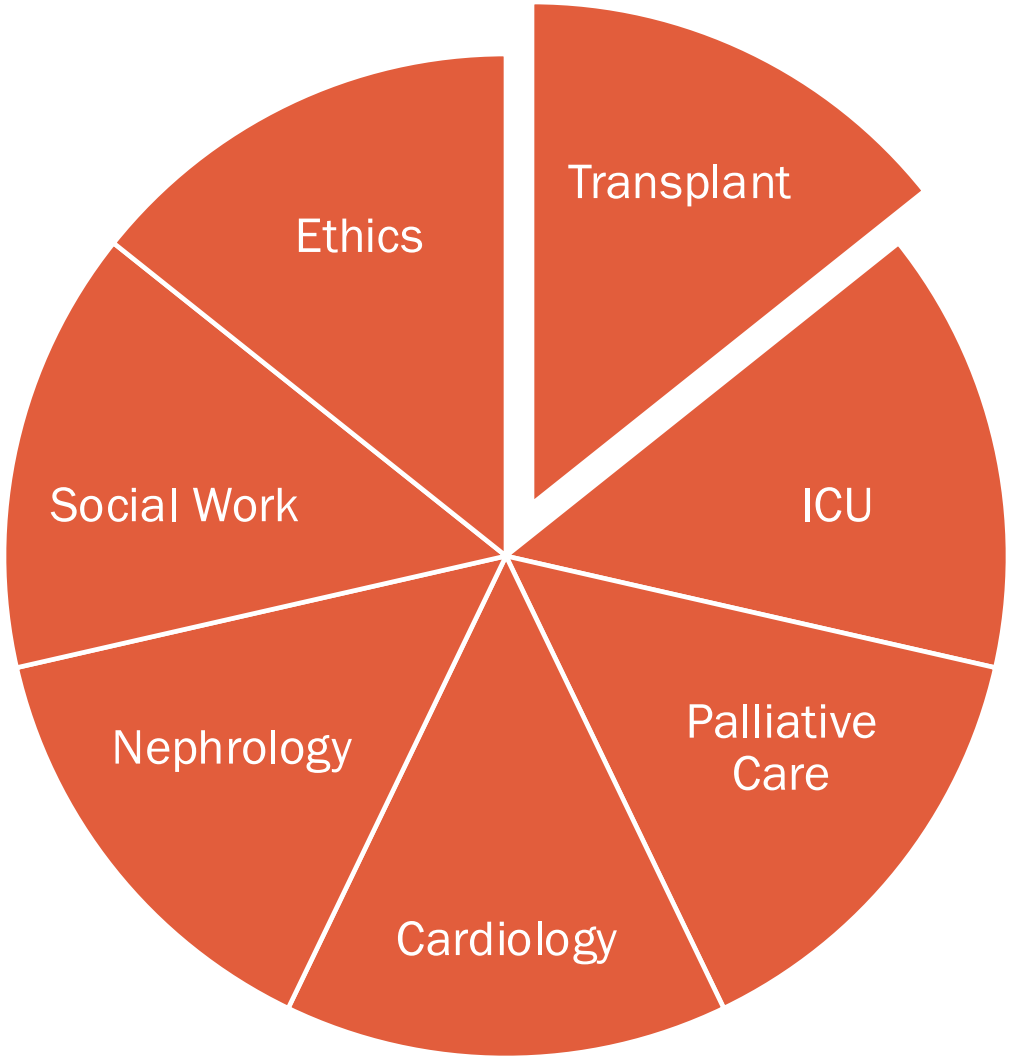
III. Consent Elements

6. Decision (in favor of a plan)
7. Authorization (of the chosen plan)

Beauchamp and Childress, 2001

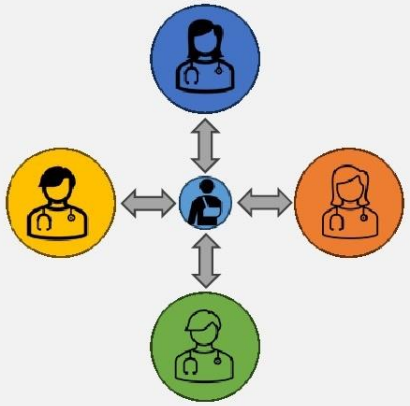
WHEN THINGS AREN'T GOING WELL

THE STAKEHOLDERS QUICKLY MULTIPLY



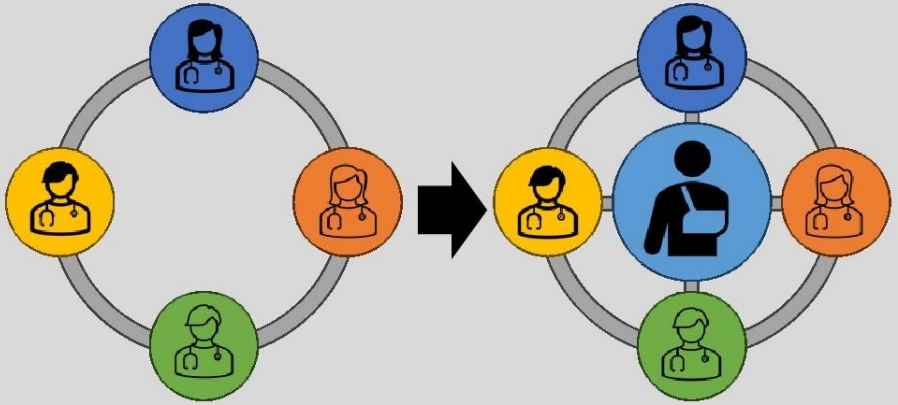
PROGNOSTIC ALIGNMENT IS CRITICAL

Prognostic Misalignment



- Each team speaks with the patient/family, shares their prognostic understanding
- It may be apparent to the patient/family that there is no prognostic consensus
- The patient/family may be left confused and/or distrusting

Prognostic Alignment

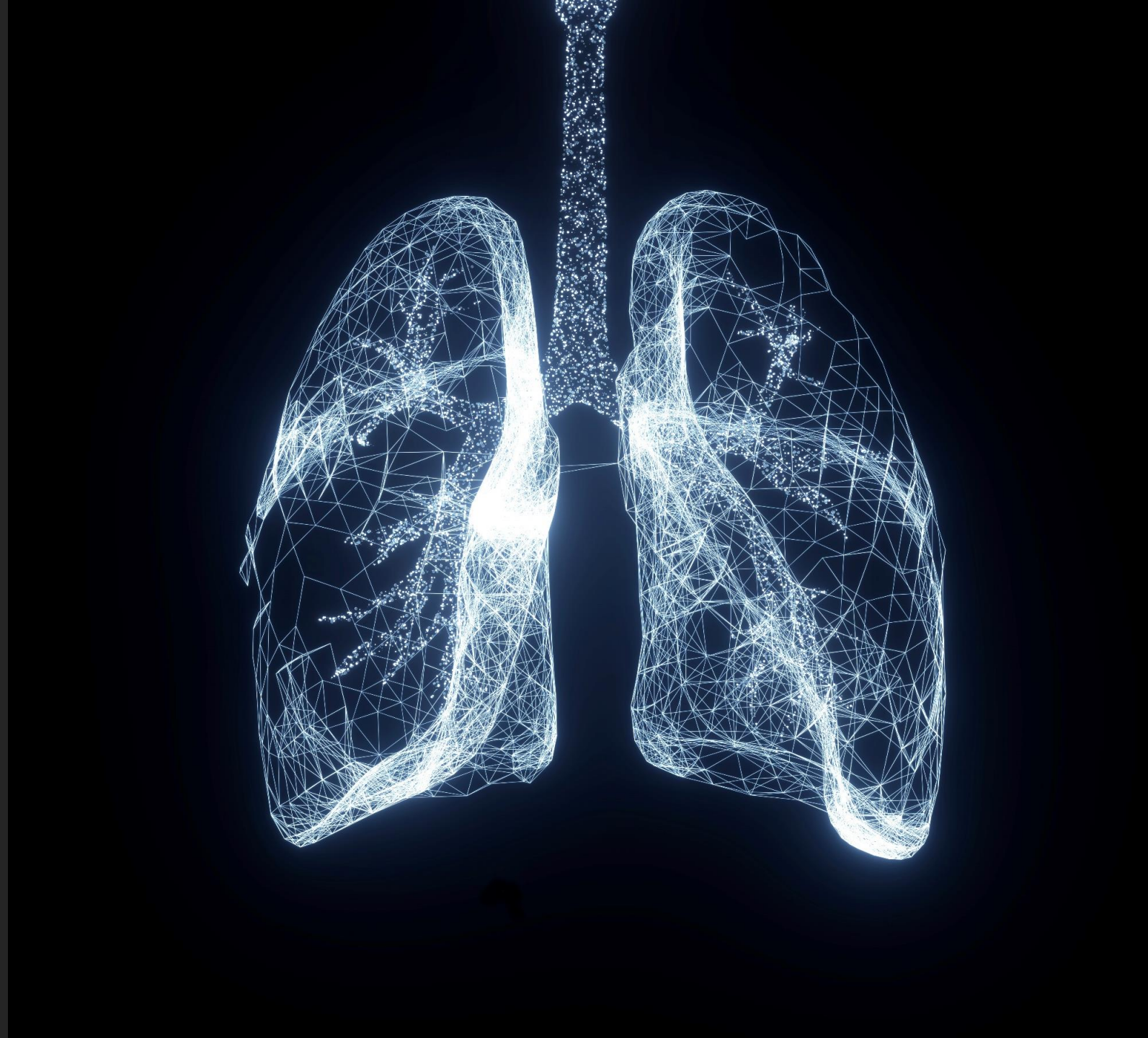


- Plan for a teams-only meeting prior to multidisciplinary family meetings
- Meetings can take place over the phone or in a workroom
- Have an informed representative from each team present, prepared to share their team's prognostic understanding
- Remember that each team offers a unique perspective informed by different areas of expertise and wants to provide the best care possible to their patient
- Be prepared to work through any disagreements that might arise
- Be open to consulting palliative care when disagreements persist
- Know that, while potentially time consuming, the process of prognostic alignment preserves your patients' trust and ultimately may streamline communication and enhance goal-concordant care

ANNALS OF SURGERY

Farber et al., Annals of Surgery, 2024

ALLOGRAFT FAILURE AS AN EXAMPLE OF COLLABORATION WITH PALLIATIVE CARE ON ETHICAL CHALLENGES



KIDNEY TRANSPLANT CLINICIANS VIEW OF PALLIATIVE CARE IN ALLOGRAFT FAILURE

Setting & Participants

Mixed methods study

Online survey:
N = 149 transplant clinicians in 80 US institutions

- 83 nephrologists
- 31 nurses
- 15 advanced practice providers
- 10 surgeons
- 6 social workers
- 4 others

Semi-structured interviews:
N = 19 clinicians

Thematic Findings

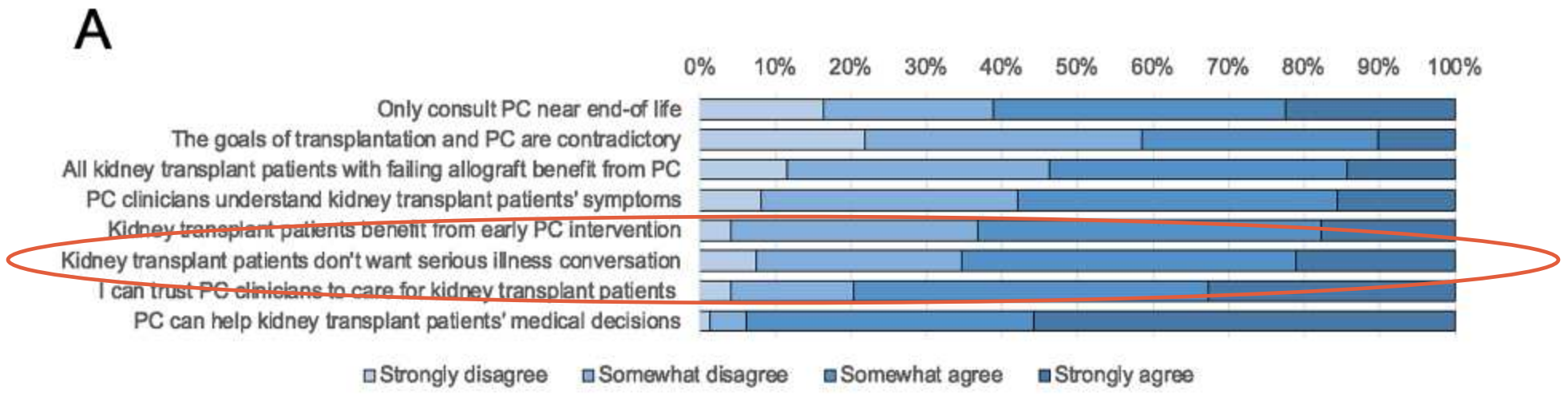
Clinicians' unique sense of personal and professional responsibility was a barrier to palliative care engagement

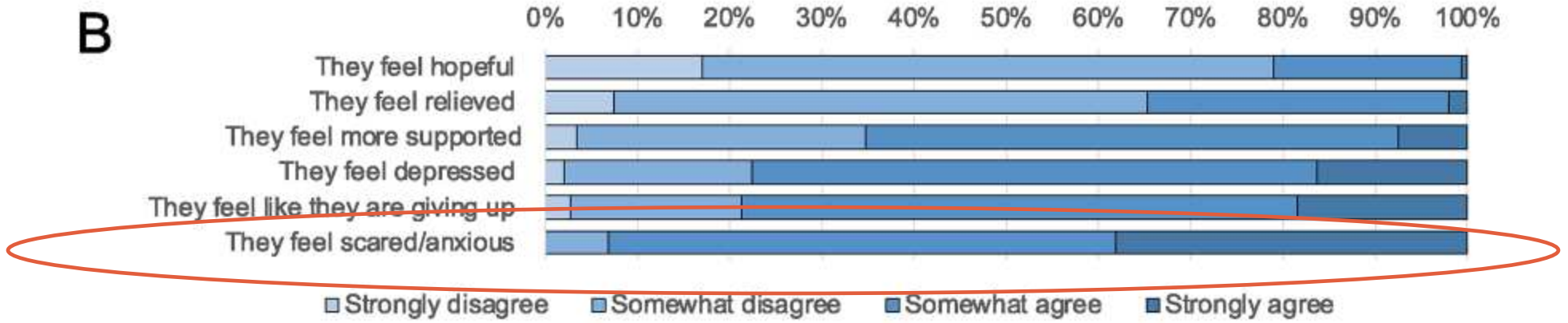
Uncertainty regarding timing of palliative care collaboration led to delayed referral

Clinicians felt challenged by factors related to patients' cultural backgrounds and identities, such as language differences

Murakami et al, Am J Kidney Dis, 2023

Clinicians worry about harming patients and making them scared and anxious





Murakami et al, Am J Kidney Dis, 2023

However, patients are feeling scared and anxious already, desire conversations and information from deeply trusted clinicians, and extra support

"If one thing that I think could be of help is that the nephrologist digs a little deeper [and] probe into the psychological effects that a person goes through… we tend to, 'Oh no, everything's okay.' But really probe because you kind of treat the whole person, you know." (participant 11)
"I would just like to know– really, I know [my doctor] can't tell me exactly, but I would just like to have a little better idea of maybe what the next three or four years may look like for me. I would like to know when [my doctor] thinks that the kidney would start to go the other way." (participant 5)
"I don't know what [palliative care] is like, but I think I would get something out of having those talks." (participant 9) "Of course [I am interested in palliative care]. Why not, right? Any support is good support." (participant 6)

Comrie et al, Kidney Med, 2024

CONCLUSIONS

- Communication skills for balancing hope/worry or best case/worst case can be helpful for holding uncertainty in the pre-transplant period
- Talking with patients about their worries around transplantation is therapeutic and creates ethical tensions for transplant clinicians, patients, and caregivers
- Clinicians and patients alike feel obligations to organ/donor and ethical conflict with how to proceed when things don't go as expected in the post-transplant period. Communication and ongoing support are critical

THANK YOU!

Dana-Farber
Cancer Institute

BRIGHAM HEALTH
BWH BRIGHAM AND WOMEN'S HOSPITAL

QUESTIONS?
THOUGHTS?

A Special Thanks to Our Presenters

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Q&A
QUESTIONS & ANSWERS