

# Learner Manual: Nephrology

Learning the Best Case/Worst Case Communication  
Framework

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# Learner Manual: Nephrology

## Learning the Best Case/Worst Case Communication Framework

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### Introduction and Background Information

Think about one of your patients, maybe they are old or frail, who is having a really difficult time on dialysis. This patient is in and out of the hospital every month, and you're called to help take care of them every time this happens. Although you get them through their admissions, each time they leave the hospital you know their baseline health is worse than it was before, and that they will be back soon with another problem.

No one wants to see their patients suffer like this.

To help your patients live for as long and as well as possible, we should go back... to before they started dialysis - to talk about what it might be like to experience dialysis and allow them to anticipate and prepare for upcoming health events.

These conversations are challenging. To make decisions consistent with their values and preferences, older adults need information about possible interventions contextualized into a personal framework.<sup>6-8</sup> To meet this need, we have developed an intervention, called **Best Case/Worst Case**, to support shared decision making in the context of life-limiting illness. Best Case/Worst Case uses narrative and a hand-written graphic aid to illustrate a choice between treatments and engage patients in deliberation. We have previously tested Best Case/Worst Case with surgeons and acutely ill surgical patients. We found that this intervention transforms the structure of the decision-making conversation and improves shared decision making on objective measures.<sup>9, 10</sup> (see supplementary materials). This tool provides a vehicle for empowering you and your patients as you make decisions about dialysis together, while introducing them to palliative care as a way to support them through life with or life without dialysis.

Many physicians find Best Case/Worst Case intuitively appealing and some note they already do it. Yet it is different enough from our usual conversations with patients that it takes training and practice to do it correctly. ***This manual provides instructions on how to use the Best Case/Worst Case communication framework with frail or older patients for whom dialysis may not provide a survival advantage.*** We have worked with nephrologists and palliative care

clinicians to adapt this training program, as well as the Best Case/Worst Case framework itself, to address the specific needs of nephrologists and patients with ESKD.

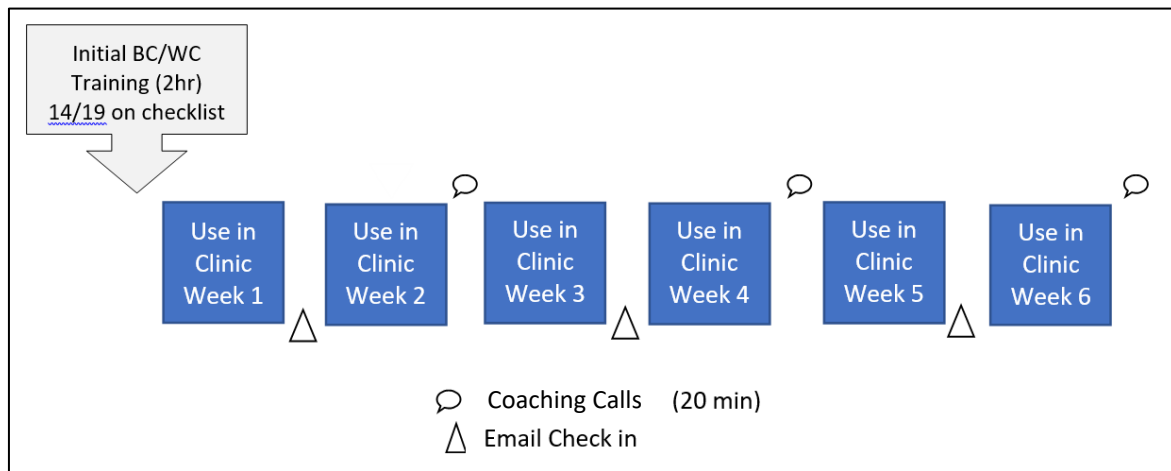
### Study Procedures

We believe that this framework will help clinicians and patients, but we need to test it first. That is where you come in. You are an essential part of the study team and we are grateful for your willingness to help us test this method. We will cover study-specific protocols at the end of the training and you will have local and national resources to answer your questions along the way. We will also spend time during training to discuss the barriers you see to implementing Best Case / Worst Case in your practice.

### Session Agenda

- 1. Orientation to Virtual Platform (5 min)**
- 2. Introduction to Best Case/Worst Case (BC/WC) (30 minutes)**
  - a. Introduction to the BC/WC framework and its application to nephrology
  - b. Create a BC/WC graphic aid for Case #1 (if time allows)
  - c. Demo video that corresponds to Case #1
- 3. 1:1 exercise (35 minutes) with time-outs**
  - a. Create a BC/WC graphic aid with your coach using Case #2 (20 min)
  - b. Practice with a standardized patient and coach using time-outs (15 min)
  - c. Discussion and feedback (5 min)
- 4. 1:1 exercise (30 minutes) without time-outs**
  - a. Create a BC/WC graphic aid (pre-filled or blank) using Case #3 (10 min)
  - b. Practice with a standardized patient and coach (15 min)
  - c. Discussion and feedback at end of case (5 min)
- 5. Proficiency Check (15 min)**
  - a. Create a BC/WC graphic aid using Case #4 (5 min)
  - b. Test with a standardized patient (5 min)
  - c. Discuss checklist and score (5 min)
- 6. Follow-up plan and Tips for Incorporating this into Practice (5 minutes)**
  - a. Schedule follow up calls
  - b. Discuss implementation strategies
  - c. Tour of website resources

## Training and Coaching Timeline

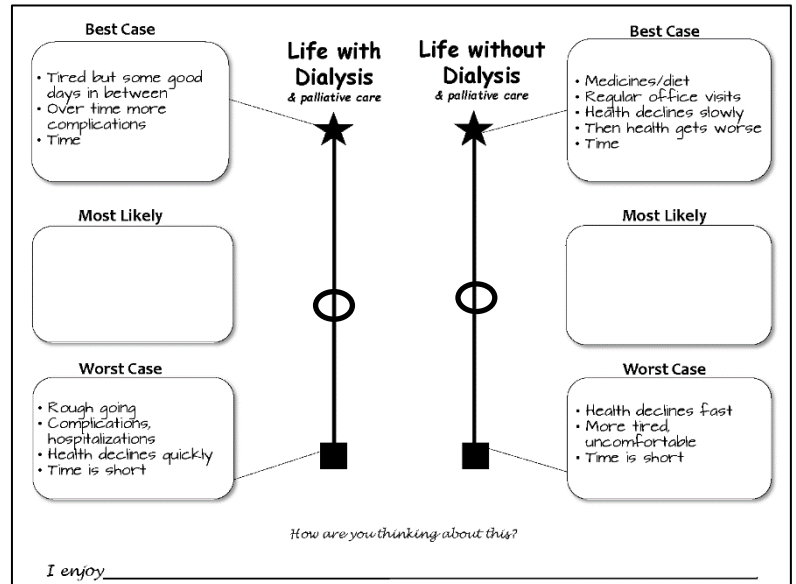


## What You Will Learn During this Session

- **You will learn how to create a Best Case/Worst Case graphic aid**
  - This includes the best, worst, and most likely stories about life with dialysis and life without dialysis specific to the clinical conditions of an older patient with ESKD.
  - You will learn how to include phrases to elicit values and goals for the graphic aid.
  - You will learn how to recommend palliative care for all older patients with life-limiting ESKD.
- **You will practice using the graphic aid with a simulated patient**
  - Practice breaking bad news about poor kidney function and what that means.
  - Use stories to describe a range of short and long-term treatment outcomes using the Best Case /Worst Case framework to facilitate shared decision-making.
  - Practice eliciting patient preferences and making a treatment recommendation.
  - Practice talking to a patient about a referral to palliative care clinic.
- **You will consider how to fit this into clinic once you feel confident using Best Case/Worst Case**
  - Practice completing a decision-making conversation using the graphic aid until you have reached competency.
  - Learn from other nephrologists how to troubleshoot common barriers to use in a busy clinic.
  - Learn how to incorporate this into phone, video, and in-person visits.

## Constructing the Best Case/Worst Case Framework

- Start with the pre-filled or blank template
- Each vertical line represents a different treatment option
  - Life with Dialysis & Palliative Care
  - Life without Dialysis & Palliative Care
- A star at the top ★ of the line represents the “Best Case,” a box at the bottom ■ represents the “Worst Case,” and an oval on the line ○ represents “Most Likely.”



## Discussing Best Case/Worst Case with Patients

- Before you start discussing treatments, it is crucial to **break bad news**. This will help your patient understand the gravity of ESKD. Tell the patient, “I have some bad news. Your kidneys have gotten worse. They are failing, which at some point will lead to your death. We need to start planning for your future and I want make sure you understand our options.”
- Acknowledge a **choice between two valid options**.
  - “We have a choice between two options...”
  - “There are 2 paths we might consider...”
- Briefly describe the **routine treatment experience**. (You may choose which treatment to describe first. For this example, we will start by describing life with dialysis and palliative care.)
  - Describe a realistic experience of routine dialysis. These are the logistical elements of dialysis that will occur regardless of the outcome.
    - e.g. “You will have dialysis for 4 hours a day, 3 times a week for the rest of your life”
    - If there are more than one valid option for method of dialysis (PD, hemo, etc.), choose one for your example. Think of this as the **first** choice you will make together (dialysis vs. no dialysis). If you and your patient decide to go with dialysis, then you can talk about mode of dialysis.

- **Next, tell a story about what the patient's life would look like in the best case scenario. In the story, be sure to include:**
  - Short-term day-to-day implications: quality of life, hospitalizations, living situation
    - e.g. "You may feel a little tired after dialysis but you will have good days in between"
  - Long-term outcomes: trajectory (kidney failure accelerates health problems/complications), time to death, how and location of death
    - e.g. "Over time, 1-3 years, your kidney disease will make your health worse. You will be in the hospital more often and you may get very sick and die in the hospital from complications or decide you want to start hospice."
- **Tell the story about what you imagine to be the worst case scenario. As before, be sure to include:**
  - Short-term day-to-day implications
    - e.g. "Dialysis could be hard on you. I worry that you might feel so tired on the days in between that you just have a few good hours. You could also have complications that land you in the hospital a lot."
  - Long-term outcomes
    - e.g. "I worry that time is short, on the order of weeks to months your health may decline rapidly and you will die, either due to complications that we cannot get you through or you decide to stop dialysis and start hospice care"
- **Describe what is most likely**
  - Draw a circle on the line representing where most likely falls between best and worst case
    - In some cases, most likely may be closer to – or the same as – best case or worst case. You should acknowledge this, e.g. "What I think is most likely is more like best (worst) case..."
  - Incorporate the patient's health history to explain why this scenario is most likely
    - e.g. "I know you had a heart attack last year and unfortunately your kidney disease is only going to make things worse. Most likely, I think you'll continue to have heart problems, maybe even another heart attack, and even problems with the blood vessels in your legs that make it hard to walk. I suspect you'll be in the hospital a few times in the next year, and each time will make you weaker. I know you are living by yourself now, but you rely on a lot of help from your kids. I think in the next year or so you're going to need even more help to take care of yourself, so much that it won't be possible to live at home anymore and we'll talk about moving to a nursing home."
  - Language to use: "What I think is most likely..." or "Given what I know about your x, y, z problems I think the most likely scenario is..."
- **Be clear that the stories describe the connection between the patient's kidney failure and overall prognosis. Use expressions like:**

- “Your kidney disease could be hard on your heart. You likely will have more symptoms, like getting tired easily and shortness of breath or even another heart attack.”
  - “Because of your kidney failure, it could be hard to recover from infections like pneumonia and you may get sick enough to be in the hospital.”
  - “Because of your kidney failure, you could have problems with your blood vessels that require surgery, like amputations.”
- **Write short notes on the graphic aid describing each scenario**
- It’s easier to do if you prepare the graphic aid in advance or simply edit the pre-printed graphic aid for your specific patient. Either way, you can add notes and clarifications during the conversation
  - Make sure the words you use are legible and easily accessible for patients, avoid medical jargon
    - e.g. Instead of writing “MI”, write “heart attack”
- **The process is the same for life without dialysis**
- Describe the experience of treatment if the patient forgoes dialysis: Doctor visits, labs, watching diet, medications to treat symptoms, palliative care, etc.
- **Then tell the story for the best case scenario, followed by the worst case scenario for life without dialysis. Like the dialysis option, in each scenario be sure to include:**
- Short-term day-to-day implications
    - Best case example: “You will feel pretty good most days. We’re able to control your symptoms with medications so that you can do many of the things you enjoy now.”
    - Worse case example: “You will experience side effects from medications, such as being sleepy and will have to stay in bed most of the time. You’ll have more bad days than good and you won’t have energy to do many of the activities you do now.”
  - Long-term outcomes
    - Best case example: “You will feel good for a while, maybe even a year or longer, but your kidney disease will continue to worsen and you’ll feel weaker and start to experience more symptoms like shortness of breath.”
    - Worse case example: “In the worst case things happen more quickly. We’ll have to increase your medicines to try to control your symptoms, but we won’t be able to make them go away. At this point you might decide to start hospice.”
- **Again, next you will describe what is most likely**
- Similar to the most likely outcome with dialysis, remember to incorporate the patient’s other comorbidities and underlying frailty into your description of what you think is most likely.



- Once you've discussed the possible stories for each treatment, the next step is to **encourage deliberation**. You need to elicit what is important to your patient in order to determine how the treatments you have described align with what your patient values. Say things such as:
  - "How are you thinking about this?"
  - "What can you tell me about how you feel about these stories?"
  - "What's the most important thing for you, now that you've heard all of this?"
- Write on the bottom of the graphic aid, **"What is important to you now?"**
  - This phrase is used to help patients think about how they feel when they imagine different states of health and helps them articulate that to you and their family.
- **Make a treatment recommendation based on what you hear from the patient/family**
  - Ask your patient, "Is it okay if I make a recommendation?"
  - "Based on what I know about your health and what you have said is important to you, I would recommend...."
  - ***Note this is a recommendation based on what you've heard from the patient, it is a recommendation that aligns with what is important/valuable to him/her. This is not just what you would do if you knew nothing about the patient's preferences/goals. Ideally when you make the recommendation it's important to also explain how the recommendation supports the patient's stated goals.***
- **If the patient is not ready to make a decision right now, that's OK!**
  - Say "We may decide not to decide today." This is important: it states that a decision does need to be made at some point, but more time for deliberation is perfectly fine.
  - Some patients will not feel that they are on the verge of needing dialysis because they have not had symptoms yet. Others will just want more time to deliberate at home. Your diagram will help them remember this conversation and can help them pick an option that best aligns with their goals.
  - Encourage them to call or come back to clinic once they have made a decision or if they have more questions. "It would be best if you made this decision with me, not with the emergency room doctor who doesn't know you as well when you come in with a problem."
- **Use Best Case/Worst Case to help patients recognize the importance of palliative care and encourage them to see a palliative care clinician in the outpatient setting**
  - Patients may be hesitant to see another doctor or not understand why they need palliative care. Some may worry that palliative care is the same as hospice. You can use the Best Case/Worst Case framework to talk to patients about prognosis and the life-limiting nature of ESKD to help them understand why outpatient palliative care has benefits for them.
  - Outpatient palliative care can offer your patient:
    - Help with symptoms, e.g. pain, restless legs, and fatigue

- Advance care planning
- Support family/caregiver needs
- End of life care when the time comes
- During the conversation, tell the patient that you would like them to see a doctor in palliative care clinic, regardless of whether they choose dialysis or no dialysis. Here are some phrases you can use:
  - “I would like to send you to see a palliative care doctor. These doctors can help you feel as well as you can for as long as you can. Would that be ok?”
  - “This is difficult news. Regardless of what treatment path you choose, I'd like you to see one of our palliative care doctors. They can help preserve the quality of life you're used to for as long as possible.”
  - “Regardless of what we decide to do, I would like you to meet with a palliative care doctor, because this is a lot to take in. Would that be ok?”

➤ **Key tips for using Best Case/Worst Case:**

- *Avoid jargon and percentages:* Try to avoid using jargon or percentages and numbers when discussing estimated risk. Instead, interpret the information you know in this format into what it might be like to experience such outcomes so that patients can understand what it might mean for his or her life.
- *Have ideas of the scenarios you want to describe before meeting with the patient:* You should have an idea of possible clinical scenarios prior to meeting with patient. You can fill out most of the elements of the BC/WC graphic aid ahead of time.
- *Be prepared to talk about prognosis:* No one expects you to know for sure how long this patient will live. You can give patients with life-limiting illness some sense of time in general terms (e.g. “days to months” or “months to one year”). The graphic aid can help provide space in the conversation to work through the uncertainty of prognosis while making sure that important information about time is discussed.

## At the End of the Conversation...

➤ **Give a copy of the graphic aid to the patient and family**

- The patients and family members from our pilot study said the graphic aid was very important to them. They loved being able to refer to it after meeting with the doctor and they held on to it for a long time even after their decision because it allowed them to make sense of what was happening.
- The graphic aid can also be used to share information with family, nurses and other clinicians.
- The graphic aid may be a way for other consultants/ clinicians to contribute to the decision-making, understand the rationale or adjust best case/worst case scenario using their expertise. It may also help facilitate discussions with palliative care clinicians.

- You may want to keep a copy of the graphic aid in the patient's chart so other providers can see it. OR you may want to use this graphic aid again when the patient returns to see you in clinic or if they come to the hospital acutely ill. Use your phone to take a picture of the graphic and then insert the picture in the EHR, often this goes in the media tab

➤ Tips for Integrating into your Busy Clinic

- Complete the Graphic Aid in advance.
- Set aside an appointment to discuss dialysis and only focus on that during the visit.
- See website for tips from Nephrologists- link below or use QR code [www.patientpreferences.org/BCWC-Nephrology](http://www.patientpreferences.org/BCWC-Nephrology)



## Telephone and Video Appointments

- Options for completing the Graphic Aid:
  - Fillable electronic forms ([www.patientpreferences.org/BCWC-Nephrology](http://www.patientpreferences.org/BCWC-Nephrology))
  - Pen and paper
- Focus on the storytelling
- Send the Graphic Aid to the patient via MyChart or other patient portal, mail, text an image (with patient permission) with a cover letter to remind them of the conversation

### Study Procedures

1. Mail or hand one copy to the patient.
2. Put one copy in the purple folder to return in the white, postage prepaid return mail envelope provided and give that envelope to the Research Coordinator (or, if this is a telehealth appointment and no Research Coordinator is present, you may drop this envelope in the mail yourself).
3. Keep one copy for the medical record.

## The Best Case/Worst Case Communication Tool



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### Session Roadmap

- Introduce Best/Case Worst Case
  - Storytelling
  - Graphic aid
- Using Best Case/Worst Case in clinic
  - Setting up the decision
  - Making a decision
  - Introducing Palliative Care
- Individual practice
  - With coach & standardized patients
- Proficiency Check
  - With standardized patient
- Follow up Logistics

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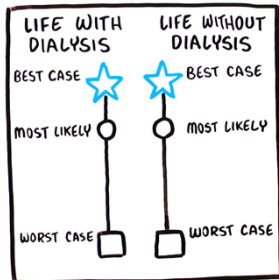
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## How to do it

### BEST CASE/WORST CASE



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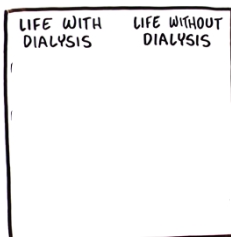
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## First: Describe the Options

Realistic daily treatment description:

"You will have surgery to make a fistula/have a catheter placed in your abdomen..."

"You will go have dialysis for 4 hours a day, three times per week..."



Realistic daily treatment description:

"You will continue with doctor visits, lab checks, watching your diet, and medication changes..."

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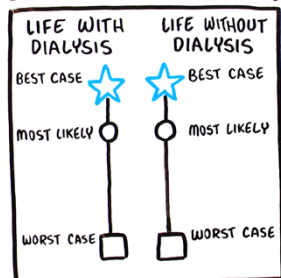
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## Storytelling: Describe what would happen if everything goes well...

### BEST CASE/WORST CASE



TELL A STORY...



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### In the best case scenario...

**Short term:** "You will be tired after dialysis but have good days in between. You'll need to watch your diet and be in the hospital for some procedures and tests."

**Long term:** "Over time, a few years, your kidney disease will make your health worse. You will be in the hospital more and get very sick and die or decide you would like to start Hospice."

### In the worst case scenario...

**Short term:** "You have more bad days than good days, and you have complications, problems with access, problems with your heart, and you spend a lot of time in the hospital..."

**Long term:** "Time is short, you get sick quickly..."

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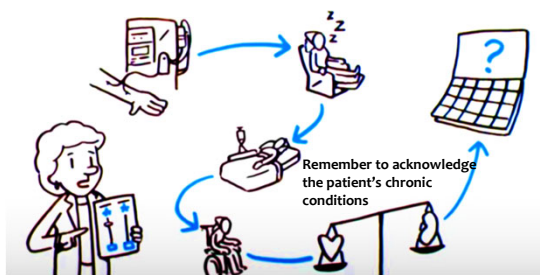
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### Based on what I know about you what I think is most likely...




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### Write short notes about what life would be like ...

**BEST CASE**  
-Short term  
-Long term

**Most Likely**  
-Short term  
-Long term

**Worst Case**  
-Short term  
-Long term

#### BEST CASE/WORST CASE

LIFE WITH DIALYSIS	LIFE WITHOUT DIALYSIS
BEST CASE ★	BEST CASE ★
MOST LIKELY ○	MOST LIKELY ○
WORST CASE □	WORST CASE □

**Short-term** day-to-day implications  
For example:  
• Diet, quality of life  
• Hospitalizations  
• Living situation

**Long-term** implications  
For example:  
• Health trajectory  
• Time to death  
• How and location of death

**Worst Case**  
-Short term  
-Long term

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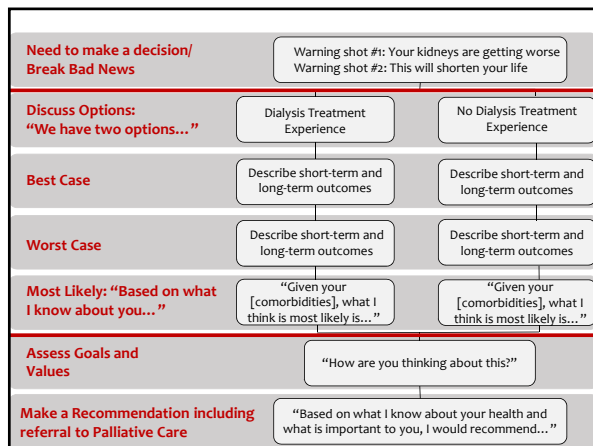
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## Break Bad News: Start with Perception

- Assess their understanding of their kidney disease
  - "What is your sense of where we are at with your kidney disease?"
  - "Tell me what you know about your kidneys and when we might discuss dialysis?"

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## Break Bad News: Reframe

- Patients who know their kidneys are failing**  
**Reinforce:** "You're right, your kidneys are getting worse and we need to talk about what that means..."  
**Build on this:** "I know, things haven't changed much, and you are worried about what the future might hold. We have to look at the options..."
- Patients who have limited understanding of what's going on:**  
**Patiently reframe:**  
"Unfortunately, your kidneys are getting worse...we need to talk about your options."  
"What this means is your kidneys aren't working well anymore...and we need to talk about what this means for you."  
"You are right, things haven't changed much lately, yet your kidneys are still not working well..."

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## Break Bad News: This IS Bad News!



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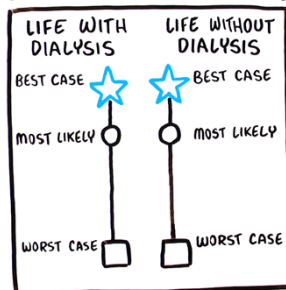
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## BEST CASE/WORST CASE



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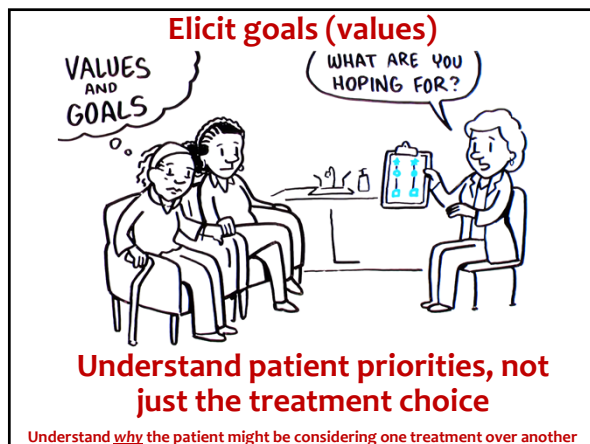
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## Elicit goals (values)



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## Make treatment recommendation to support the patient's goals

I think when the time comes we should start dialysis.

OR

I think, given what is most important to you now, that dialysis is not a good idea



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## Maybe today is not the time to decide...

Maybe the best decision is to not decide today...



I want you to make this decision *me*, not the ER doctor



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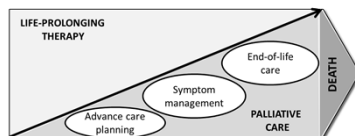
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## Introduce Palliative Care

No matter what we decide today, I want you to meet our palliative care team



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### Referral to Palliative Care

- o "I would like to send you to see a palliative care doctor. These doctors can help you feel as well as you can for as long as you can. Would that be ok?"
- o "This is difficult news. Regardless of what treatment path you choose, I'd like you to see one of our palliative care doctors. They can help preserve the quality of life you're used to for as long as possible."
- o "Regardless of what we decide to do, I would like you to meet with a palliative care doctor, because this is a lot to take in. Would that be ok?"

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### Let's see how it works—Case #1

Mr. Robinson is an 85 year old gentleman with a history of CAD and MI s/p DES x2 5 years ago, diet and metformin-controlled DM2, COPD not on home oxygen, and ESKD not yet on HD who presents to nephrology clinic to discuss his most recent lab work. His GFR has decreased from 18 → 15 since his last appointment 6 months ago.

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### Demonstration

[www.patientpreferences.org/BCWC-Nephrology](http://www.patientpreferences.org/BCWC-Nephrology)

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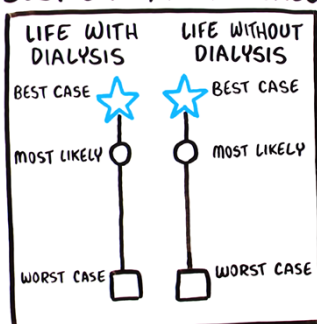
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**NEXT:  
INDIVIDUAL  
PRACTICE  
& COACHING**

**BEST CASE/WORST CASE**



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**Case #2**

Medical overview: Ms. Susan Olson is an 83 year old female with HL, HTN, and CAD s/p DES for angina a few years ago who returns to nephrology clinic for follow up of her CKD. Today her GFR is 15; it was 16 at her last appointment 6 months ago.

Social history: She currently lives at home with her husband. She has 3 adult children, including a son who is a nephrologist.

Function: She walks her dog 1 mile each morning. She still drives and does her own housework. She is a retired pharmacist.

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**Case #3**

Medical overview: Ms. Rhonda Montgomery is a 78 year old female with poorly controlled insulin-dependent DM (last Hgb A1c was 9), HTN, HL, severe neuropathy and severe PVD s/p R BKA 1 year ago for gangrene of the foot from a diabetic ulcer followed by a R AKA two months later for a non-healing wound. She was hospitalized 2 months ago for PNA and an NSTEMI. She returns to clinic today for follow up of her CKD. Today her GFR is 14, which is fairly stable since her most recent hospitalization. Her GFR 6 months ago was 17.

Social history: She is living at a SNF and requires help with IADLs and most ADLs except feeding.

Function: She is wheelchair bound and needs 1 person assistance for slide-board transfer to her wheelchair.

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### Case #4

**Medical overview:** Ms. Linda Snyder is an 80 year old female with HTN, history of breast cancer s/p R mastectomy and chemo-radiation 8 years ago, moderate systolic CHF with EF 35-40%, mild mitral regurgitation, who returns to clinic for follow up of her CKD. Her last GFR 6 months ago was 18; today it is 15.

**Social history:** She is married; her first husband died from a stroke 25 years ago. She now lives at home with her second husband, but he was recently diagnosed with Alzheimer's and they are discussing moving to an assisted living facility together. She has three adult children, but only one lives in Wisconsin. She is a retired accountant.

**Function:** She is the primary caregiver for her husband; she stopped driving 5 years ago. She has had brief rehab stays after two hospitalizations in the past 3 years for acute on chronic CHF.

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### Follow up and Questions

Coaching sessions every two weeks

1<sup>st</sup> Date/Time:

2<sup>nd</sup> Date/Time:

3<sup>rd</sup> Date/Time:

I will email you on the in-between weeks

- Resources: [www.patientpreferences.org/BCWC-Nephrology](http://www.patientpreferences.org/BCWC-Nephrology)

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### Study Procedures

Your on-site Research Coordinator will cue you when you have a study patient.

Feel free to use BCWC with non-study patients as well.

Let's look at your folder...

You will give one copy of the Graphic Aid to your patient, one will go in their record, and one will be sent back to us.

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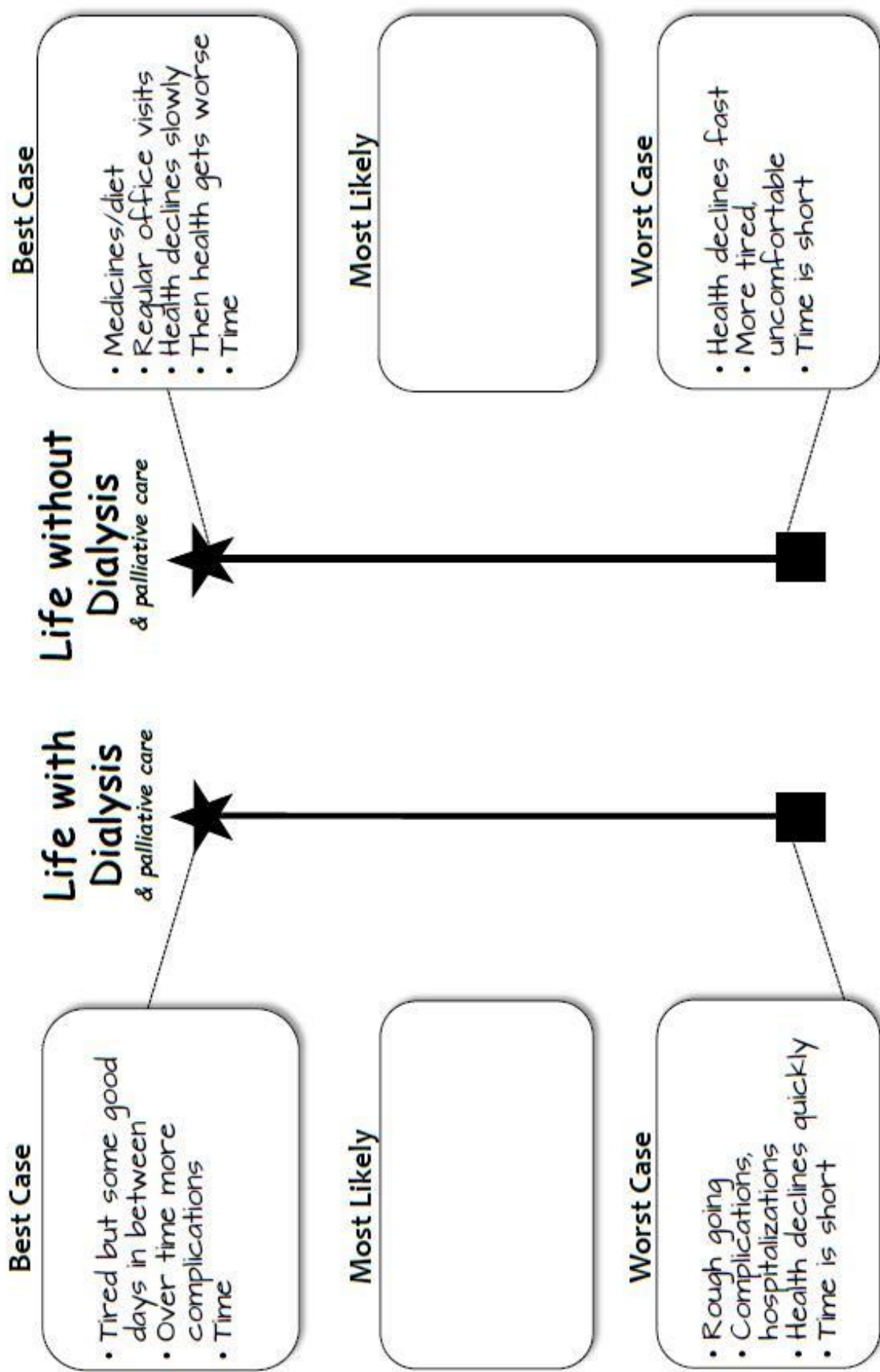
## Practice Case #1 (Demo)

Medical Overview: Mr. Robinson is an 85 year old gentleman with a history of CAD and MI s/p DES x2 5 years ago, diet and metformin-controlled DM2, COPD not on home oxygen, and ESKD not yet on HD who presents to nephrology clinic to discuss his most recent lab work. His GFR has decreased from 20 to 17 since his last appointment 6 months ago.

Social history: He lives with his wife. They have 3 adult children and 5 grandchildren.

Function: He gardens and rides his bike on the weekends. Takes his dogs for walks twice a day.

Physician instructions: You are about to meet with Mr. Robinson clinic. As his kidney function continues to worsen, your job today is to discuss his prognosis and treatment options.



*How are you thinking about this?*

*I enjoy* \_\_\_\_\_

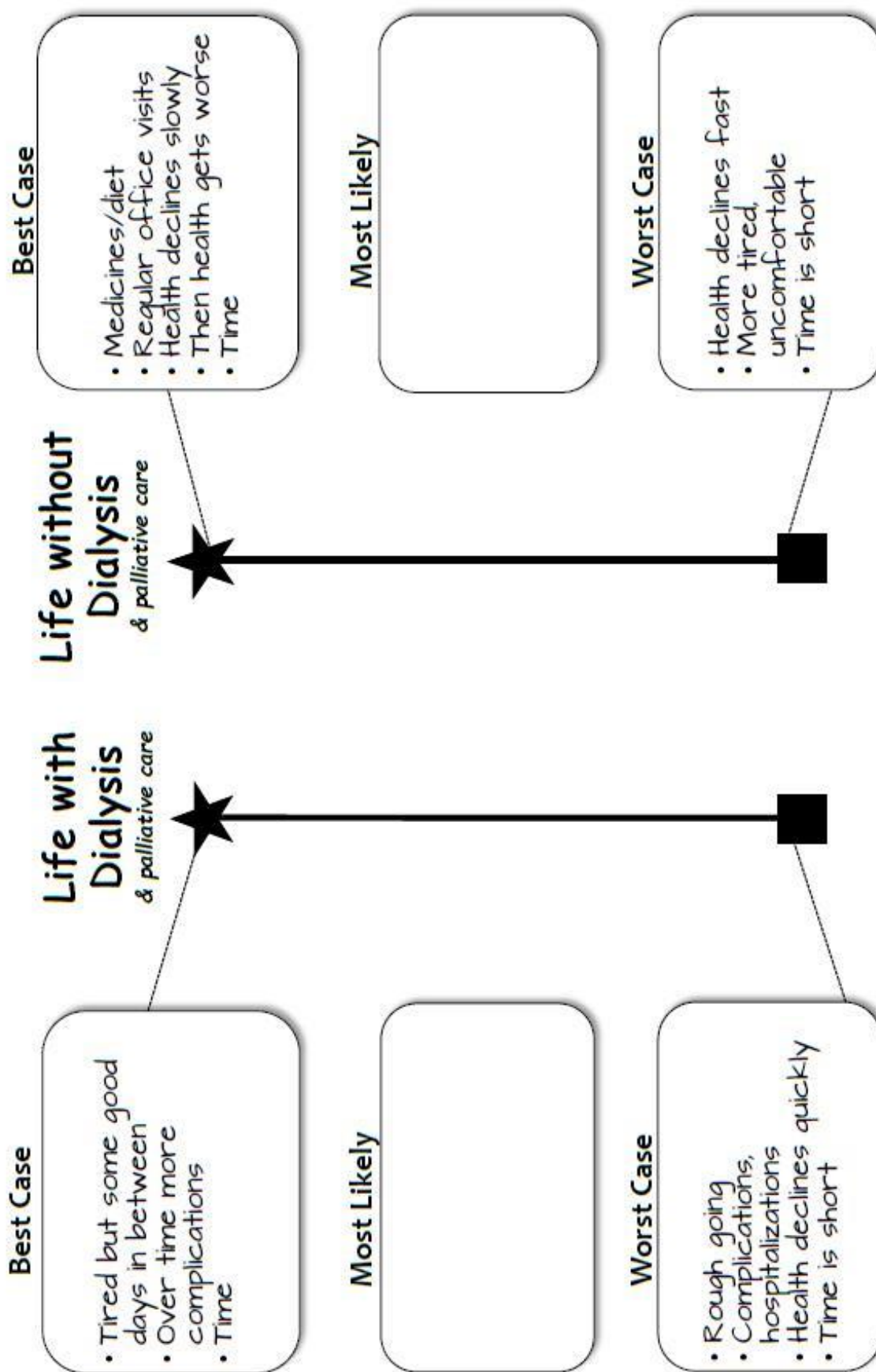
## Practice Case #2

Medical overview: Ms. Susan Olson is an 83 year old female with HL, HTN, and CAD s/p DES for angina a few years ago who returns to nephrology clinic for follow up of her CKD. Today her GFR is 15; it was 16 at her last appointment 6 months ago.

Social history: She currently lives at home with her husband. She has 3 adult children, including a son who is a nephrologist.

Function: She walks her dog 1 mile each morning. She still drives and does her own housework. She is a retired pharmacist.

Physician instructions: You are about to meet with Mrs. Olson in clinic. Assume she has been a patient of yours for years and you are her primary nephrologist. As her kidney function continues to worsen, your job today is to discuss her prognosis and treatment options.



*How are you thinking about this?*

*I enjoy* \_\_\_\_\_



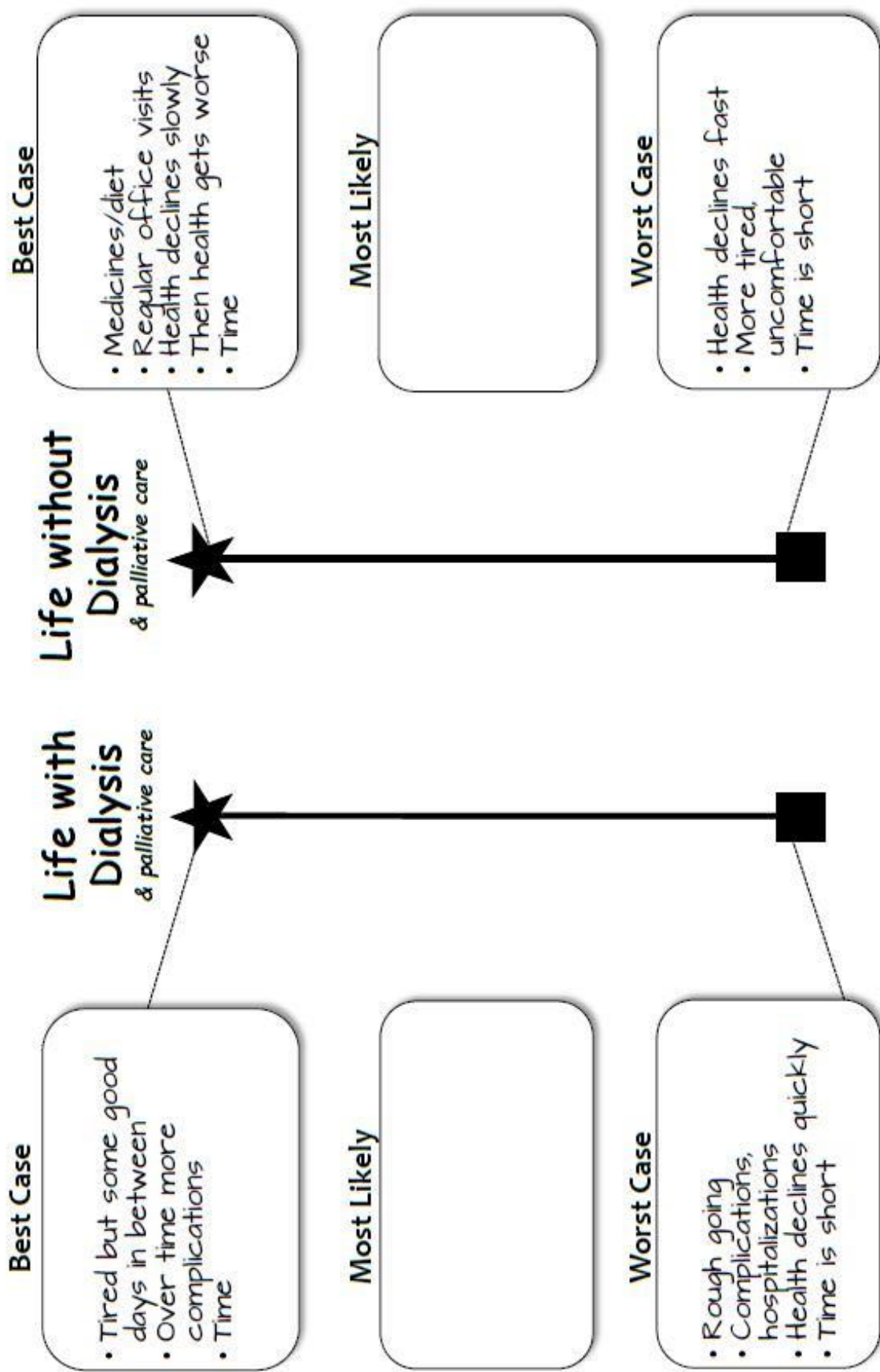
## Practice Case #3

Medical overview: Ms. Rhonda Montgomery is a 78 year old female with poorly controlled insulin-dependent DM (last Hgb A1c was 9), HTN, HL, severe neuropathy and severe PVD s/p R BKA 1 year ago for gangrene of the foot from a diabetic ulcer followed by a R AKA two months later for a non-healing wound. She was hospitalized 2 months ago for PNA and an NSTEMI. She returns to clinic today for follow up of her CKD. Today her GFR is 14, which is fairly stable since her most recent hospitalization. Her GFR 6 months ago was 17.

Social history: She lives in a nursing home and requires help with IADLs and most ADLs except feeding.

Function: She is wheelchair bound and needs 1 person assistance for slide-board transfer to her wheelchair.

Physician instructions: You are about to meet with Mrs. Montgomery in clinic. Assume she has been a patient of yours for years and you are her primary nephrologist. As her kidney function continues to worsen, your job today is to discuss her prognosis and treatment options.



*How are you thinking about this?*

*I enjoy* \_\_\_\_\_

Best Case

Most Likely

Worst Case

Life with Dialysis & palliative care

Life without Dialysis & palliative care

Best Case

Most Likely

Worst Case

How are you thinking about this?

I enjoy \_\_\_\_\_

## Practice Case #4

Medical overview: Ms. Linda Snyder is an 80 year old female with HTN, history of breast cancer s/p R mastectomy and chemo-radiation 8 years ago, moderate systolic CHF with EF 35-40%, mild mitral regurgitation, who returns to clinic for follow up of her CKD. Her last GFR 6 months ago was 18; today it is 15.

Social history: She is married; her first husband died from a stroke 25 years ago. She now lives at home with her second husband, but he was recently diagnosed with Alzheimer's and they are discussing moving to an assisted living facility together. She has three adult children, but only one lives in Wisconsin. She is a retired accountant.

Function: She is the primary caregiver for her husband; she stopped driving 5 years ago. She has had brief rehab stays after two hospitalizations in the past 3 years for acute on chronic CHF.

Physician instructions: You are about to meet with Ms. Snyder in clinic. Assume she has been a patient of yours for years and you are her primary nephrologist. As her kidney function continues to worsen, your job today is to discuss her prognosis and treatment options.

Best Case

Most Likely

Worst Case

**Life with  
Dialysis  
& palliative care**

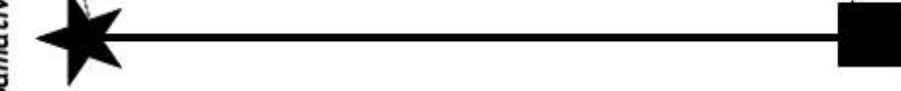


Best Case

Most Likely

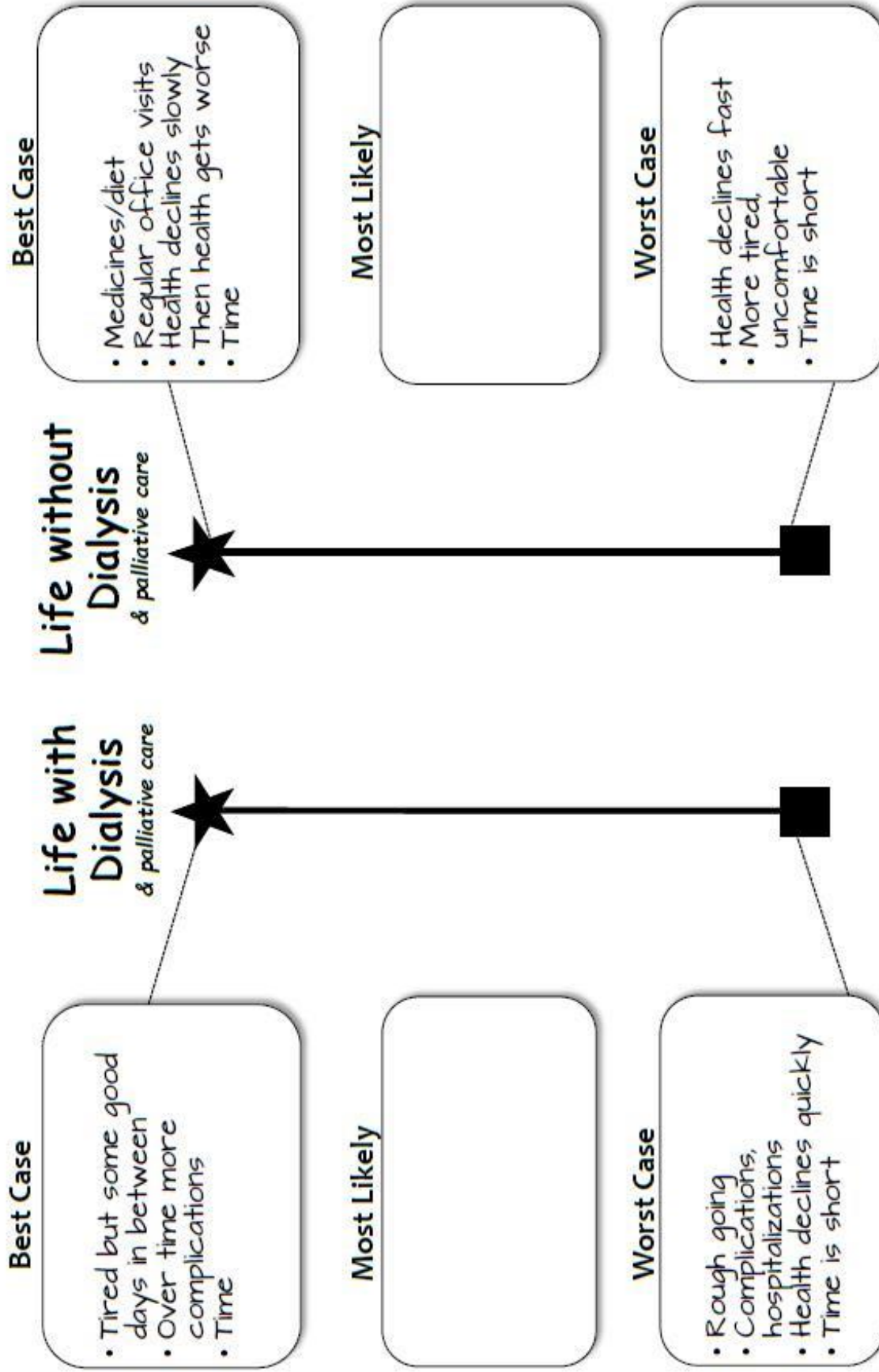
Worst Case

**Life without  
Dialysis  
& palliative care**



*How are you thinking about this?*

*I enjoy* \_\_\_\_\_



*How are you thinking about this?*

*I enjoy* \_\_\_\_\_

## Follow up Schedule

Initial Training Date: \_\_\_\_\_

Follow up #1: \_\_\_\_\_

Follow up #2: \_\_\_\_\_

Follow up #3: \_\_\_\_\_

Follow up calls will take place every 2 weeks. You will receive an email one week and two days prior with the call/login information.

After Follow up #3, Debriefing sessions will occur every 2 months for the first year of the study and quarterly during the second year. The purpose of these are to check in on the use of the tool and troubleshoot any questions/barriers to use.

## Pocket card

### **Best Case/Worst Case**

**Bad news: Stage 5 kidney disease is bad news.**

**We have a choice between 2 options, ...The first option is life with dialysis and palliative care.**

- **1. Description of treatment:**
  - Realistic experience of routine dialysis
- **2. Short-term day-to-day implications:**
  - Diet/QOL
  - Hospitalizations
  - Living situation
- **3. Long-term prognosis:**
  - Trajectory (kidney failure accelerates health problems/complications)
  - Time to death
  - How and location of death

*In the **best case scenario**, you will be tired after dialysis. You'll need to watch your diet and be in the hospital for some procedures and tests....over time, 1-3 years, your kidney disease will make your health worse, you will be in the hospital more and get very sick and eventually die or decide you would like to start Hospice before that happens.*

*In the **worst case** time is short... (describe 2&3).*

*Based on what I know about you, given (your very old age, heart failure, diabetes, etc), what I think is **most likely**... is closer to ... (describe 2&3)*

**...The second option is life without dialysis and palliative care..."**

*In the **best case** ...your life will continue as it is for many months, maybe even 1-2 years...as your kidneys get worse, you will develop symptoms and likely need medications. You will sleep more and more. You will die from your kidneys not working, either because you get sick and die in the hospital or you decide to start Hospice.*

*In the **worst case** ...you develop complications and get sick very quickly... (describe 2&3)*

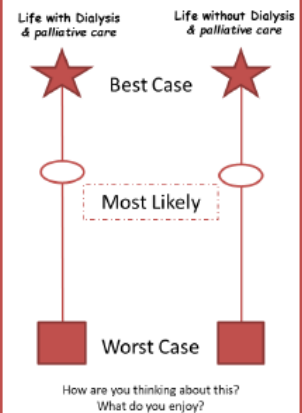
*Based on your (health conditions), what I think is **most likely**... (describe 2&3)*

- **How are you thinking about this?**
- **What are you hoping for with your treatments?**
- **What are you most afraid of?**

**Based on what you said is important to you, I would recommend....**

**And, I would also like to send you to see a palliative care doctor. Is that okay?**

### **Best Case/Worst Case**





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## *Curbside Rounds: State-of-the-Art in Palliative Care*

# Integrating Supportive Care Principles Into Dialysis Decision Making: A Primer for Palliative Medicine Providers



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*Sections of Nephrology and Supportive Care, West Virginia University School of Medicine, Morgantown, West Virginia, USA*

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### **Abstract**

*Despite advances in predialysis care and dialysis technology, patients with advanced chronic kidney disease and end-stage renal disease continue to experience multiple comorbidities, a high symptom burden, a shortened life expectancy, and substantial physical, emotional, and spiritual suffering. Patients with acute kidney injury and end-stage renal disease, especially if they are older, often undergo prolonged hospitalizations, greater use of intensive medical treatment, and limited survival. Unfortunately, most nephrologists are not trained to conduct shared decision-making conversations to elicit patients' values, preferences, and goals for treatment and address their patients' multifactorial suffering. These patients would benefit from the integration of supportive care principles into their care. This article addresses how supportive care specialists can collaborate with nephrology clinicians to provide patient-centered supportive care and identifies resources to assist them in this endeavor. J Pain Symptom Manage 2017;53:656–662 © 2017 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

### **Key Words**

*Shared decision making, dialysis, end-of-life care, prognosis*

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### **Introduction**

Over the past decade, there has been accumulating evidence that older patients with acute kidney injury (AKI) or end-stage renal disease (ESRD) may derive little or no benefit from dialysis, especially if they have multiple comorbidities, which is the case for many patients.<sup>1</sup> Because of this finding, nephrology professional organizations have recommended that dialysis not be initiated in such patients before a process of shared decision making.<sup>1,2</sup> Shared decision-making conversations may be difficult for nephrologists with patients and families who are not prepared to hear that the patient has a poor prognosis, and supportive care specialists may be consulted to assist these discussions. In addition, supportive care specialists may be consulted for assistance with decisions about stopping dialysis. The term supportive care has been chosen in preference to palliative care throughout this article because it is the preferred term selected

by the Kidney Disease Improving Global Outcomes Conference Committee<sup>3</sup> and the Coalition for Supportive Care of Kidney Patients (CCKP).<sup>4</sup> This article provides supportive care consultants with the medical evidence and resources they need to conduct shared decision-making conversations to assist patients and families to understand the patient's diagnosis, prognosis, and treatment options. It addresses the present state of end-of-life care for dialysis patients, why supportive care is particularly needed by patients with kidney disease, and the clinical practice guideline and other resources available to assist supportive care consultants in treating patients with kidney disease.

### **The Present State of Supportive Care for Kidney Patients and Why They Need It**

Compared with many chronic disease populations, kidney disease patients are arguably among the sickest

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and particularly in need of supportive care.<sup>3,5</sup> In a three-year cross-sectional retrospective study of 57,753 deceased Veterans Affairs patients, those with ESRD had the greatest comorbid disease burden, and their families rated the quality of their end-of-life care significantly worse than that for those who died of cancer or dementia.<sup>6</sup> Patients with chronic kidney disease (CKD) are characterized by not only multiple comorbidities but also a high symptom burden, increasing age, and a shortened life expectancy. They frequently have hypertension, diabetes mellitus, hyperlipidemia, and cardiovascular disease in addition to kidney disease,<sup>6–8</sup> and they report on average nine concurrent symptoms, a symptom burden comparable to patients with cancer.<sup>7</sup> Patients older than 75 years are the fastest growing population on dialysis, and dialysis patients live on average less than one-third as long as age-matched patients without kidney failure.<sup>9</sup>

In both Medicare and Veterans Affairs' large administrative data sets, researchers have shown that supportive care is not well integrated into the hospital end-of-life care of ESRD patients. ESRD patients are much more likely to be admitted to the intensive care unit (ICU) and much less likely to be admitted to hospice in the final month of life than cancer or congestive heart failure patients.<sup>8</sup> In the Veterans Affairs' data set, ESRD patients were also more likely to have an order for cardiopulmonary resuscitation and less likely to receive a supportive care consultation.<sup>6</sup>

The outcomes for older patients starting chronic dialysis in the hospital are particularly worth noting. The extent of shared decision making before initiation of dialysis is unknown, but older patients starting dialysis more often have prolonged hospitalizations, greater use of intensive medical treatments (mechanical ventilation, feeding tube, and/or cardiopulmonary resuscitation), and limited survival compared with those started in the outpatient setting.<sup>10</sup> Supplying this kind of information about anticipated outcomes to older patients starting chronic dialysis in the hospital can help to provide realistic expectations about the future treatment course that may assist patients and families align their decisions with their values, preferences, and goals. Recognizing the challenges for kidney patients and their families, the CSCKP is an interdisciplinary group with a mission to advance quality patient-centered care for kidney patients. CSCKP has many resources for patients and professionals on their Web site.<sup>4</sup>

In 2013, the state of supportive care implementation in U.S. dialysis units was surveyed and found to have little penetration. Only 4.5% of the respondents thought their units were providing high-quality interdisciplinary supportive care to their patients. In addition to physicians, nurses, nurse practitioners, physician assistants, social workers, and chaplains

ideally would be members of a dialysis center supportive care team and could assist directly in the top three identified supportive care needs in the dialysis center survey: bereavement support, spiritual support, and end-of-life care discussions. Dialysis personnel rated guidelines to assist in decision making with seriously ill patients and the availability of supportive care consultation as the two top priorities to improve supportive care in their units. Most did not know that such guidelines were already available.<sup>5</sup>

Not surprisingly given these results, most nephrology fellows report that during their fellowships they were not trained to assess and manage pain, inform a patient of a poor prognosis, determine when to consult supportive care, refer a patient to hospice, and conduct a family meeting about treatment options. Almost all fellows believed it was their responsibility to care for dying dialysis patients and learn how to do so. The number one thing fellows cited to improve their fellowship end-of-life care training was a rotation on the supportive care service.<sup>11</sup>

### ***Shared Decision Making for Patients with AKI***

Since 2000, the American Society of Nephrology (ASN) and the Renal Physicians Association (RPA) have recommended shared decision making as the approach to assist patients and families in making decisions to start, continue, and stop dialysis (Table 1).<sup>12</sup> They did so then because nephrologists were increasingly reporting that they were being asked to dialyze patients for whom they perceived the benefit of dialysis to be marginal. In the 2010 second edition of the clinical practice guideline, they acknowledged that shared decision making is the preferred model for medical decision making because it ensures that patients are fully informed about the risks and benefits of treatments, and their values and preferences play a prominent role in the process. The guideline stressed the importance of a patient-specific estimate of prognosis to aid the informed consent process.<sup>1</sup>

The aging kidney undergoes anatomic and physiologic changes predisposing to AKI. Reasons for this increased risk of AKI include an increased burden of comorbidities affecting kidney function, more frequent exposure to medications and interventions that are nephrotoxic or alter kidney hemodynamics, and alterations in drug metabolism and clearance with aging. Multiple studies have shown that older patients are more susceptible to AKI.<sup>13</sup> In patients younger than 65 years compared with those who are older, the increased risk of AKI is approximately three- to fivefold. Moreover in the elderly, AKI is often not a self-limited disease but a significant risk factor for long-term morbidity, prolonged hospitalization, and

Table 1

**Recommendations in the Shared Decision Making in the Appropriate Initiation of and Withdrawal From Dialysis, Second Edition, Clinical Practice Guideline<sup>a</sup>**

Establishing a shared decision-making relationship
Recommendation no. 1
Develop a physician-patient relationship for shared decision making
Informing patients
Recommendation no. 2
Fully inform AKI, Stage 4 and 5 CKD, and ESRD patients about their diagnosis, prognosis, and all treatment options
Providing prognosis
Recommendation no. 3
Give all patients with AKI, Stage 5 CKD, or ESRD an estimate of prognosis specific to their overall condition
Facilitating advance care planning
Recommendation no. 4
Institute advance care planning
Making a decision to not initiate or to discontinue dialysis
Recommendation no. 5
If appropriate, forgo (withhold initiating or withdraw ongoing) dialysis for patients with AKI, CKD, or ESRD in certain well-defined situations
Recommendation no. 6
Consider forgoing dialysis for AKI, CKD, or ESRD patients who have a very poor prognosis or for whom dialysis cannot be provided safely
Resolving conflicts about what dialysis decisions to make
Recommendation no. 7
Consider a time-limited trial of dialysis for patients requiring dialysis, but who have an uncertain prognosis, or for whom a consensus cannot be reached about providing dialysis
Recommendation no. 8
Establish a systematic due process approach for conflict resolution if there is disagreement about what decision should be made with regard to dialysis.
Providing effective palliative care
Recommendation no. 9
To improve patient-centered outcomes, offer palliative care services and interventions to all AKI, CKD, and ESRD patients who suffer from burdens of their disease
Using systematic communication
Recommendation no. 10
Use a systematic approach to communicate about diagnosis, prognosis, treatment options, and goals of care

AKI = acute kidney injury; CKD = chronic kidney disease; ESRD = end-stage renal disease.

<sup>a</sup>Reproduced with permission from Ref. 1.

mortality. The hazard for Medicare beneficiaries with AKI alone developing ESRD is 13 times that of Medicare beneficiaries without AKI.<sup>14</sup> Depending on the study, between one-third and two-third of older patients with AKI develop ESRD and remain dialysis dependent. Most studies in the ICU find that 50% or more patients who require dialysis for AKI die during the hospitalization.<sup>13,15</sup> The prognosis is particularly poor for older patients discharged to a long-term acute care hospital.<sup>16</sup> Of 110 patients with a mean age of 59.8 years with AKI, most were readmitted to acute care hospitals, required nursing home placement, or died. Older age was associated with lower odds of returning home. Patients and families should be informed of the poor prognosis for recovery of functional independence for those with AKI admitted to a long-term acute care hospital.

The prognosis is also particularly poor for nursing home residents starting dialysis for AKI or ESRD. Most patients do not survive a year, and only 13% maintain their predialysis level of functional performance.<sup>17</sup>

In another study of 1124 critically ill patients (mean age 59.7 years) with AKI requiring dialysis that examined quality of life of 60-day survivors, 47.4% were alive at Day 60 and only 18.2% were discharged home without requiring dialysis.<sup>15</sup> The 60-day survivors severely compromised quality of life with 27% rating their quality of life equivalent to or worse than death (Health Utilities Index Score = 0).<sup>18</sup> The investigators noted that patients who survive 60 days after initiation of dialysis in the ICU can expect to encounter severe limitation in health-related quality of life. Taken together, these studies suggest that shared decision-making discussions about dialysis for AKI in the ICU should include the issues of high mortality, permanent dialysis dependence, impaired quality of life, and low likelihood of returning home.

Because of the limited benefits of dialysis for AKI in the ICU setting for older adults, nephrologists and supportive care specialists seeing patients in consultation may want to suggest a time-limited trial of dialysis.<sup>13,19</sup> A time-limited trial is a patient-centered process incorporating the clinician's best estimate of prognosis, quality-of-life factors, and patient values. It is a goal-directed trial of dialysis limited by predetermined outcomes that are evaluated at planned intervals.<sup>19</sup> Time-limited trials of dialysis are specifically recommended when the benefit of dialysis is uncertain. Whenever there is apparent conflict about initiating dialysis (the nephrologist recommends it, but the patient is hesitant, or the nephrologist counsels against it but the patient or the patient's family requests dialysis), a time-limited trial of dialysis may promote more informed shared decision making and help to resolve conflict about the dialysis decision. Both the nephrologist and the patient (or the patient's legal agent if the patient lacks decision-making capacity) will see how the patient tolerates dialysis and if the patient's overall condition improves with it. Before a time-limited trial of dialysis is begun, the length of the trial and the parameters to be assessed during and at the completion of the trial should be agreed on so that at the trial's conclusion the decision about continuing or stopping dialysis can be made according to predefined parameters.

Interestingly, in a 2005 survey of the RPA membership, nephrologists who had been in practice longer and who were knowledgeable of the RPA and the ASN Shared Decision-Making guideline published in 2000 reported greater preparedness to make end-of-life decisions and use time-limited trials of dialysis.<sup>20</sup> At the initiation of a time-limited trial, it is important



for the nephrologist (and the supportive care clinician if involved in reaching the agreement on the time-limited trial) to specify that if the predetermined outcomes are not achieved that dialysis will be stopped and that the focus of the patient's care will be changed to intensive supportive care in which the goal will be the patient's comfort. Supportive care clinicians can assist in patient and family understanding of prognosis, elicitation of goals of care, and coping with emotional and spiritual distress. They add an extra layer of support for the patient and family throughout the illness and can facilitate transitions of care to comfort care as appropriate.<sup>19</sup>

### **Shared Decision-Making for Patients with ESRD**

One of the five questions that the ASN recommended physicians and patients discuss in the ASN's Choosing Wisely Campaign was shared decision making.<sup>2</sup> The recommendation stated not to initiate chronic dialysis without ensuring an individualized shared decision-making conversation was held by physicians with patients and their families. This recommendation was made because of the accumulating evidence that survival may not differ substantially for older adults with a high burden of comorbidity who initiate chronic dialysis vs. those managed conservatively.

In the process of shared decision making, physicians and patients reach agreement on a specific course of treatment and share responsibility in the decision based on an understanding of the patient's overall condition and values.<sup>1</sup> Shared decision making is appropriate for making decisions about starting, continuing, and stopping dialysis. Shared decision making achieves the goal of the Institute of Medicine 2001 report *Crossing the Quality Chasm: A New Health System for the 21st Century* by facilitating individualized patient-centered care that is respectful of and responsive to individual patient preferences, needs, and values and ensures that patient values guide all clinical decisions.<sup>21</sup> In fact, shared decision making has been described as the pinnacle of patient-centered care.<sup>22</sup> Unfortunately, data from numerous studies of dialysis patients performed between 2006 and 2013 show that shared decision making has been poorly integrated into the process of dialysis initiation for many patients.<sup>23</sup> There is the expectation that dialysis decision making will improve as the recommendations of the ASN and RPA are implemented through the more widespread use of advance care planning and the involvement of an interdisciplinary team including supportive care clinicians in the shared decision-making process.

The RPA clinical practice guideline specifically identified CKD patients 75 years of age and older as ones for whom shared decision making is especially indicated

before deciding to initiate dialysis.<sup>1</sup> The reason is because if these patients also have comorbidities, functional impairments, or malnutrition, they may not live any longer with dialysis than without. Age and comorbidity are additive in predicting dialysis patient survival. Although age alone should not be considered a contraindication to starting dialysis, an age-neutral approach is not recommended because age is a statistically significant, independent, powerful, and consistent risk factor for death in ESRD patients. Thus, before placement of an arteriovenous access or peritoneal dialysis catheter, elderly patients with Stage 4 or 5 CKD and severe comorbidities should be specifically informed of the burdens that dialysis may entail for them (Table 2).

Multiple options exist for patients starting chronic dialysis. In older patients with AKI and ESRD with an uncertain prognosis, a time-limited trial of dialysis may be appropriate. Other options for starting chronic dialysis include dialysis for long-term maintenance treatment of ESRD; dialysis as destination therapy; and active medical management without dialysis,<sup>24</sup> which has recently been termed comprehensive conservative care.<sup>25</sup> A time-limited trial at the start of chronic dialysis could be considered for patients who would be candidates for dialysis as destination therapy. At the outset, it is important to elicit patients' goals for care because multiple studies show that many CKD and dialysis patients value quality of life, dignity, independence, and comfort over survival.

Palliative dialysis is an option for patients predicted to be in their last year of life who want to start or are already receiving chronic dialysis. It is a shift from a

Table 2  
**Informed Consent for Older Patients Considering Chronic Dialysis<sup>1</sup>**

For patients 75 years of age and older with significant comorbid conditions and Stage 4 or 5 CKD, they should be informed of the following as they are considering whether they want to have a dialysis access placed to prepare for dialysis:

- Dialysis may not confer a survival advantage.
- Patients with their level of illness are more likely to die than live long enough to progress to ESRD.
- It is likely that they may not experience any functional improvement with dialysis and that they may undergo significant functional decline during the first year after dialysis initiation.
- The burdens of dialysis include surgery for vascular or peritoneal access placement and complications from the vascular access or peritoneal dialysis catheter.
- They may experience adverse physical symptoms on dialysis, such as dizziness, fatigue, and cramping, and a feeling of unwellness after dialysis.
- There will be travel time and expense to and from dialysis, long hours spent on dialysis, and a reduction in the time available for activities they enjoy.
- Dialysis may entail an unnecessary medicalization of death resulting in invasive tests, procedures, and hospitalizations.
- Forgoing dialysis may entail worsening symptoms of uremia, including weakness, nausea, anorexia, vomiting, somnolence, itching, and twitching.

CKD = chronic kidney disease; ESRD = end-stage renal disease.

Table 3  
Responding to a Patient Request to Stop Dialysis<sup>1</sup>

- Assess decision-making capacity and whether it is compromised by major depression or other disorder. Determine whether the patient's perceptions about dialysis are accurate. Does the patient understand what will happen if dialysis is stopped?
- Does the patient really mean what he and/or she says or is the decision being made to get attention, control, or help?
- Are there changes that might improve the patient's quality of life and is the patient willing to continue dialysis while they are being made to see if his and/or her quality of life improves?
- Determine the reasons or conditions underlying the patient and/or surrogate request for withdrawal of dialysis. Such assessment should include specific medical, physical, spiritual, and psychological issues, as well as interventions that could be appropriate.
- Identify potentially treatable factors such as the following:
  - Underlying medical disorders, including the prognosis for short-term or long-term survival on dialysis,
  - Difficulties with dialysis treatments,
  - The patient's assessment of his and/or her quality of life and ability to function,
  - The patient's short-term and long-term goals,
  - The burden that costs of continued treatment/medications/diet/transportation may have on the patient/family/others,
  - The patient's psychological condition, including depression and/or conditions/symptoms that may be caused by uremia,
  - Undue influence or pressure from outside sources, including the patient's family,
  - Conflict between the patient and others,
  - Dissatisfaction with the dialysis modality, the time, or the setting of treatment.
- Depending on the assessment of potentially treatable factors, recommend psychiatric treatment or refer for counseling.
- Encourage the patient to discuss reasons for dialysis withdrawal with family or support system.
- If a fully informed patient with capacity who has undergone treatment for potentially reversible factors still persists in the request for dialysis withdrawal, the patient's request should be honored to respect patient autonomy.
- If the patient lacks decision-making capacity, determine if the surrogate is making decisions according to the patient's prior expressed wishes for his and/or her current condition or according to what the surrogate determines to be the patient's best interest. If either is the case and there are not potentially treatable factors that could improve the patient's quality of life, agree to the request to respect the patient's autonomous decision when he and/or she had capacity or to prevent harm from a life in which there is suffering prolonged by dialysis.

conventional disease-oriented focus of dialysis as rehabilitative treatment to an approach prioritizing alignment with patient preferences and goals of care to improve quality of life and reduce symptom burden.<sup>24</sup> Specific clinical scenarios of maintenance dialysis patients for whom a palliative approach to dialysis care may be considered include the maintenance dialysis patient who develops a severe illness that causes an abrupt decline in life expectancy, the patient started on dialysis in the setting of AKI with unclear life expectancy and goals of care, and the maintenance dialysis patient with progressive functional or cognitive decline. By definition, a palliative approach to dialysis targets maintenance dialysis patients near the end of life who want to minimize the intensity of care to focus on living as comfortably as possible rather than on meeting current standard-of-care metrics for maximal rehabilitation and survival. Proposed quality metrics for palliative dialysis with which supportive clinicians could assist nephrologists include documentation of discussion of prognosis and goals of care and preferences for life-sustaining treatment with completion of a physician orders for life-sustaining treatment or similar form; documentation of a global assessment of symptoms with measures initiated to manage them and changes in symptom scores over time; documentation of offering of psychosocial and spiritual supports to the patient and caregiver and response; assessment of patient and caregiver satisfaction with care with change of scores over time; and documentation of referral to hospice as the patient's condition worsens and discussion of option of dialysis withdrawal. For patients being treated with palliative

dialysis, diet would be liberalized, medication regimens simplified, and laboratory monitoring decreased. As a patient-centered rather than disease-oriented approach to the delivery of dialysis care for patients with limited life expectancy, a palliative approach to dialysis care may alleviate the suffering of such patients. Although conceptually palliative dialysis is appealing to patients because they value their time and independence,<sup>26</sup> research is needed on the outcomes of palliative dialysis to see if there are some approaches that lead to better patient quality of life than others. Much work is needed to facilitate incorporation of this approach into the existing dialysis delivery infrastructure including public policy in the U.S.<sup>24</sup> In this regard, nephrology professional organizations will need to conduct a dialogue with the Centers for Medicare and Medicaid Services about

Table 4  
Approach to Decision to Withdraw From Dialysis<sup>29</sup>

1. Confirm that patient really wishes to withdraw from dialysis (Table 3); if the patient lacks DMC, confirm decision with the legal agent in the patient's advance directive or surrogate decisionmaker according to the state law.
2. Advise patient with DMC to put affairs in order and advise that median survival after stopping dialysis is eight days although it could be shorter or longer depending on residual kidney function.
3. Implement end-of-life care plan including do-not-resuscitate order or physician orders for life-sustaining treatment or similar form depending on state ([www.polst.org](http://www.polst.org)).
4. Determine patient's preferred site of death and whether feasible.
5. Recommend hospice if patient not already on hospice.
6. Initiate comprehensive symptom control (physical, emotional, and spiritual).

DMC = decision-making capacity.

billing and being reimbursed for palliative dialysis so that the quality metrics proposed previously rather than present performance standards in the ESRD Quality Incentive Program will be used to evaluate palliative dialysis.<sup>24</sup> Nephrologists will need to learn and incorporate primary supportive care skills into their care of ESRD patients, and supportive care specialists will need to be available to assist nephrologists with communication for shared decision making and establishing time-limited trials.<sup>27</sup> Knowledge of the prognosis and treatment options will help supportive care clinicians talk to patients and families and reach consensus on what course of treatment best aligns with patients' values, preferences, and goals.

U.S. nephrologists will also need assistance in developing comprehensive conservative care programs for patients with ESRD who are choosing not to initiate dialysis.<sup>25</sup> Comprehensive conservative care is better developed in the U.K., Canada, and Australia. Outcomes there have included reduced hospitalization rates and increased home death rates. Such programs include not only interventions to delay progression of kidney disease and minimize symptoms and complications of disease progression but also multiple supportive care interventions. Among them are active symptom management, detailed communication including advance care planning and what to expect as the illness progresses, and psychosocial and spiritual supports for the patient and caregivers.<sup>25</sup>

Shared decision making is also the preferred approach for reaching decisions about stopping dialysis when requested by the patient or the family.<sup>1</sup> Supportive care specialists can be consulted for assistance with such decisions because most nephrologists have not been trained how to respond to such requests or when to consider stopping dialysis on a patient who is failing to thrive on dialysis.<sup>11</sup> Before the shared decision-making discussion, there should be a systematic evaluation that determines the reasons or conditions underlying the request, assesses the medical, psychological, social, and spiritual motivations for such a request, and identifies what interventions could be undertaken to address the factors motivating the request (Table 3).<sup>1</sup> A patient-specific estimate of prognosis from an online validated integrated prognostic model for hemodialysis patients may also help inform the discussion (<http://touchcalc.com/calculators/sq>). This model uses the surprise question and objective measures of comorbidity, age, and nutritional status.<sup>28</sup> Determination of the patient's decision-making capacity and ruling out depression or encephalopathy are important first steps in the evaluation.

Strong consideration should be given to stopping dialysis when the goals for which the patient started

dialysis are no longer being accomplished. The U.S. Renal Data System reports that withdrawal from dialysis is the second most common reason for dialysis patient death after cardiovascular disease. The most common reason for withdrawal of dialysis is failure to thrive.<sup>9</sup> An acute medical complication such as a stroke has been found to be the second most common reason for dialysis withdrawal. Common clinical scenarios in which patients or their family members make a decision to stop dialysis include acceleration of chronic comorbid illness, which may be manifested by clinical deterioration that is subtle and not immediately life-threatening but is emotionally debilitating for patients and their families.<sup>29</sup> Patients receiving dialysis often report loss of independence, the inability to engage in enjoyable activities, and decline in functional status and other measures of health-related quality of life. Nephrologists or supportive care specialists seeing patients in consultation have been recommended to use an Ask-Tell-Ask approach in the process of evaluating a patient for dialysis withdrawal (Table 4).<sup>29</sup> Supportive care specialists have expertise in the skills noted in the table.

## Summary

Because of their multiple comorbidities, high symptom burden, and limited life expectancy, CKD patients would benefit from the integration of supportive care principles into their routine care. Nephrologists have not been trained to provide this care, and collaboration between supportive care specialists and nephrologists is urgently needed to improve the quality of care for these patients (see Appendix).

## Pearls

- Shared decision making is the recommended approach for making decisions with AKI and ESRD patients about starting, continuing, and stopping dialysis.
- ESRD patients live only about one-third as long as age-matched patients without kidney disease.
- A time-limited trial of dialysis is recommended for AKI and ESRD patients for whom the benefits of dialysis are uncertain.
- Patients 75 years of age or older with advanced CKD and multiple comorbidities may not live any longer with dialysis than without it.
- Comprehensive conservative care is an option for advanced CKD patients who choose not to start dialysis and prefer treatment to optimize their comfort and avoid that which would entail a medicalization of their death—tests, procedures, and hospitalizations.



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Dialysis professionals report significant unmet supportive care needs and barriers in their centers with only a small minority rating themselves as competently providing supportive care. Most were unaware of already available evidence-based resources to help with supportive care for their patients.

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An international group of multidisciplinary experts in chronic kidney disease, supportive care, methodology, economics, and education identified the key issues related to the provision of supportive care in this population and agreed on a roadmap for improving kidney supportive care.

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Most older adults initiate chronic dialysis in the hospital. Compared with patients who initiated dialysis in the outpatient setting, those who received the highest intensity of care at dialysis initiation (those hospitalized two weeks and/or more and receiving at least one intensive procedure) had a shorter median survival, spent a greater percentage of remaining follow-up time in the hospital, were more likely to undergo subsequent intensive procedures (mechanical

ventilation, feeding tube insertion, and/or cardiopulmonary resuscitation), and were less likely to have discontinued dialysis before death.

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This clinical practice guideline presents recommendations and the evidence supporting them for shared decision making in decisions to withhold, initiate, continue, and stop dialysis. It recommends providing patients with patient-specific estimates of prognosis to aid the process of informed consent, reviews the literature on key prognostic markers for ESRD patients, and identifies the older patient population with comorbidities who may not experience a survival benefit from dialysis.

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This retrospective review of the deaths of 57,753 patients in the Veterans Affairs health care system found that ESRD patients had the greatest comorbid disease burden and received significantly worse overall family reported quality of end-of-life care ratings compared with patients with cancer or dementia. ESRD patients were much more likely to receive intensive medical treatments at the end of life and much less likely to be admitted to inpatient hospice units. Significantly fewer ESRD patients received palliative care consultation than patients with cancer and dementia, and when the ESRD patient family reported overall quality of end-of-life care was adjusted for palliative care consultation, there was no longer a difference in their families' ratings of their quality of end-of-life care compared with those from families of cancer and dementia patients.

# A Framework to Improve Surgeon Communication in High-Stakes Surgical Decisions

## Best Case/Worst Case

Lauren J. Taylor, MD; Michael J. Nabozny, MD; Nicole M. Steffens, MPH; Jennifer L. Tucholka, BS; Karen J. Brasel, MD, MPH; Sara K. Johnson, MD; Amy Zelenski, PhD; Paul J. Rathouz, PhD; Qianqian Zhao, MS; Kristine L. Kwekkeboom, RN, PhD; Toby C. Campbell, MD, MSc; Margaret L. Schwarze, MD, MPP

**IMPORTANCE** Although many older adults prefer to avoid burdensome interventions with limited ability to preserve their functional status, aggressive treatments, including surgery, are common near the end of life. Shared decision making is critical to achieve value-concordant treatment decisions and minimize unwanted care. However, communication in the acute inpatient setting is challenging.

**OBJECTIVE** To evaluate the proof of concept of an intervention to teach surgeons to use the Best Case/Worst Case framework as a strategy to change surgeon communication and promote shared decision making during high-stakes surgical decisions.

**DESIGN, SETTING, AND PARTICIPANTS** Our prospective pre-post study was conducted from June 2014 to August 2015, and data were analyzed using a mixed methods approach. The data were drawn from decision-making conversations between 32 older inpatients with an acute nonemergent surgical problem, 30 family members, and 25 surgeons at 1 tertiary care hospital in Madison, Wisconsin.

**INTERVENTIONS** A 2-hour training session to teach each study-enrolled surgeon to use the Best Case/Worst Case communication framework.

**MAIN OUTCOMES AND MEASURES** We scored conversation transcripts using OPTION 5, an observer measure of shared decision making, and used qualitative content analysis to characterize patterns in conversation structure, description of outcomes, and deliberation over treatment alternatives.

**RESULTS** The study participants were patients aged 68 to 95 years ( $n = 32$ ), 44% of whom had 5 or more comorbid conditions; family members of patients ( $n = 30$ ); and surgeons ( $n = 17$ ). The median OPTION 5 score improved from 41 preintervention (interquartile range, 26-66) to 74 after Best Case/Worst Case training (interquartile range, 60-81). Before training, surgeons described the patient's problem in conjunction with an operative solution, directed deliberation over options, listed discrete procedural risks, and did not integrate preferences into a treatment recommendation. After training, surgeons using Best Case/Worst Case clearly presented a choice between treatments, described a range of postoperative trajectories including functional decline, and involved patients and families in deliberation.

**CONCLUSIONS AND RELEVANCE** Using the Best Case/Worst Case framework changed surgeon communication by shifting the focus of decision-making conversations from an isolated surgical problem to a discussion about treatment alternatives and outcomes. This intervention can help surgeons structure challenging conversations to promote shared decision making in the acute setting.

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← Invited Commentary

+ Supplemental content

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For frail older adults, acute surgical problems often have life-altering effects. Serious complications are common<sup>1-4</sup>; 20% of patients aged older than 65 years who undergo urgent or emergent abdominal surgery die within 30 days,<sup>5</sup> and those who survive often lose their independence.<sup>6,7</sup> Despite this grim trajectory, nearly one-third of Medicare beneficiaries have an operation during their last year of life.<sup>8</sup> These procedures may be inconsistent with patients' long-term goals, as most Americans prefer to avoid onerous treatments with limited capacity to preserve their functional status.<sup>9,10</sup>

Best-practice guidelines endorse shared decision making (SDM) in the context of serious illness to present options, engage patients in deliberation about treatment outcomes, and integrate patient preferences into a recommendation.<sup>11-13</sup> However, describing a complex and often uncertain prognosis is a formidable task. In accordance with informed consent, surgeons traditionally rely on disclosure of discrete procedural complications<sup>14</sup> aided by robust risk calculators.<sup>15,16</sup> Nonetheless, enumerating a 20% chance of stroke or a 25% risk of renal failure does not allow patients to consider how they might experience adverse outcomes or encourage deliberation to ensure decisions align with individual preferences.<sup>14,17,18</sup> Furthermore, efforts to assist patients and families are hindered by the acute nature of surgical illness and lack of preexisting patient-doctor relationships.<sup>12</sup>

Scenario planning is a strategy to facilitate decision making in the setting of uncertainty. A well-constructed scenario encourages people to comprehend a new, previously unimaginable reality and prepare for major shifts in a way simple forecasting cannot.<sup>19-21</sup> This approach may be useful for older patients because acute surgical conditions portend a major health change compounded by prognostic uncertainty.

Building on the practice of scenario planning<sup>19,20</sup> and a conceptual model of SDM,<sup>22,23</sup> we designed the Best Case/Worst Case (BC/WC) framework as a strategy to change how surgeons communicate with patients about serious illness.<sup>24-26</sup> Best Case/Worst Case combines narrative description and a handwritten graphic aid to illustrate choice between treatments and engage patients and families. Surgeons use stories to describe how patients might experience a range of possible outcomes in the best case, worst case, and most likely scenarios (Figure 1). We hypothesize that training surgeons to use BC/WC will promote SDM during preoperative communication in high-stakes surgical decisions.

## Methods

From July 2014 until August 2015, we performed a prospective, pre-post pilot study to evaluate the proof of concept of an intervention training surgeons to use the BC/WC framework at a tertiary care hospital in Madison, Wisconsin. The University of Wisconsin institutional review board approved this study and participants gave written informed consent. Surgeons were compensated \$245 for completing the training session, and all other study participants were not compensated.

## Key Points

**Question** Does an intervention to train surgeons to use the Best Case/Worst Case framework change surgeon communication and promote shared decision making for high-stakes surgical decisions?

**Findings** In this pre- and postintervention study that included 32 frail older inpatients with acute surgical problems, objective measures of shared decision making improved postintervention. Surgeons who used Best Case/Worst Case emphasized a treatment choice, described outcomes rather than discrete procedural risks, and involved patients and families in deliberation.

**Meaning** Use of the Best Case/Worst Case framework can promote shared decision making, and this intervention may help surgeons structure challenging treatment conversations to support patients and families.

## Participants

Study staff screened inpatient rosters to identify patients aged 65 years and older with acute, nonemergent surgical problems and confirmed the surgeon would offer surgery and an alternative treatment. Eligible patients met 1 of the following criteria: a Porock frailty score<sup>27</sup> of 21 or more, a more than 40% risk for serious complication or more than 8% risk for perioperative mortality using the American College of Surgeons risk calculator,<sup>28</sup> or indication from the surgeon that comorbidities would affect long-term outcomes. We also recruited 1 family member present during the decision-making conversation. Patients without decision-making capacity were enrolled with consent from their surrogate. We excluded deaf or non-English speaking individuals and patients with an emergent indication for surgery—such as ruptured aneurysm or perforated viscus—as these patients are typically rushed to the operating room with little time for shared decision making.

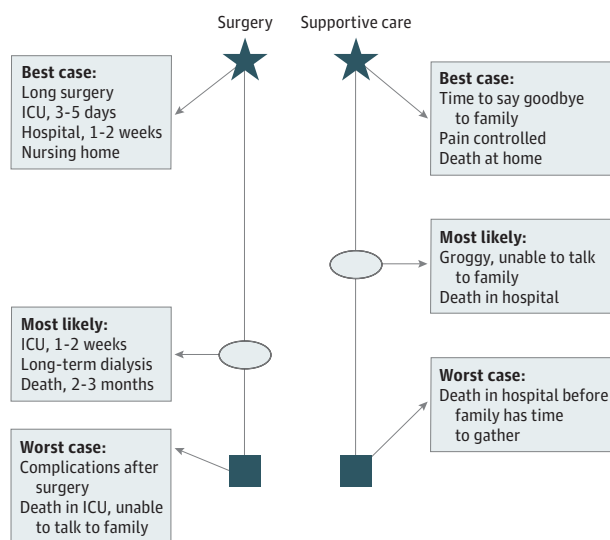
## Intervention

Excepting the senior author, we invited all 30 surgeons at the University of Wisconsin Hospital who practice cardiothoracic, vascular, or acute care surgery to participate. Surgeons completed a 2-hour training session to learn the BC/WC framework using simulation with standardized patients and 1-on-1 coaching with an expert in palliative care and education (S.K.J., A.Z., and T.C.C.). Postintervention, surgeons used BC/WC with study-enrolled inpatients. Details of surgeon training are reported elsewhere<sup>29</sup> and training materials are available online (<http://www.hipxchange.org/BCWC>).

## Data Collection

We recorded demographics, presenting diagnosis, operations performed, intensive care admissions, palliative care consultations, discharge disposition, and death within 30 days. We audio-recorded and transcribed verbatim the primary surgeon-patient decision-making conversation for each patient enrolled pre- and postintervention and archived copies of the graphic aid for patients enrolled after the surgeon completed BC/WC training.

Figure 1. Best Case/Worst Case Graphic Aid



Example of a Best Case/Worst Case graphic aid that the surgeon would create and use during a decision-making discussion for an older patient with a serious surgical problem. The box represents the worst case scenario, the star represents the best case scenario, and the oval indicates the most likely outcome. ICU indicates intensive care unit.

### Data Analysis

OPTION 5 is an observer measure of shared decision making based on a 100 point scale.<sup>30</sup> Originally developed for primary care consultations, this validated instrument permits quantitative measurement of the physician's effort to include patients in decision making. We calibrated this measure to the surgical setting within 5 domains: presentation of treatment options, surgeon-patient partnership, description of treatments, elicitation of preferences, and integration of preferences with a recommendation (eAppendix in the [Supplement](#)). Four investigators (L.J.T., J.L.T., K.J.B., and M.L.S.) independently scored each transcript. We summarized quantitative data using descriptive statistics and calculated intraclass correlation (ICC) between the 4 raters using the "psych" package in R version 3.2.1 (R Foundation for Statistical Computing), assuming raters were a random sample from the population of raters (ICC: 2, k).<sup>31,32</sup> We also computed ICC to quantify the reliability expected in a new set of 2 raters.

After OPTION 5 scoring, investigators independently analyzed all preintervention and postintervention transcripts using qualitative content analysis. We used an inductive coding strategy to generate and attach codes to the data to catalog themes, constructs and occurrences, and a group process with code adjudication as a gateway to higher-level analysis. We also employed a deductive strategy to compare pre- and postintervention transcripts by examining conversation content within the domains of OPTION 5. This approach served as an additional opportunity to ensure the rigor of our inductive analysis and pinpoint disconfirming data. We drafted construct tables to ensure that the themes were accurately represented in the data and used qualitative research software, NVivo 10 (QSR International), to organize codes and support theme comparison.

## Results

Twenty-five surgeons completed the BC/WC training; 1 declined participation and 4 were unable to attend a session after multiple scheduling attempts. Seventeen of these trained surgeons led a decision-making conversation with study-enrolled patients. We approached 53 patients; 32 patients and 30 family members enrolled. Surgical problems ranged from intestinal obstruction to critical limb ischemia ([Table 1](#)). Alternative treatments included antibiotics, less-invasive procedures including feeding tubes or drain placement, or simply "no surgery." Postintervention, all surgeons offered at least 2 options and used BC/WC to present best and worst case scenarios; 1 did not construct the graphic aid and 1 failed to describe the most likely scenarios. We lost the data for 1 conversation because of a technical failure.

### Assessment of Shared Decision Making

The median OPTION 5 score improved from 41 preintervention (interquartile range, 26-66) to 74 (interquartile range, 60-81) after training ([Figure 2](#)). The intraclass correlation was 0.80 (95% CI, 0.64-0.90) for the mean score across 4 raters. Assuming scores were generated as the average of 2 raters, the estimated ICC was 0.67 (95% CI, 0.48-0.81).

Our qualitative analysis reinforced these findings. Our deductive analysis demonstrated a postintervention difference in communication content for each OPTION 5 domain ([Table 2](#)), and our inductive analysis revealed a shift in how surgeons structured conversations according to 3 primary elements: presentation of treatment options, description of treatments, and deliberation over alternatives ([Figure 3](#)). Before the surgeons underwent training, conversations with patients began with an explanation of the problem and an operative solution followed by a surgeon-led deliberation about the patient's candidacy for surgery. Postintervention, the discussion focused on making a treatment decision within the context of the patient's overall health. Surgeons described outcomes rather than risks, and sought to clarify patient values and goals, using this information during deliberation to revise treatment options to match preferences.

### Presentation of Options: Preintervention

Before training, surgeons universally initiated conversations with detailed explanations of the disease process, linking the acute illnesses to a surgical solution. Surgeons introduced illness as something that required action, for example, "The problem is a mechanical problem, so now something needs to be done here to solve the problem." To illustrate how surgery could remedy an abnormality, surgeons explained the disease using language like "blockage" or "narrowing" coupled with an intervention to "bypass" or "widen."

While all surgeons offered a choice, framing diseases as deviations from normal undermined the value of nonoperative treatment because surgery was initially described as the solution. One surgeon explained, "the choice to help you fix that and avoid that outcome [death], it's obviously another surgery" without conceding that surgery could also result in death.



Table 1. Description of Patient Characteristics

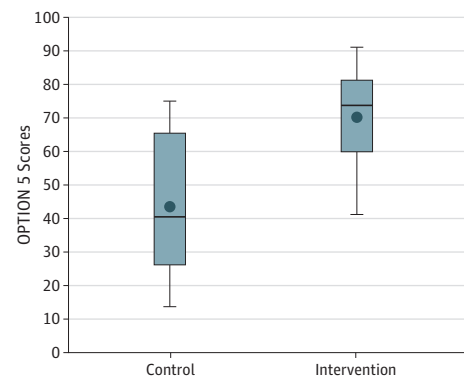
Characteristic	Control (n=12)	Intervention (n=20)
Age, median (range)	78.5 (68-88)	86.5 (67-95)
Male, No. (%)	9 (75)	7 (35)
White, No. (%)	12 (100)	19 (95)
Comorbid conditions, No. (%)		
0 to ≤2	2 (17)	7 (35)
>2 to ≤4	1 (8)	8 (40)
≥5	9 (75)	5 (25)
Patients without decision making capacity, No. (%)	0	5 (20)
Education, No. (%)		
Some high school or less	0 (0)	2 (10)
High school diploma or GED	4 (33)	7 (35)
Vocational degree or some college	1 (8)	2 (10)
College degree	5 (42)	1 (5)
Graduate degree or higher	1 (8)	2 (10)
Unknown	1 (8)	6 (30)
Proposed surgical treatment, No. (%)		
General surgery	5 (42)	16 (80)
Bowel resection	4	11
Cholecystectomy	1	2
Nonemergent surgery for trauma <sup>a</sup>	0	2
Paraesophageal hernia repair	0	1
Cardiothoracic	5 (42)	1 (5)
Pleurodesis	1	0
Esophagectomy	1	0
Cardiac valve replacement/repair	2	1
Coronary artery bypass grafting	1	0
Vascular	2 (16)	3 (15)
Vascular bypass	2	2
Amputation	0	1
Received proposed surgery, No. (%)	5 (42)	10 (50)
ICU admission within 30 d, No. (%)	2 (16)	3 (15)
Palliative care consult or hospice admission within 30 d, No. (%)	4 (33)	6 (30)
Discharge disposition, No. (%)		
Home	6 (50)	4 (20)
Assisted living	0 (0)	1 (5)
Skilled nursing facility	3 (25)	9 (45)
Hospice	2 (17)	1 (5)
Death in hospital within 30 d of treatment	1 (8)	5 (25)

Abbreviations: GED, general education development; ICU, intensive care unit.

<sup>a</sup>Hip hemiarthroplasty and tracheostomy for patients admitted to the trauma service following a fall and motor vehicle collision, respectively.

To describe alternatives, surgeons favored “no surgery” or “medical management” without explicitly offering palliative care or hospice. Some surgeons did not offer any nonoperative treatment, asking patients to choose between surgery now or surgery in the future. A few emphasized valid alternatives and aimed to promote value-concordant decisions, for example, “I wanted to come and talk to you guys about different options because I think neither of them is wrong... we need to know what you think would be best for him.”

Figure 2. OPTION 5 Scores



Box plots depicting OPTION 5 scores for patients in the control and intervention arms. Dot indicates mean score within each treatment arm.

### Description of Treatments: Preintervention

Surgeons candidly disclosed discrete procedural risks like “a risk of stroke to the brain and also pneumonia because we have to put the [breathing] tube in,” noting that some complications necessitated further procedures, for example, “water may accumulate in the chest, then we may need to put the needle and remove the water.” Some used percentages to quantify the likelihood of adverse events such as “the risk of re-intubation is... 7 to 8 percent” and referenced patient age, comorbidities, and past operations to support their overall risk assessment.

Surgeons acknowledged treatment impact on quality of life, noting that “complications...may keep him in the hospital for a while and have significant impact on his life.” However, they did not integrate comorbidities or functional status within a description of how patients might experience adverse outcomes, whether patients could live independently or enjoy specific activities. Rather than describing how death might occur, some used overt statements like “there is risk of death with esophagectomy,” while others favored using euphemism to suggest postoperative mortality, for example, “Chances of having something come up that we can’t get over and get you out of the hospital are... fairly possible.”

### Deliberation: Preintervention

Surgeons cited physical examination findings and physiologic signs like leukocytosis or tachycardia as cause to reject nonoperative options. One surgeon explained, “If your abdominal exam gets much worse...we’re finished. We go to the operating room.” Surgeons rationalized decisions based on patient eligibility, discussing comorbidities, overall functional status, and preoperative testing to justify specific treatments. Others described surgery as a “big deal,” placing onus on the patient with questions like “the decision you have to make is...what you’re willing to go through to sort of get better or not” to evaluate whether the patient had the “mental drive and the willingness to live” to tolerate the burdens of surgery and postoperative care.

Few surgeons engaged in more explicit discussions of goals and values, favoring generalized statements like “Some people

Table 2. Results of Deductive Coding Analysis Demonstrating the Contrast Between Content of Pre- and Postintervention Conversations Based on the Domains of OPTION 5

OPTION 5 Domain	Preintervention Observations	Representative Quotations	Postintervention Observations	Representative Quotations
Presentation of options	<ul style="list-style-type: none"> <li>• Surgeon described the acute problem with a surgical solution</li> <li>• Surgeon described the nonoperative alternative as secondary</li> </ul>	<p>"To get that opened up, we need surgery."</p> <p>"If we do not do the procedure and the focus becomes on comfortable care, then obviously that ...will not take care of your heart [valve] problem."</p>	<ul style="list-style-type: none"> <li>• Surgeon called attention to a clear treatment choice</li> <li>• Surgeon presented the nonoperative option as a valid choice</li> </ul>	<p>"We have a choice to make..."</p> <p>"The other option is to take him home and make him comfortable and not to have the surgical procedure."</p>
Surgeon-patient partnership	<ul style="list-style-type: none"> <li>• Surgeon supported patient as decision maker</li> <li>• Surgeon provided information to assist decision making but decision left up to the patient</li> </ul>	<p>"It's your decision, so it's the right decision."</p> <p>"... to give you the most information that you can have to make the decision for yourself."</p>	<ul style="list-style-type: none"> <li>• Surgeon provided explicit support and offered guidance to the patient and family in deliberation</li> </ul>	<p>"...[I'm] try[ing] to relate to what your choices are...but also I think to guide you."</p>
Treatment description	<ul style="list-style-type: none"> <li>• Surgeon described isolated risks using probabilities to convey likelihood of adverse events</li> <li>• Surgeon described death as a risk of surgery</li> </ul>	<p>"Those risks are bleeding, um, infection in the area we operate, damaging the liver...damaging the intestines around in that area."</p> <p>"Expected mortality rate is in between 5 and 10 percent"</p>	<ul style="list-style-type: none"> <li>• Surgeon used stories to describe treatment outcomes</li> <li>• Surgeon incorporated the patient's chronic health problems and frailty</li> <li>• Surgeon described death as an outcome of treatment rather than a risk</li> </ul>	<p>"Under the best of circumstances, that would involve being in the hospital for probably a week maybe two...because of your age and the heart problems...that might involve being in the intensive care unit."</p> <p>"Worst case scenario we pull the breathing tube...you're struggling with coughing and secretions that you have, you, your ribs hurt...and you pass away fairly quickly."</p>
Preference elicitation	<ul style="list-style-type: none"> <li>• Surgeon assessed for understanding</li> <li>• Surgeon requested a treatment decision</li> <li>• Surgeon queried if patient was willing to tolerate the burdens of treatment</li> </ul>	<p>"Do you have any questions?"</p> <p>"What do you think you'd be interested in?"</p> <p>"The decision you have to make is...what you're willing to do given what this is."</p>	<ul style="list-style-type: none"> <li>• Surgeon solicited information about the patient's appraisal of specific outcomes</li> </ul>	<p>"How are you thinking about the difference between walking and not walking, because to me that was the big difference between these 2 [choices]...And so I wonder if you could tell us how you think about that?"</p>
Preference integration	<ul style="list-style-type: none"> <li>• Surgeon encouraged the patient to choose</li> <li>• Surgeon made a recommendation based on operative risk or disease characteristics</li> </ul>	<p>"The choice is up to you."</p> <p>"After looking at the foot I'm inclined not to be doing more angioplasty... I'm leaning to you choosing the antibiotics and getting him off his foot right now."</p>	<ul style="list-style-type: none"> <li>• Surgeon made an effort to match patient preferences with treatment decisions</li> </ul>	<p>"But to really recover from this, and really have a reasonable outcome, you'd have to be aggressive, and not everyone wants that, and I'm not sure that you would want that."</p>

tell me they don't want an operation regardless" and queries like "Does that make sense?" to evaluate understanding. They did not personalize these assertions with elicitation and integration of the patient's goals with a course of action. After presenting options, surgeons noted, "it's up to you [to decide];" only 1 surgeon clearly reinforced partnership, referencing "the decision that you and I make."

### Presentation of Options: Postintervention

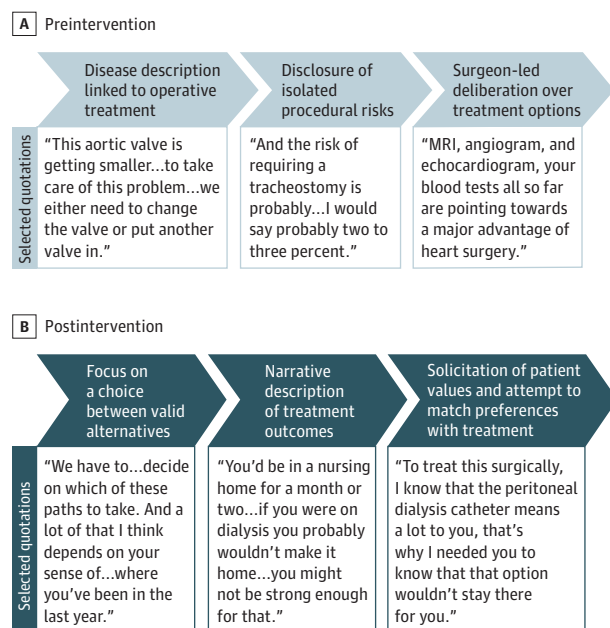
After their training, surgeons abbreviated description of the disease process and treatment and explicitly demonstrated a choice between surgery and a valid alternative, using the graphic aid to augment discussion. One surgeon stated, "We have a choice to make...I want to use this little diagram to...go through the choices." By presenting the decision as preference-sensitive, surgeons highlighted the importance of patient and family input because "either choice is reasonable given your sense of where this problem has hit you in your life." Surgeons integrated description of the proposed operation into their narrative about how patients might experience best and worst case scenarios, for example, "even under the best of circumstances that would be a big enough operation for you that even if you did great, you'd be in the hospital for another week, and it'd be a couple of months probably to get over this...it's certainly not going to make you any stronger than you were a month ago."

### Description of Treatments: Postintervention

Instead of discrete risks, surgeons discussed the expected hospital course, incorporated patients' unique comorbidities, and described anticipated functional decline. Surgeons explained complications by illustrating the worst case scenario involving a constellation of setbacks and burdensome interventions, for example, "Your breathing would get worse, you'd stay in the ICU with a breathing tube, we'd have to talk about feeding tubes... you'd still have that pain, and you still wouldn't be able to move around." Similarly, surgeons provided clear descriptions about how death might occur, for example, "You'd have complications from the surgery that wouldn't allow you to really get better. And you'd die in the intensive care unit or somewhere in the hospital...that wouldn't occur right away, but it might occur in a few weeks."

To convey prognostic uncertainty, surgeons positioned the most likely scenario between the boundaries of the best and worst case. Rather than using statistics, surgeons incorporated phrases like "I think it's more likely that we can get you through the thing than not, but it's kind of more in the middle than you might want" and referenced the graphic aid to illustrate the location of the most likely outcome. An example of this was, "If you look at where we are between best case and worst case, with nonsurgical treatment we're here. And with surgical treatment, we're somewhere in here."

Figure 3. Conversation Structure



Results of inductive coding analysis demonstrating the differences in communication patterns preintervention (A) and postintervention (B).

### Deliberation: Postintervention

Surgeons involved patients and families by explicitly asking them to evaluate plausible health trajectories because "different people in this moment could feel differently...how do you feel about that?" Surgeons requested input about specific outcomes, asking, for example, "if we do surgery you're likely going to a nursing facility, is that something you'd be ok with?" However, the ability to incorporate patient inclinations within a recommendation was mixed. Some revised options based on patient input, adjusting "no surgery" to hospice after sensing interest in a palliative strategy and aimed to match treatment choice with patient preferences, noting "...[I'm] try[ing] to relate to what your choices are...but also I think to guide you." Others provided less assistance, asking patients to decide independently. A few clearly integrated patient preferences within their recommendation, for example, "This is what I know about her...she didn't want a lot of these interventions...we're gonna do a maximum amount of those things if we decide to go for surgery...so...surgery where she ends up in a nursing home, with complications from surgery, is not something that she ever wanted."

## Discussion

We trained surgeons to use the BC/WC framework to discuss treatment options with frail older inpatients facing high-stakes surgical decisions. This intervention promoted SDM as measured by a combination of OPTION 5 and qualitative analysis whereby we observed a pronounced shift in conversation structure and content postintervention in 3 primary areas: pre-

sensation of options, description of treatments, and deliberation over alternatives. Surgeons who used BC/WC emphasized a difficult decision and presented 2 authentic options. Rather than disclosing isolated procedural risks, trained surgeons described how patients might experience treatments and asked them to evaluate outcomes based on personal goals. Nonetheless, surgeons' ability to integrate patient preferences into a recommendation varied.

The aim of the BC/WC framework is to clarify the limits of what is possible so patients and families can manage uncertainty and prepare for poor outcomes. Similar to corporate decision making, simple forecasting and risk prediction are only helpful in times of relative stability, when decision makers can assume that tomorrow will be similar to today.<sup>19,20</sup> Akin to conditions of economic volatility, assumptions of stability fail frail older patients and their families in the setting of acute illness. Thus, a well-designed scenario does not seek to predict the future. Rather, the goal is to explore a set of plausible futures and describe a path from the present to a longer-term outcome.<sup>33</sup> Scenarios improve decisions by allowing people to understand the interplay between elements<sup>34</sup>—an acute surgical problem and underlying frailty—and develop a new mental model. Within this new reality, patients can think strategically and make decisions based on what is most important to them. These observations have important implications for surgeons, patients, and families.

For surgeons, BC/WC provides a framework to promote SDM and clarify outcomes. Despite efforts to improve prognostication, studies suggest that surgeons' risk estimates are highly variable<sup>35,36</sup> and physicians are overly optimistic in communicating prognosis.<sup>37,38</sup> In part, this inconsistency stems from a lack of confidence in prognostic accuracy, particularly for long-term outcomes, and a desire to preserve hope.<sup>37,39</sup> Presenting a range of plausible scenarios within the boundaries of a best and worst case may mitigate concerns about delivering an inaccurate prediction and help define the limits of what is possible with surgery. Best Case/Worst Case allows surgeons to set expectations so patients can maintain hope for the best and prepare for the worst.<sup>40</sup> Furthermore, incorporating descriptions of the effect of surgery on overall quality of life can help surgeons preoperatively identify patients for whom even the best case surgical outcome is unacceptable.

For patients and families, BC/WC promotes a comparison of treatment outcomes and structures conversations so surgeons can learn what outcomes matter to them. While traditional models suggest desire for decision-making responsibility varies by individual and clinical scenario,<sup>41,42</sup> newer theories posit that most patients prefer to be involved but are unsure how to engage.<sup>43</sup> Best Case/Worst Case can help surgeons encourage patients to consider how they might value postoperative outcomes and avoid the perception that surgery is imperative. By presenting multiple scenarios, BC/WC supports the Lynn and DeGrazia<sup>44</sup> "outcomes model" of medical decision making in which the physician avoids the need to fix the physiologic abnormality<sup>45,46</sup> and elevates the validity of non-operative alternatives. Furthermore, visualizing scenarios may clarify important misunderstandings, for example, the



perception of the worst case as a painless death in the operating room<sup>47</sup> or assumptions about postoperative quality of life.

## Limitations

This study has strengths and limitations. Taken together, our mixed-methods approach suggests teaching surgeons to use BC/WC improves observer-rated SDM in the acute setting, but our small, single-center study was not powered to observe differences in OPTION 5 as a stand-alone measure. Because of significant challenges recruiting seriously ill older patients, we were unable to gather data from a postintervention conversation with all of the trained surgeons. Given space constraints, the formal analysis of our training program is reported elsewhere.<sup>29</sup> Although we demonstrated that our intervention can distinctly change how surgeons communicate in high-stakes discussions, we were unable to identify a measurable health outcome that would allow us to test whether this in-

tervention improves clinical outcomes beyond shared decision making. All patients in this study were old and frail, yet significant heterogeneity in patient preferences, surgical indication, and postoperative consequences makes defining the “right treatment choice” and the “good outcome” a formidable methodological challenge for this and future studies.

## Conclusions

Training surgeons to use the BC/WC framework promotes SDM for frail older patients with acute surgical problems. This intervention helps surgeons present treatment outcomes and engage patients and families in a conversation closer to best practice guidelines.<sup>12</sup> With this proof of concept, this intervention can be used to change surgeon behavior to support patients and families in difficult treatment decisions.

## ARTICLE INFORMATION

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## Notes on Best Case/Worst Case Communication Framework training

## Questions about Best Case/Worst Case?

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