From Diagnosis to Establishing Care Goals: A Provider's Guide on How to Approach Difficult Conversations with Transplant Patients

TODAY'S PANEL

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

Tuesday, October 8, 2024, 3:00pm – 4:00pm ET

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Deanna Fenton

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THE Alliance

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Meet Our Moderator

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Meet Our Presenters

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Case presentation

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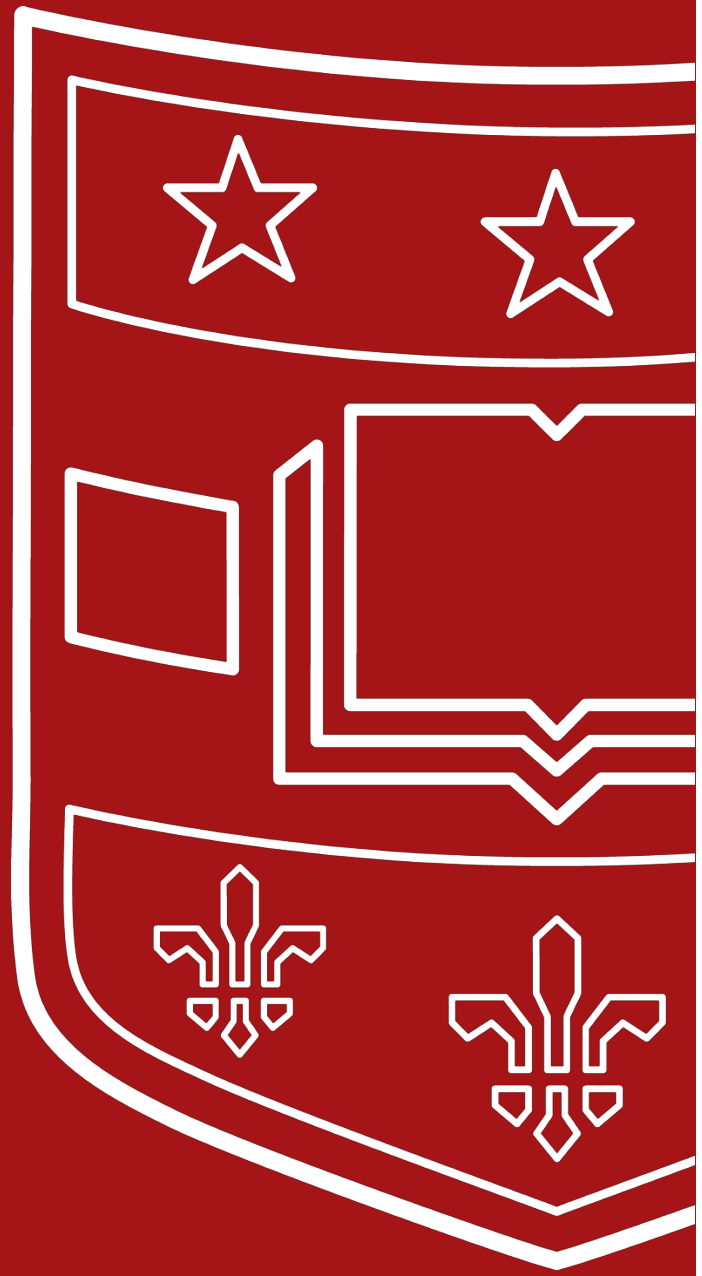


Washington University School of Medicine in St. Louis

Case: kidney transplant evaluation

- A 67-year-old man with type 2 diabetes and coronary artery disease, s/p 3-vessel CABG, and ischemic heart failure (EF 30%).
  - Cr 3.8 mg/dl, eGFR 18 ml/min.
  - His eGFR has gradually declined over the past 3 years.
  - 4 admissions due to fluid overload during the past year.

- His primary nephrologist has advised him to discuss options for renal replacement therapy, including kidney transplant.

Case (continues)

- Social history:
  - He lives with his 70-year-old wife. She has diabetes and hypertension and had a stroke last year and now has limited mobility.
  - The patient is a primary caregiver for her daily living.
  - He has 2 daughters, who live far away.
  - He's a retired teacher
  - No living donor for kidney transplant is available. He is motivated to receive kidney transplant to better take care of his wife.

After evaluation, the transplant team has decided he is not a candidate for kidney transplant, due to his history of heart failure and medical instability.

Question to audience (poll)

- How comfortable are you telling him that the transplant team has decided against transplantation?
  - Very comfortable
  - Somewhat comfortable
  - Neutral
  - Somewhat uncomfortable
  - Very uncomfortable

What makes you feel like you do?

- Does your patient want to hear this news?
- Who should discuss the transplant non-eligibility with the patient?
- How do we relay this news to them?
- How can I best address their reaction?

Let’s learn from what research suggests…

Case: kidney transplant evaluation

- A 67-year-old man with type 2 diabetes and coronary artery disease, s/p 3-vessel CABG, and ischemic heart failure (EF 30%).

- His primary nephrologist advised him to discuss options for renal replacement therapy, including kidney transplant.

- After evaluation, the transplant team has decided he is not a candidate for kidney transplant, due to history of heart failure and medical instability.

Delivering Hard News

- As a palliative care clinician, when I hear your discussion of the complexity and challenges of telling people about non-eligibility for transplant, it sounds like a Breaking Bad News conversation

- Two important tools for doing so:
  - Structured delivery
  - Addressing emotion

Structured delivery

- Structure is helpful for anxiety provoking tasks – think of checklists for landing planes
- **SPIKES**
  - **SET up the communication interaction – Prepare for Success**
  - **assess PERCEPTION – Diagnose your Foundation**
  - **obtain INVITATION - Permission**
  - **give KNOWLEDGE – Deliver a Clear Headline**
  - **address EMOTION – Manage the Encounter**
  - **SUMMARIZE and STRATEGIZE – Plan Next Steps**

Baile, W. F., et al., 2000, Oncologist

Addressing Emotion

- If you deliver your news clearly, there will be an emotional reaction
- Completing your visit successfully requires addressing that emotion
  - **NAME**: “This seems surprising to hear”
  - **UNDERSTAND** “I was really hoping things would be different too.”
  - **RESPECT** “You have done everything you were supposed to, I am impressed.”
  - **SUPPORT** “We are here to help you through the next steps”
  - **EXPLORE** “Tell me more about what you are feeling”
  - **(SILENCE)** “…”

https://www.vitaltalk.org/guides/responding-to-emotion-respecting/
Fischer GS, Tulsky JA, Arnold RM. Communicating a poor prognosis. In: Topics in Palliative Care. 2000.

Questions?

Case with a twist…

- A 67-year-old man with type 2 diabetes and coronary artery disease s/p 3-vessel CABG, and ischemic heart failure (EF 30%), is being evaluated for kidney transplantation. His eGFR gradually declined over the past 3 years (Cr currently is 3.8 mg/dl, eGFR 18 ml/min) and he has had 4 admissions due to fluid overload during the past year.

- What if… He is a previous kidney transplant recipient with a failing allograft (history of ADPKD, received a kidney from his wife 15 years ago).

- Let's consider how this conversation would be different? What if he had a very bad experience with hemodialysis, and didn't want to do hemodialysis?

Goals of Care Conversation

- Here, based on what I have learned of transplant care, there remains the task of delivering bad news but now also layering on a decision about next steps
- This sounds to me like a goals of care conversation, again, as before, structure can be helpful - **REMAP**
  - **REFRAME**: As before, deliver serious news – reframing that things are different now
  - **EXPECT EMOTION:** As before, expect and address the emotion, time to lean in
  - **MAP** patient goals and values – what matters most to them in the context of the news will shape your recommendations
  - **ALIGN WITH GOALS:** Reflect back what you have heard
  - **PLAN NEXT STEPS:** Grounded in those goals

Childers JW et al., REMAP: A Framework for Goals of Care Conversations. Journal of Oncology Practice 2017

https://www.ariadnelabs.org/wp-content/uploads/2023/05/Serious-Illness-Conversation-Guide.2023-05-18.pdf

THE UNIVERSITY OF ALABAMA AT BIRMINGHAM

Department of Surgery

Research Overview

Rhiannon D. Reed, DrPH

Division of Transplant Surgery, University of Alabama at Birmingham

Overview

- What is the existing research on decision-making and planning for future medical needs in advanced kidney disease and transplantation?

- How do transplant providers, patients and caregivers feel about discussions of ineligibility for transplantation and the role of PC and ACP?

Palliative care and advance care planning

- Palliative care: specialized medical care for people living with a serious illness, focused on symptom and stress relief[1]
- Advance care planning: enhances patient understanding and sharing of their own goals and preferences for future medical care[2]

- Patients with uncertain prognosis, including transplant recipients or those considering transplantation, may benefit from PC and ACP

1- Center to Advance Palliative Care; 2- Sudore et al 2017

Relevance of PC/ACP in advanced kidney disease

- High symptom burden and poor quality-of-life
- Dialysis and transplant are not always preferred
- Meaningful palliative care and hospice options rarely available to those with ESKD
- Existing PC interventions do not comprehensively integrate provider, patient, caregiver, and health system factors[1] or are limited to the inpatient setting[2]

1- Luckett T (2014), *AJKD*, 2- Lakin et al, *J Pain Sympt Management*, 2022

Patients desire these conversations

- Prior work identified decisional disempowerment, with patients believing key information is withheld[1]
- Patients have expressed a desire for more frequent discussions about their disease, prognosis, and planning[2]
- Even when clinicians align, patients and caregivers report lack of clarity and a desire for earlier conversations[3]

1- Sellars et al, *AJKD*, 2018; 2- Saeed et al, *Clin Nephrol*, 2019; 3- Eneanya et al, *BMC Nephrol*, 2020

PC and ACP discussions are not occurring

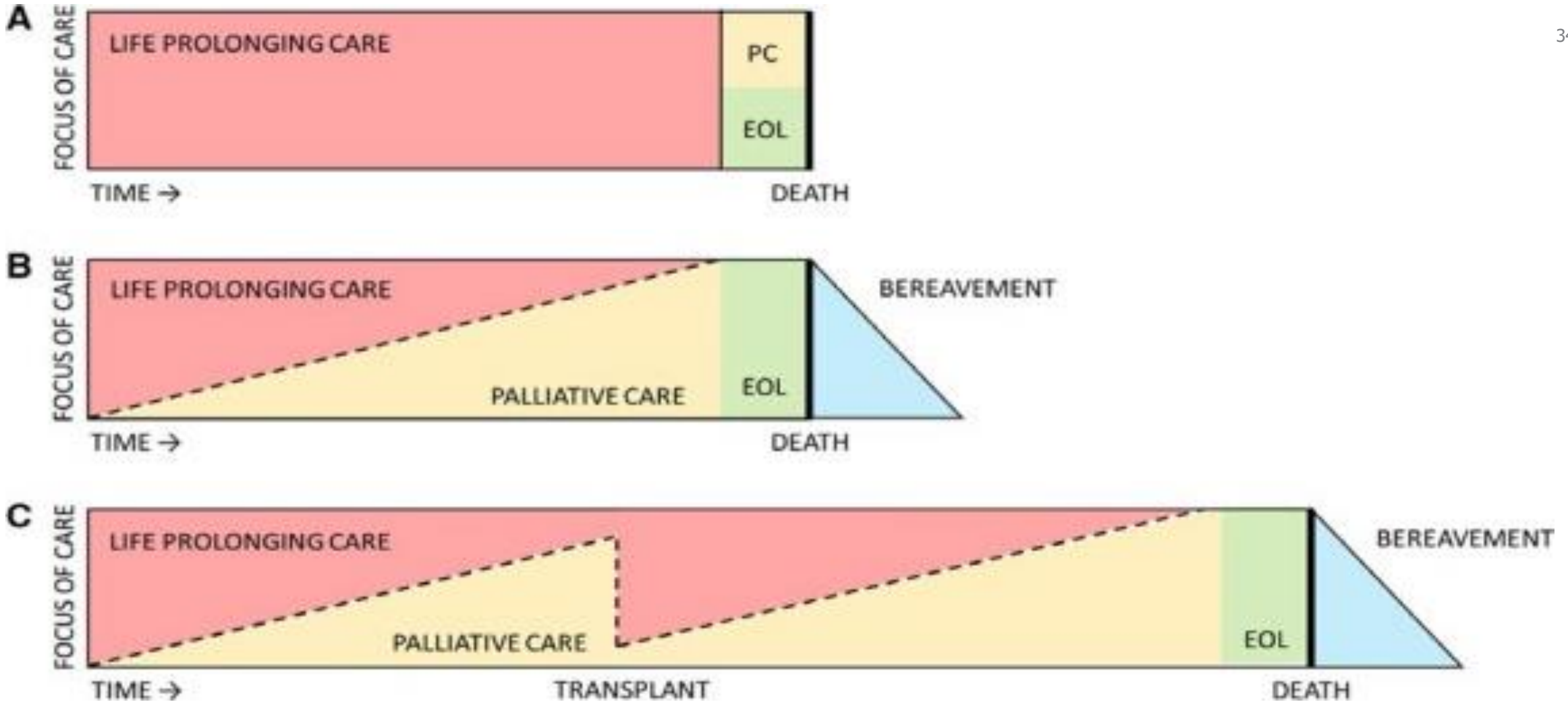
- ACP occurs in <half of patients with CKD/ESKD[1-2]
- Significant racial disparities[3-5]
- Barriers stem from[6]:
  - Misperceptions about what ACP entails
  - Ambiguity about who should be responsible
  - Changing preferences as health deteriorates
  - Lack of time and training

1- Davison et al, *CJASN*, 2010; 2- Tamura et al, *CJASN,* 2017; 3- Eneanya et al, *Am J Nephrology*, 2016; 4- Foley et al, *JASN*, 2018; 5- Wen et al, *JASN,* 2019; 6- Ladin et al, *JASN*, 2021

PC and ACP are scarce in transplantation

- 21.4% of kidney transplant candidates and 34.9% of recipients engaged in ACP, lowest among older Black patients[1]
- Even fewer engaged in PC (4.2% of candidates and 5.1% of recipients)[1]
- These proportions mirror the general population, despite the higher burden of morbidity and mortality
- Wentlandt at al describe a model of PC in their transplant center[2]

1- Fisher et al, *AJKD*, 2024; 2- Wentlandt et al, AJT, 2017



1- Fisher et al, *AJKD*, 2024; 2- Wentlandt et al, AJT, 2017

Original Investigation AJKD

Kidney Transplant Clinicians' Perceptions of Palliative Care for Patients With Failing Allografts in the US: A Mixed Methods Study

Naoka Murakami, Amanda J. Reich,* Katherine He, Samantha L. Gelfand, Richard E. Leiter, Kate Sciacca, Joel T. Adler, Emily Lu, Song C. Ong, Beatrice P. Concepcion, Neeraj Singh, Haris Murad, Prince Anand, Sarah J. Ramer, Darshana M. Dadhania, Krista L. Lentine, Joshua R. Lakin, and Tarek Alhamad*

- Collaboration between KT and PC is mostly limited to the inpatient, EOL setting
- Barriers to PC for patients with a failing allograft include:
  - PC equates to abandonment of curative therapy
  - May produce anxiety, fear, and depression among patients and caregivers
- Transplant survival metrics and payment structures also complicate the use of PC in transplantation

1- Murakami et al, *AJKD*, 2023

What happens when curative therapy is not an option?

- Frandsen et al interviewed ineligible Danish patients and their caregivers[1]
  - Lack of transplant candidacy brings up thoughts of uncertainty and vulnerability
  - No discussion of PC or planning for the future, other than caregivers expressing their thoughts on life without the patient

- Lack of data on difficult conversations in transplantation seems to suggest that this responsibility is left to other non-transplant providers

- Persistent gap in the literature for how we approach the ineligibility conversation and best prepare patients and families for future healthcare needs

1- Frandsen et al, *Nurs Open*, 2020

ACCEPT Study

The ACCEPT Study

Assessing Provider, Patient, and Caregiver Perspectives for Palliative Care and Advance Care Planning in Kidney Transplantation

Jayme Locke, MD MPH

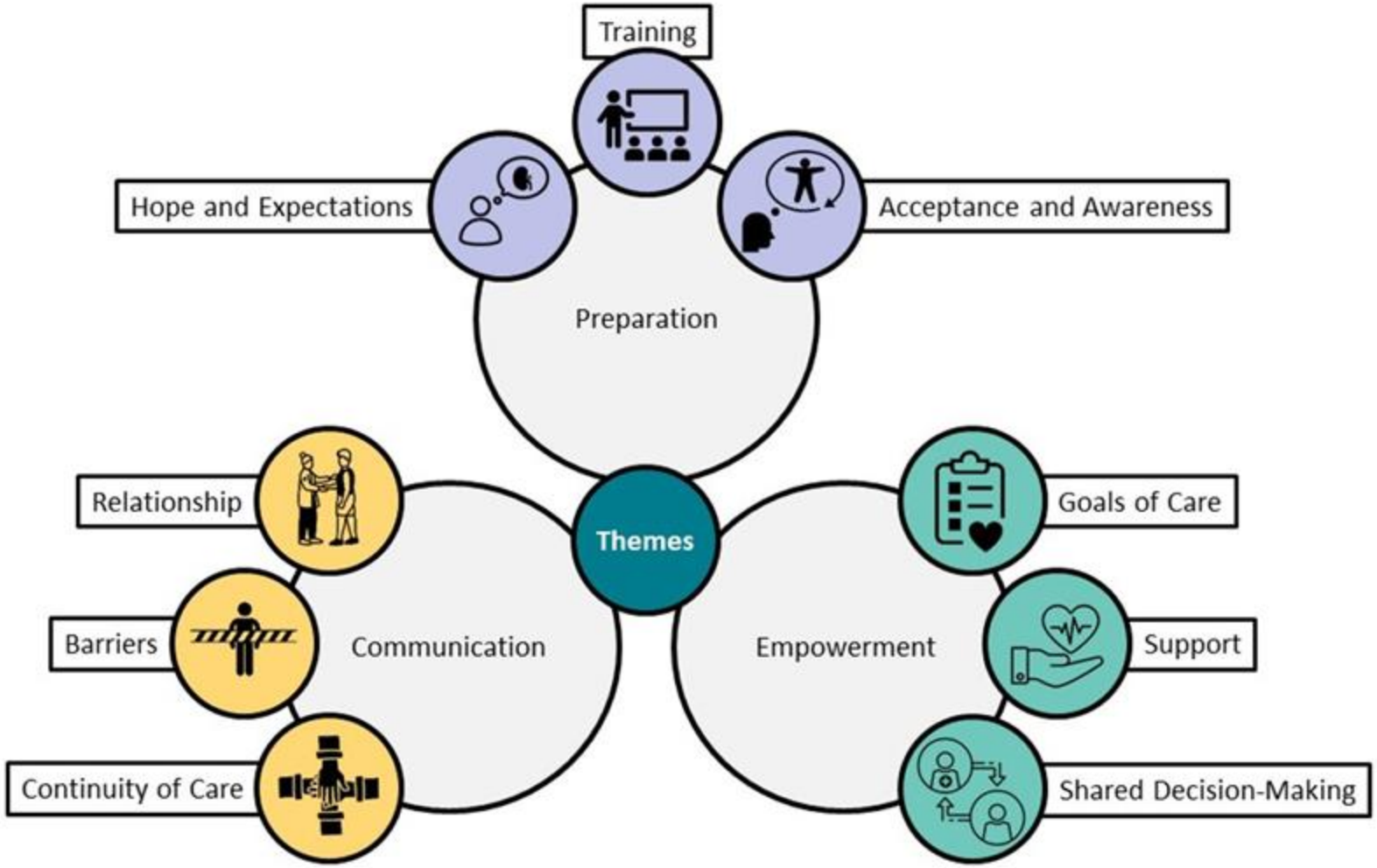
Vineeta Kumar, MD

J. Nicholas Odom, PhD

William Haynes, MD

Shena Gazaway, PhD

- Qualitative study of semi-structured interviews with:
  - 12 providers (Surgery, Social Work, Coordinators, Transplant Nephrology, General Nephrology)
  - 7 patients with end-stage kidney disease
  - 3 caregivers for these patients
- In-depth interviews transcribed and in vivo coded



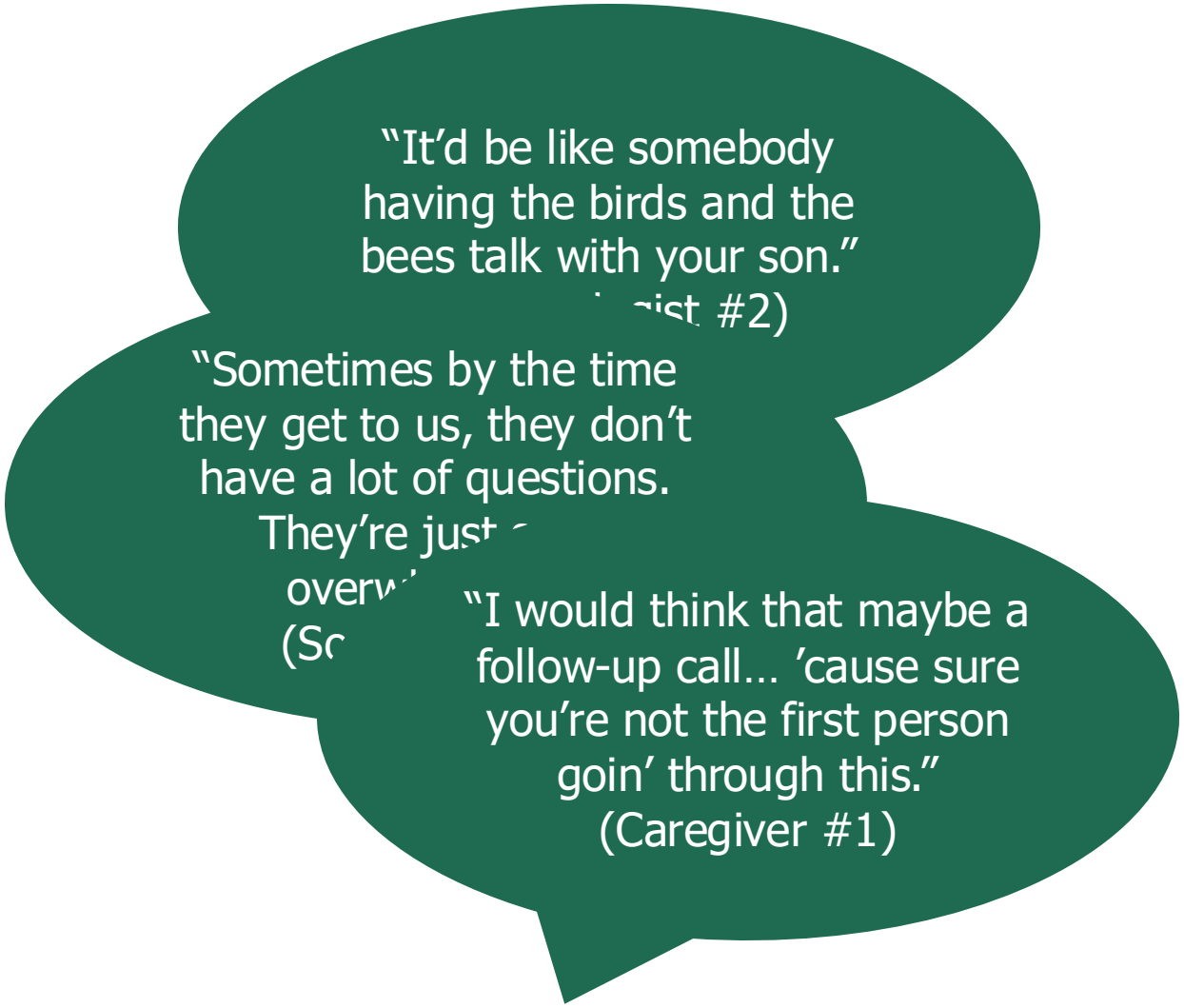
Preparation

- Awareness/Acceptance: a patient's perception of their current health and preparation by referring physician impacted the candidacy conversation

- Hope/expectations: patient preparedness also influenced by hope that transplantation would return them to a normal life

- Training: patients desired education earlier in their disease to prepare for potentially tough conversations

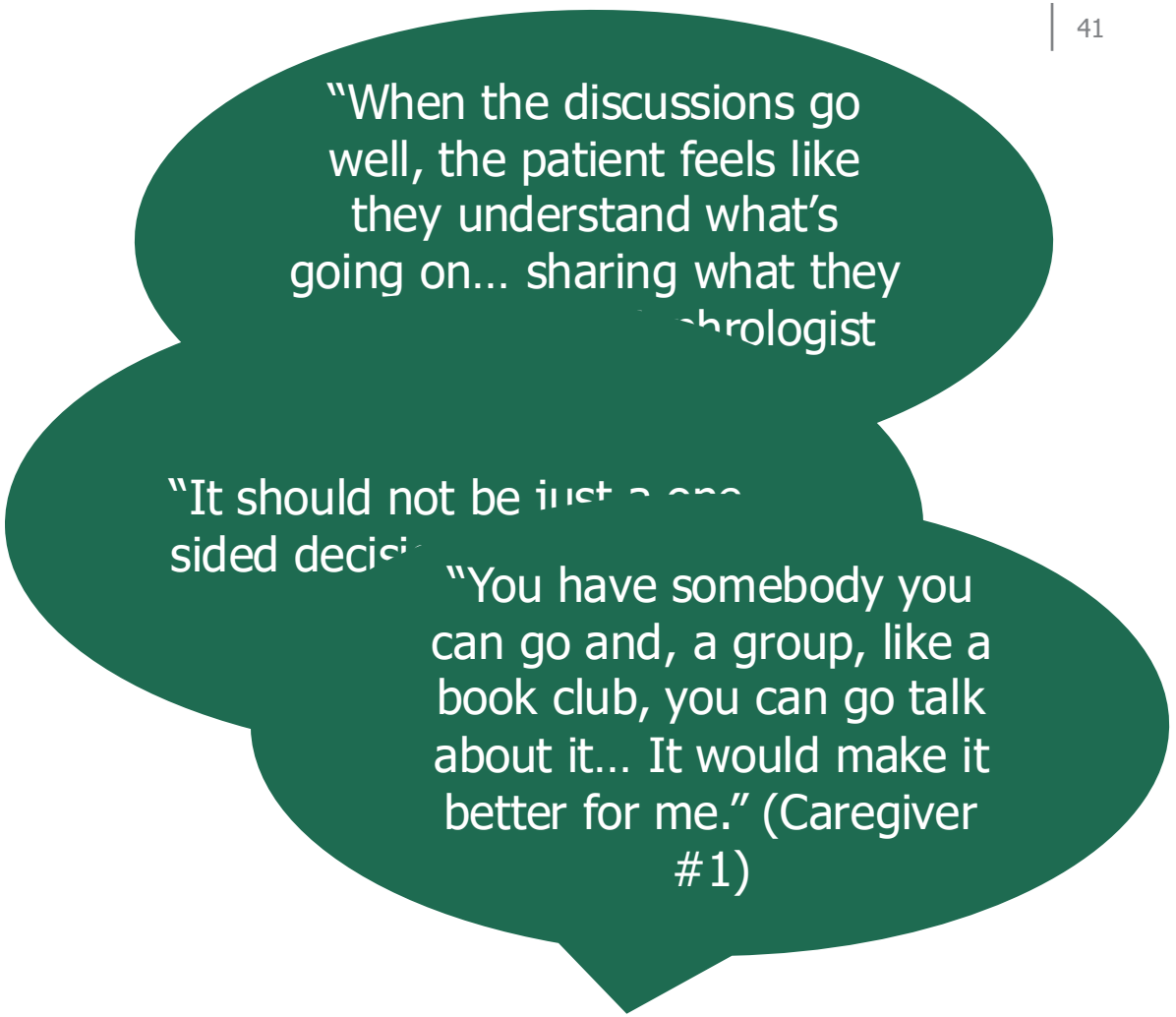
Communication



- Relationship: no established relationship with the transplant center, except in the case of re-transplant patients
- Barriers: information overload and lack of time to help patients understand, and all equated PC to hospice care
- Continuity of care: referring nephrologists desired better communication from the transplant team, and patients wished for more follow-up

Empowerment

- Goals of care: providers endorsed empowering patients to express desires for their health care, and patients wished to discuss their options
- Shared decision-making: patients should have time to ask about what to expect moving forward
- Support/resources: patients and families want more dedicated support, which providers believe should be tailored to the patient's health status and literacy



Summary

- There are opportunities to incorporate PC and ACP into the transplant process, particularly for non-candidates
- Need to empower patients and families to have these conversations
- Connect with referring physician to maintain continuity of care

A Special Thanks to Our Presenters

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Q&A
QUESTIONS & ANSWERS