Poll Everywhere Participation

SMS: Text CHRISTINERES715 to 22333 once to join

Web: pollev.com/christineres715

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Communication
Eyes
Paths
Wrong
Gatekeeper
Pressure
Right
Know
Time
Life
Support
Conflict
Suffer
Process
Directives
Reassurance
Decisions
Guessing
Directives
Quality

Complexities of Surrogate Decision Making Workshop

GREAT LAKES PALLIATIVE CARE CONFERENCE

MAY 4TH, 2023

1-4PM

Froedtert & MEDICAL COLLEGE of WISCONSIN

Who We Are

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What is your discipline?

Social Work/Case Management

Chaplain

Physician

Psychology

Registered Nurse

Advanced Practice Nurse

Physician Assistant

Other

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Where do you practice?

Wisconsin

Outside of Wisconsin

This workshop is an opportunity to use a case study-based approach to explore surrogate decision making.

We will review different types of healthcare agents, communication strategies for supporting surrogates faced with complex decisions, as well as approaches for the healthcare team to consider when working with surrogates.

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Schedule & Objectives

LAYING THE FOUNDATION:

- Assessing for incapacity
- Documents identifying legal surrogate decision makers
- What the surrogate decision maker role entails

CASE STUDY EXPLORATION:

- Deep dive in to the case-based study approach

Q&A

AT THE END OF THIS WORKSHOP OUR GOAL IS THAT THERE IS A GAINED UNDERSTANDING OF:

- Identify different types of surrogate decision makers and their role
- Discuss communication strategies that support surrogate decision makers
- Identify approaches for the healthcare team to consider in working with surrogate decision makers

WE HAVE NO FINANCIAL DISCLOSURES

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TAKE 5 MINUTES

Think about when you have worked with surrogate decision makers in your practice.

What did that process look like?
What worked well?
What were the challenges?

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Decision Making Assessment

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Capacity Evaluation

- Decision-making **capacity** is the ability to utilize information about an illness and proposed treatment options to make a choice that is congruent with one's own values and preferences
- **Competency** is a global assessment (financial and medical) and legal determination is made by a judge in a court of law (ie: Guardianship)

- 4 necessary elements to be included in a capacity assessment:
  - The ability to **express** a choice
  - The ability to **understand** the relevant information
  - The ability to **appreciate** a situation and its consequences
  - The ability to state **rationale** for choice

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True or false: In order to assess decision making capacity, you must consult a mental health professional (e.g. psychologist or psychiatrist).

True

False

Why evaluate your patient's capacity?

- Can give insight into:
  - the patient's understanding of the medical situation
  - cognitive function
  - values
- To make sure your patient can make a truly autonomous choice
- Promote quality communication
- For patient safety and protection from harm

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Autonomous Choices

General Characteristics

- Adequately informed
- Voluntary (not coerced)
- Based on reasoning

Ganzini *et al.* “Ten myths about decision-making capacity,” J Am Med Dir Assoc. 2004, 5(4):263-7

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Ethical Obligations
A Balancing Act

Autonomous choice

Patient's health and well being

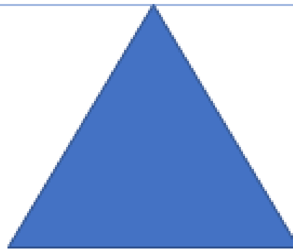

Image modified from Applebaum and Grisso

Appelbaum and Grisso, *Assessing Patient's Capacity to Consent to Treatment.* NEJM 1998.

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Assessing for Incapacity

Potential for harm	Patient refuses	Patient consents
Benefits outweigh risks	Higher “capacity” threshold	Lower capacity threshold
Risks outweigh benefits	Lower capacity threshold	Higher capacity threshold

Appelbaum and Grisso, *Assessing Patient’s Capacity to Consent to Treatment.* NEJM 1998.

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Betty

Betty is a 60 year old woman with cognitive impairment who lives independently and works at a grocery store. She is found to have uterine cancer and is in need of a hysterectomy.

Case courtesy of Jaime Konerman-Sease

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Betty does not have capacity because she is cognitively impaired

True

False

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Approach to Capacity Evaluation

Avoiding common pitfalls

1) Not a "one and done"
2) Patients can retain or lack capacity based on:
   - The complexity of the decision (e.g. consent to IV placement vs. consent to pacemaker placement)
   - Fluctuations in their cognitive function (e.g. delirium)
3) Should be evaluated:
   - at major decision points
   - when cognitive function is in question
   - periodically in routine care of terminally ill patients or patients with dementia.
4) Approach depends on the clinical decision – capacity for *what*?
5) Not just "gestalt"

Ganzini *et al.* "Ten myths about decision-making capacity," J Am Med Dir Assoc. 2004, 5(4):263-7

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Approach to Capacity Evaluation

Avoiding common pitfalls

6) Should be based on the patient's ability to work through a decision

- *Not based on clinical diagnosis or results of assessments (e.g. MOCA, SLUMS) alone*

7) Patients must demonstrate several basic cognitive and functional abilities and be able to apply their values

8) Appelbaum and Grisso outline four functional abilities required for decision making capacity

- Understand
- Appreciate
- Reason
- Express (a choice)

Appelbaum and Grisso, *Assessing Patient's Capacity to Consent to Treatment.* NEJM 1998.

Hamilton *et al*, *The U-ARE* protocol. J. Alzheimers dis. 2020

Approach to Capacity Evaluation

Tools

- “U ARE”
  - Understanding
    - Current medical situation and available options
  - Appreciation
    - Risks and benefits of different options
  - Reasoning
    - Provide rationale for choice
  - Expression
    - Communicate a choice
- Aid to Capacity Evaluation (ACE)
- Cognitive screening tests, assessment of capacity for everyday decision-making (ACED), vignettes of hypothetical scenarios, brief informed consent evaluation protocol (BICEP), & more…

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Aid to Capacity Evaluation (ACE)

- A semi-structured interview that assesses the four components of decision making capacity
- Takes 15-20 minutes to administer

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Aid To Capacity Evaluation (ACE) – Administration

Name of patient: ______________________________ Date: ______________

Record observations that support your score in each domain, including exact responses of the patient. Indicate your score for each domain with a check mark.

1. Able to understand medical problem

(Sample questions: What problem are you having now? What problem is bothering you most? Why are you in the hospital? Do you have (name problem)?)

Observations: ____

____

- ☐ **Yes**
- ☐ **Unsure**
- ☐ **No**

2. Able to understand proposed treatment

(Sample questions: What is the treatment for [your problem]? What else can we do to help you? Can you have [proposed treatment]?

Observations: ____

____

- ☐ **Yes**
- ☐ **Unsure**
- ☐ **No**

3. Able to understand alternative to proposed treatment (if any)

(Sample questions: Are there any other [treatments]? What other options do you have? Can you have [alternative treatment]?

Observations: ____

____

- ☐ **Yes**
- ☐ **Unsure**
- ☐ **No**
- ☐ **None Disclosed**

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4. **Able to understand option of refusing proposed treatment (including withholding or withdrawing proposed treatment)**
(Sample questions: Can you refuse [proposed treatment]? Can we stop [proposed treatment]?
Observations: ____

____

- ☐ **Yes**
- ☐ **Unsure**
- ☐ **No**

5. **Able to appreciate reasonably foreseeable consequences of accepting proposed treatment**
(Sample questions: What could happen to you if you have [proposed treatment]? Can [proposed treatment] cause problems/side effects? Can [proposed treatment] help you live longer?)
Observations: ____

____

- ☐ **Yes**
- ☐ **Unsure**
- ☐ **No**

6. **Able to appreciate reasonable foreseeable consequences of refusing proposed treatment (including withholding or withdrawing proposed treatment)**
(Sample questions: What could happen to you if you don't have [proposed treatment]? Could you get sicker/die if you don't have [proposed treatment]? What could happen if you have [alternative treatment]? *(If alternatives are available)*
Observations: ____

____

- ☐ **Yes**
- ☐ **Unsure**
- ☐ **No**

(Note: for questions 7a and 7b, a "yes" answer means the person's decision is affected by depression or psychosis)

7a. The person's decision is affected by depression

(Sample questions: Can you help me understand why you've decided to accept/refuse treatment? Do you feel that you're being punished? Do you think you're a bad person? Do you have any hope for the future? Do you deserve to be treated?)

Observations: ____

____

- ☐ **Yes**
- ☐ **Unsure**
- ☐ **No**

7b. The person's decision is affected by psychosis

(Sample questions: Can you help me understand why you've decided to accept/refuse treatment? Do you think anyone is trying to hurt/harm you? Do you trust your doctor/nurse?)

Observations: ____

____

- ☐ **Yes**
- ☐ **Unsure**
- ☐ **No**

Overall Impression

☐ **Definitely capable** ☐ **Probably capable** ☐ **Probably incapable** ☐ **Definitely incapable**

Comments:
(for example: need for psychiatric assessment, further disclosure and discussion with patient or consultation with family)

____

____

____

____

Limitations to the Standard Approaches to Decision Making Assessment

- Based on certain assumptions about decision making (e.g. deductive reasoning from values and preferences)
- Cultural differences
- Effect of low health literacy on decision making assessment?

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Capacity is one overarching question (all or none)

True

False

Cognitive impairment equals incapacity

True

False

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Mental illness alone means an individual does not have capacity

True

False

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Once someone is deemed incapacitated, they are always incapacitated

True

False

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Decision Makers & Documents

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Decision Makers

- Who is going to be involved in discussions and decision making?
  - Differences from state to state when there is no identified surrogate decision maker
    1. **WI is not a next of kin state.**
    2. **If states are identified as 'next of kin' for medical decision making there are still differences amongst them.**
  - When a valid document exists we involve those decision maker(s)

Documents that can legally appointment a surrogate decision maker

Side by Side Comparison for the state of WI

- 5 Wishes
  - Legally valid in 42 states
  - Designates surrogate decision maker(s)
  - Designates provisions with healthcare choices and admission to facilities
  - Sections where they must cross out anything that they do not agree with
  - Sections that they must check boxes that they do agree with
  - Specify treatment when:
    - Close to death
    - In a coma
    - Permanent and severe brain damage
  - 2 witnesses
  - 12 pages

- WI POAHC
  - Designates surrogate decision maker(s)
  - Designates provisions with healthcare choices and admission to facilities
  - Must check 'yes' or 'no' to feeding tubes, admission to nursing home and CBRF, and decisions when pregnant
  - 2 witnesses
  - 8 pages

- WI Living Will
  - NO surrogate decision maker(s) appointed
  - ONLY addresses feeding tube or life sustaining procedures in the event someone has a terminal illness or is in a persistent vegetative state
  - 2 witnesses
  - 2 pages

- Guardianship
  - Determined by a judge in a court of law
  - Designates decision maker of person (includes: health, property, finance)

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Sue is listed on Jim's POA document as his surrogate decision maker. They were divorced after Jim completed the document. Is Jim's POA document valid?

Yes

No

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Which carries more weight?

Living Will

Health Care Power of Attorney Document

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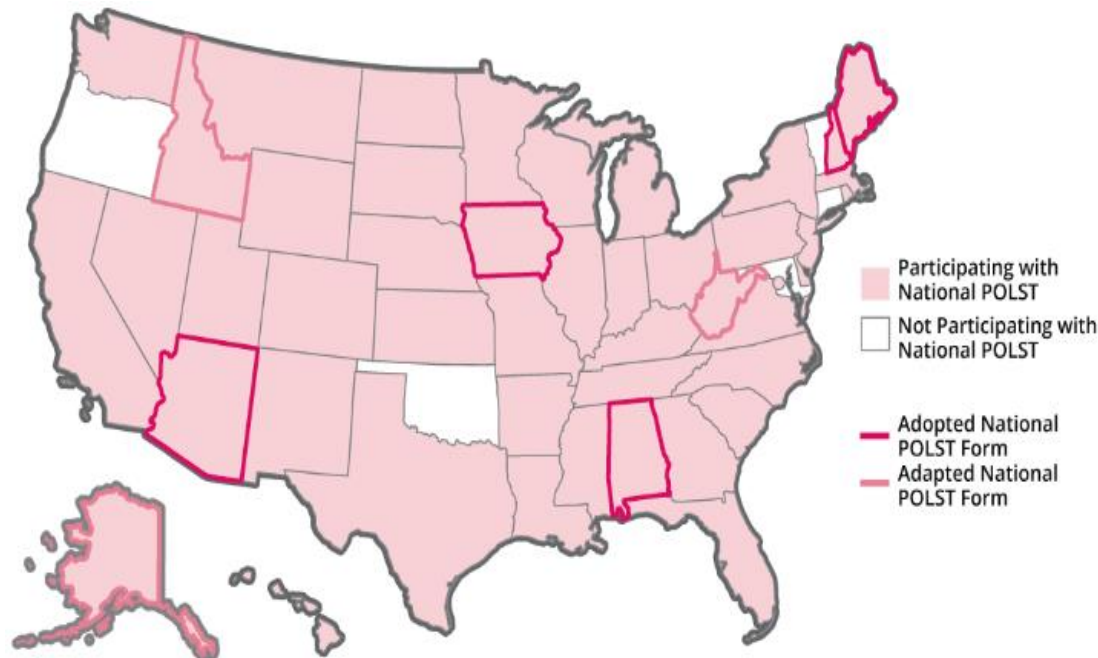
Other Considerations for Decision Making Standards

POLST: A medical order that tells emergency health care professionals what to do during a medical crisis where the patient cannot speak for him or herself.



www.polst.org

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Other Considerations for Decision Making Standards

VA

- Standard policies
  - Priority of Surrogates:
  - 1) Healthcare agent
  - 2) Legal Guardian
  - 3) Next of kin-spouse; child; parent; sibling; grandparent; grandchild.
  - 4) Close friend
- Once a pt leaves the VA, then state laws need to be followed
  - SNF/CBRF placement in WI would require a legal guardian if there was no healthcare directives in place

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Understanding the Surrogate Decision Maker Role

Role of the Surrogate Decision Maker

- Many adult patients, including most of those at end of life, cannot make their own treatment decisions

- Effects of treatment decision making on surrogates (Wendler & Rid, 2011)
  - 29 of the 40 articles reported surrogates experienced stress, anxiety, or other emotional burden as the result of making or helping to make treatment decisions for an incapacitated person
  - 1/3rd experienced negative emotional burden
  - Endorsed guilt about treatment decisions that need to be made
  - Stress symptoms consistent with a risk for the posttraumatic stress syndrome

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What are some words surrogates use to describe their experience?

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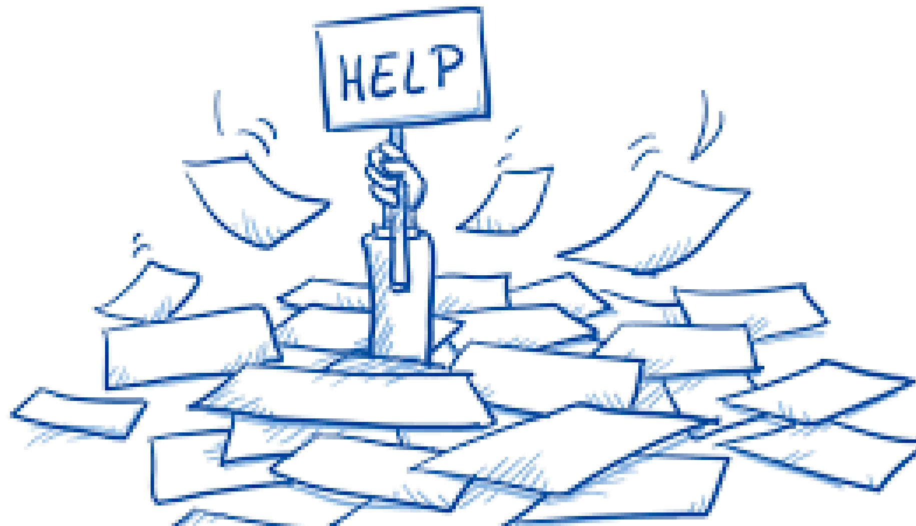
Standards of surrogate decision making

1. Pure Autonomy “Known Wishes” Standard
2. Substituted Judgement Standard
3. Best Interest Standard



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Substituted Judgement:
What would the patient have chosen?

- “They’re a fighter”
- “I’m not going to give up on them”
- “They have pulled through in the past”
- “They have been through worse and have surprised doctors”
- “They are the strongest person I know”

What are some others you have heard?

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Substituted Judgement:

Recommendations for the team

- When vague terms or statements are used, default to the patient's medical condition
- Vague medical discussions elicit vague values or preferences, ask specific questions
- Address the emotions
- Communicate with reframing
- Decision makers may get stuck on little details, open up the conversation to the big picture

Best Interest of the Patient:
What would a reasonable person do?

- Corporate guardians tend to default to this
    - Interpret this as doing all life-prolonging interventions
- Benefit> harm
- Disagreements increase when other facets of a patient's case increase
- Communication from the team to the surrogate decision maker may include any of the following to build trust:
    - Reinforcing that the team is always thinking of the patient's best interest
    - Acknowledgement that disagreements are okay
    - Make recommendations rather than asking "what should we do?"

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Themes of Surrogate Decision Maker Needs

- Struggling and reluctant
  - Responsibility/ duty, uncertainty, time pressure, unprepared, inadequate knowledge, fathering information
- Seek reassurance
  - Validation
- Communication with healthcare professional
  - Lack of understanding of medical terms, trust between professionals, lack of coordinated communication
- Family support
  - Family conflict, support from friends, family, faith
- Older adults' wishes
  - Recalling previous conversations/ memories, AD
- Negative Impact
  - Physical burden, fatigue, stress, guilt, grief, regret, sadness, anxiety, helpless, ambivalence

Bakke et al., 2022; Su, Yuki, & Hirayama 2019

Self-reported needs of surrogate decision makers

Bakke et al., 2022, Su, Yuki, & Hirayama 2019

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How can we help the surrogate?

Table 3. **Most Commonly Reported Stressors and Possible Ways to Mitigate Them**

Stressors	Possible Responses
Unsure of patient's preferences	Encourage previous discussion and advance directives
Uncertain prognosis	Difficult to address
Discomfort with hospital environment	Help to familiarize and adjust to environment
Logistics of making decisions	Evaluate and address challenges to decision making
Poor communication by clinicians	Establish a contact person, hold consistent meetings, and use clear language
Insufficient time	Prepare surrogates and give time to decide
Conflict with clinicians and family	Identify and address sources of conflict
Sense of sole responsibility	Share responsibility for decisions
Uncertainty or guilt over decisions	Support decisions and offer counseling

Wendler & Rid, 2011

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MCW Fast Facts #226
Helping Surrogates Make Decisions

- Bring in the patient’s voice
- Frame the decision around the treatment goal rather than focusing on specifics
- Don’t make the surrogate feel that they are taking full responsibility
- Make recommendations
- Acknowledge, legitimize, empathize and support emotional responses
- Use “I wish” statements to keep you in touch with the surrogate’s feelings, while simultaneously expressing medicines limitations
- Offer counseling services, grief support, etc.

Takeaways

- Substituted judgement can be used if there is a knowledge of the patient’s preferences
- Best Interest can be used when medical expertise is more so the guide
- Name the conflict! This can help to build trust.
  - “We see things differently and that’s ok”
- Conversations with surrogates are ongoing evolutions that take place over multiple encounters
- Surrogates are left with consequences of their choices and the emotional burden can last months, even years
- There is tremendous need for health care providers to provide support to family surrogates

MAY THE FOURTH BE WITH YOU

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Do you see what I see?

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Case Study #1
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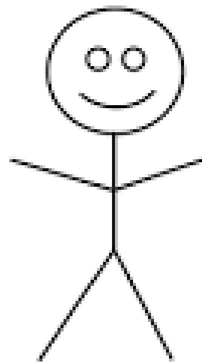
Case Study #1
Steve

Steve is a 44 y/o, single, Hispanic, male who has a history of metastatic, recurrent, penile SCC s/p partial penectomy and chemotherapy (after previously declining cancer-directed therapies). Patient has had numerous admissions for progression of disease, chemotherapy, pain, and recurrent DVTs.



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Case Study #1 Steve

Background Information

- **Social history:**
  - Grew up with his mother and stepfather
  - Estranged from biological father from a young age
  - Has a large family with excellent support from his mother, stepfather half sister, aunts, uncles, cousins
  - Divorced, no children
  - Worked for a warehouse for 10 months prior to taking medical leave
  - Grew up Catholic but does not consider himself to be religious
- **Psychological History:** Adjustment Disorder w/ depressed and anxious mood
- **Substance Use History:** Social drinker. Denies history of tobacco, marijuana, illicit drugs, opioid misuse.

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Case Study #1 Steve

History from Hospitalizations

- Refused to complete advanced directive and/or name POA until later admission
- Themes of admissions included: Frequent ICU stays, fluctuating mentation, activation and deactivation of POA, life prolonging goals
- Steve's last admission:
  - Admitted for altered mental status and septic shock
  - Told that there were no further treatment options
- Steve's most recent admission:
  - Overwhelmed
  - Slowed thoughts
  - Short responses or minimally engaged in conversations
  - Inconsistent refusal of cares

Case Study #1 Steve

Decisions to be Made

- Code Status
- Hospice:
  - At home
  - Residential
  - Inpatient

Family had a difficult time making a decision as they wanted to "do what Steve wants."

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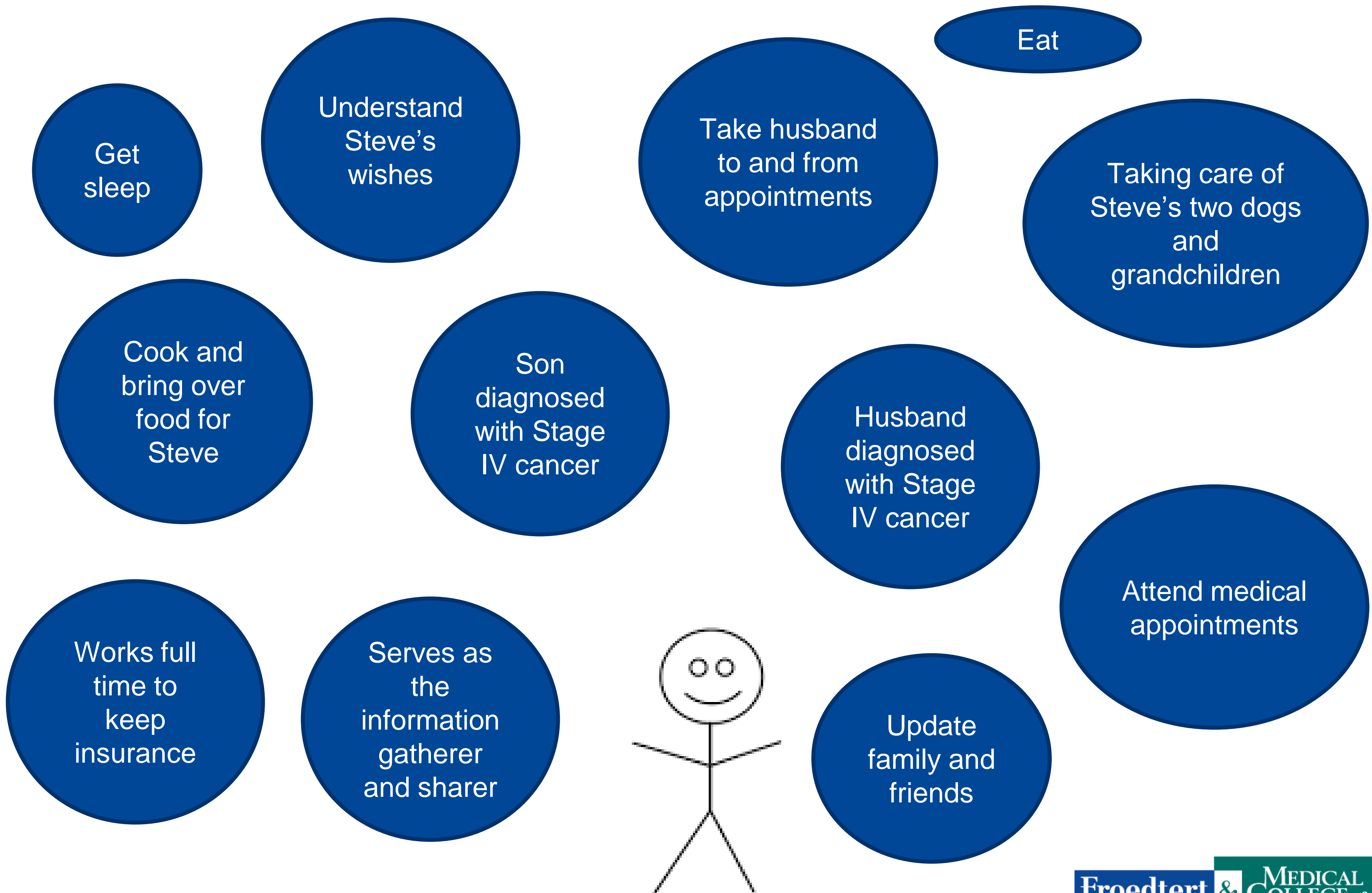
Lisa's Responsibilities



Case Study #1 Steve

Small Group Discussion Questions

1) How would you proceed?
    - Patient is activated, minimally involved in conversations, and becomes very overwhelmed when spoken to.
    - Family still deferring to patient.
2) Would you include Steve?
    - How do you best support him?
3) What questions would you pose to family to help them with decision making?
4) How do you best support the HCPoA, Lisa?

Case Study #1 Steve

Case Continues

- Continued conversations about code state and discharge planning
- Made daily visits to provide and offer support and update patient and family on medical status
- Allowed space for Steve to express his emotions and needs while simultaneously helping parse out what he has noted in the past to be important to him so that family could hear his values
- Steve ultimately shared that he wanted to be DNR/I with family present
- Family was initially supportive of his decision but were overwhelmed with the finality of their decision so they switched him back to Full Code
  - "We just want Steve to live"
- Family wanted to withhold pain and anxiety medications because he was lethargic and requested a sitter to help manage symptoms

So thus far…

- Patient activated but made statements confirming DNR/I
- Patient has a difficult time participating in family meetings and feels very overwhelmed
- Family also feeling overwhelmed because they have not had prior conversations regarding end of life planning
- Medical team has had numerous visits with patient and family regarding advanced care planning and have provided recommendations for DNR/I and transition to hospice
- Family frequently switching their decision (e.g., DNR/I → full code → DNR/I → full code)
- Ethics consulted for help with anticipatory issues that may evolve

Where do we go from here?

Case Study #1 Steve

A Note from the Clinical Ethicist

- Ethics was consulted for help with addressing potential conflict (if one were to arise) between the expressed treatment preferences of the patient and those of the healthcare agent.

<u>Ethics recommendations</u>

- Surrogate decision maker is obligated to make treatment choices that are consistent with the patient's known preferences.
- In this case, patient's preferences to be made DNR/DNI are clearly known and were explicitly stated by patient to the team and family.
- Given this information, we should follow his preference to be made DNR/I, even if the activated agent disagrees.

Case Study #1 Steve

Communication Strategies

“We want Steve to live.”

- Normalized and validated the sentiment while expressing similar hopes. “I also wish we were in a different spot.”
- Acknowledged and explored emotional response and grief
- Tied back to Steve’s expressed values (e.g., does not like hospitals, annoyed by labs and refusing cares, wants to be with family and dogs)
- Encourage family members to put Steve’s wishes in the forefront as often our own emotional distress and grief overrides patient’s wishes
- Lisa’s husband’s illness compounds her grief
  - Consulted a grief counselor
  - Allowed space for Lisa to process through her grief and how other stressors could be getting in the way of her decision making.

Case Study #1 Steve

Resolution

- Provided time and space to think about comfort cares and code status
- Patient started to decline and under urgent circumstances family decided to pursue comfort cares in the hospital
- Switched code status to DNR/I
- Steve died the following day with his mother at his bedside

Reflection Questions

Would you have approached this case differently?

What do you think impacted decision making for the HCPOA in this case?

What resources do you have at your institution to help support HCPOA's needs?

Case Study #2
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Case Study #2 Jean

Jean is a 71yo F with post-covid ILD on chronic O2, CKD, and HFpEF who was admitted to the hospital for fevers, dyspnea, and abdominal pain. She was found to have acute cholecystitis and sepsis.

Case #2 Jean, Continued

She was bacteremic with multiple organisms and was treated with broad spectrum antibiotics.

Surgery was consulted and was planning on inpatient cholecystectomy.

The night before her OR date she developed septic shock and worsening renal failure and was transferred to the medical ICU.

She was delirious from her overwhelming infection and renal failure, and the ICU team activated her HCPOA in order to obtain consent for central venous catheter placement for initiation of renal replacement therapy.

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Case Study #2 Jean

Healthcare Power of Attorney Background Information

The POA document lists:

- Primary Agent: Jean's husband.
  - He has moderate-severe dementia, lives in a SNF and has a surrogate decision maker.
- Alternate agent: Jean's daughter.
  - Jean cares for her and may have a degree of developmental delay.
  - The team calls her to obtain consent but note that communication is "difficult" due to a speech impediment.
  - The patient has brought up throughout the admission that the daughter is reliant on her, and she asks about how long she will be admitted because she is worried about the daughter being alone by herself.

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Case Study #2 Jean

A Note from the Clinical Ethicist

Clinical ethics service was consulted by ICU team due to their concerns about using the daughter as the Jean's surrogate:

Ethics recommendations

- We should assume that the patient's secondary agent (her daughter) has the capacity to make health care decisions for the patient, unless we have convincing reason to believe otherwise.
- Because Jean named her daughter as the person who is most likely to know her treatment preferences, we should trust Jean and attempt to respect her autonomous choice (to name her daughter as her surrogate)

Case Study #2 Jean

Discussion Questions

If the primary agent is not capable of making the decision, what is the appropriate next step?

If there are doubts about the agent's ability to act as surrogate, is it appropriate to assess their decision making capacity?

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Case Study #2 Jean

Communication Strategies

Approaching capacity evaluation in the setting of low literacy:

- Build rapport and describe decision to be made
- Present options with or without use of decision aids
- Elicit patient's preferences and values
- Clarify and/or confirm preferences and decision with the surrogate

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Side Note on Guardianship

- Guardianship: A legal mechanism through which a probate court appoints a surrogate decision maker for a person who has been determined by the court to be incompetent to make decisions.
  - Guardian of the person: makes decisions about healthcare, placement, support services
  - Guardian of the estate: makes decisions about property, money, signs contracts, etc
- Procedures for appointing a legal guardian for surrogate decision making vary from state to state.
  - Who can serve as legal guardian (per Wisconsin law)?
    - Court can appoint any adult, with few restrictions
    - Certain non-profit corporations can serve as guardian if they meet DHS requirements (only used if no suitable individual is available)
    - Can have co-guardians, two adults, who can divide responsibility or act jointly
    - Choice of individual must be based on the best interests of the person: Should be familiar with, or willing to become familiar with, the person's needs and situation, and should be in frequent contact with the person.

Side Note on Guardianship

- Legal preference to be appointed as a guardian is given to:
  - HCPOA (for guardian of the person), DPOA (for guardian of the estate)
  - Nominated by the person (if they are able to express a preference)
  - Parents (in the case of developmental disability or serious/permanent mental illness)
    - Or someone nominated in the will of the parent of the person
- Prior to court proceedings, notice must be given to all "interested persons"
  - Mostly family or anyone named in the person's POA documents (if they have them)
- Certifying physician's or psychologist's report:
  - Required prior to the guardianship hearing, and should be based on a recently performed examination
  - Documents the results (in detail) of your mental status examination and what your assessment of their capacity is for a variety of decisions

Corporate Guardians

Practical Tips

- There is heterogeneity among corporate guardians regarding what they are able to do regarding changes to plan of care. (e.g. policies about changing code status)
- They tend to default to the best interest standard, and interpret this to mean life prolonging medical interventions in most situations.
- Complicating factors: financial gain, little familiarity with the person in question in some cases

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Case Study #2 Jean

Case Resolution

- Consent was obtained for CVL placement using the daughter (alternate HCPOA) as the surrogate decision maker
- Delirium improved with treatment of underlying medical issues
- Was admitted to subacute rehab in a skilled nursing facility
  - POA was "deactivated" due to her improved mental status
  - It was recommended that she create a new HCPOA document

Case Study #3
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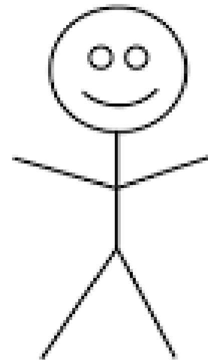
Case Study #3
James

James is a 72 year old with a medical history including mild neurocognitive impairment, chronic kidney disease stage IV, Type 2 diabetes mellitus, peripheral vascular disease, and combined chronic systolic and diastolic heart failure admitted from his assisted living facility with critical lab values indicating progression of his chronic kidney disease.



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Case Study #3 James

Consults

- The nephrology team was consulted and determined James had progressed to ESRD, recommend that James start hemodialysis.
- James provided inconsistent answers regarding whether or not he wanted to proceed with dialysis
- The palliative care team was consulted to explore James' goals of care and to facilitate decision making about dialysis.

Case Study #3 James

Palliative Care Consult

- The palliative care team determined that James had limited medical insight and did not pursue discussions about dialysis with James. A psychiatry consult was requested to determine if James had the ability to independently make medical decisions.
- The psychiatrist's evaluation found James to not have capacity for complex medical decisions, and Certificate of Incapacity was completed. James' sister Shirley is the sole agent on James' WI Health Care Power of Attorney document.
- The palliative team called Shirley and scheduled a meeting.

Case Study #3 James

Family Meeting

- Shirley was James' eldest sister. There were two other siblings in the family.
- Shirley was a retired teacher who continued to work part time as a substitute teacher
- She also took care of her grand kids several days per week.
- Shirley and James' elderly father was also hospitalized after he suffered a stroke
- Shirley described James as independent and self-reliant.   He never married, had no children, and only spoke when he had something important to say

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Case Study #3 James

Surrogate Background Information

- Shirley was unaware that James had appointed her as his health care power of attorney
- She had little knowledge about James' health as he had never talked about his health or medical problems. She was aware that he had diabetes and bad circulation
- Shirley felt unprepared to make James' medical decisions, particularly ones that may lead to James' death.

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Case Study #3 James

Case Continues

- The palliative care team reviewed James' recent medical history and current condition with Shirley. The decision point for dialysis was discussed.

- Shirley indicated she planned to ask James his thoughts on dialysis.

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Case study #3 James

Discussion Questions

- How would you counsel Shirley about her plan to talk to James?
- Is there sometimes a role to listen to the patient's voice even when they're deemed non-decisional?
- Have any of you included a non-decisional patient in goals of care discussions? What were your experiences?
- Is there a risk in eliciting treatment preferences from a non-decisional patient?

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Case Study #3 James

A note from the Clinical Ethicist

- Losing capacity does not mean losing autonomy.
- Consider whether the patient has capacity for preferences.
- Consider best interests vs current interests.

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Case Study #3 James

Surrogate Stress

- Shirley included their 2 other siblings in decision making. One of the siblings warned Shirley that if she didn't agree to dialysis, she would be killing James.
- Shirley stated, "I have a lot of eyes on me"
- Shirley decided to proceed with dialysis.

How would you support Shirley at this juncture?

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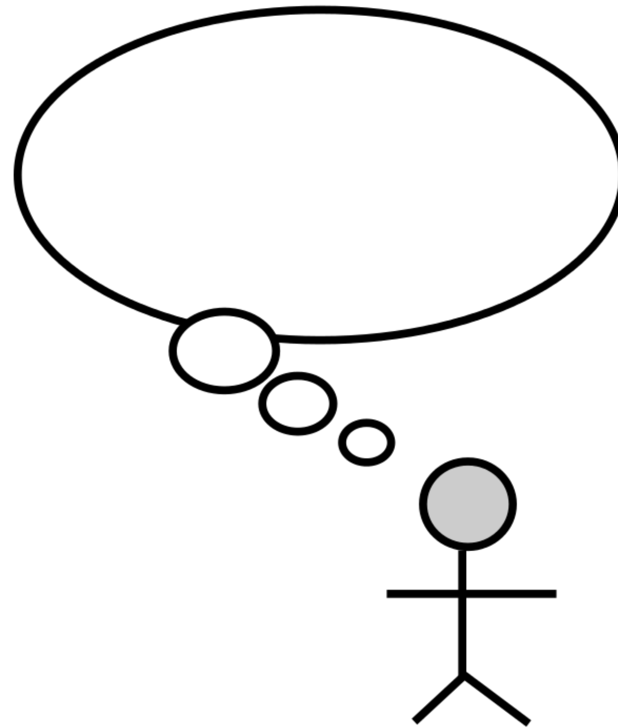
What we think surrogate decision makers thoughts are like…



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What surrogate decision maker thoughts likely look like!

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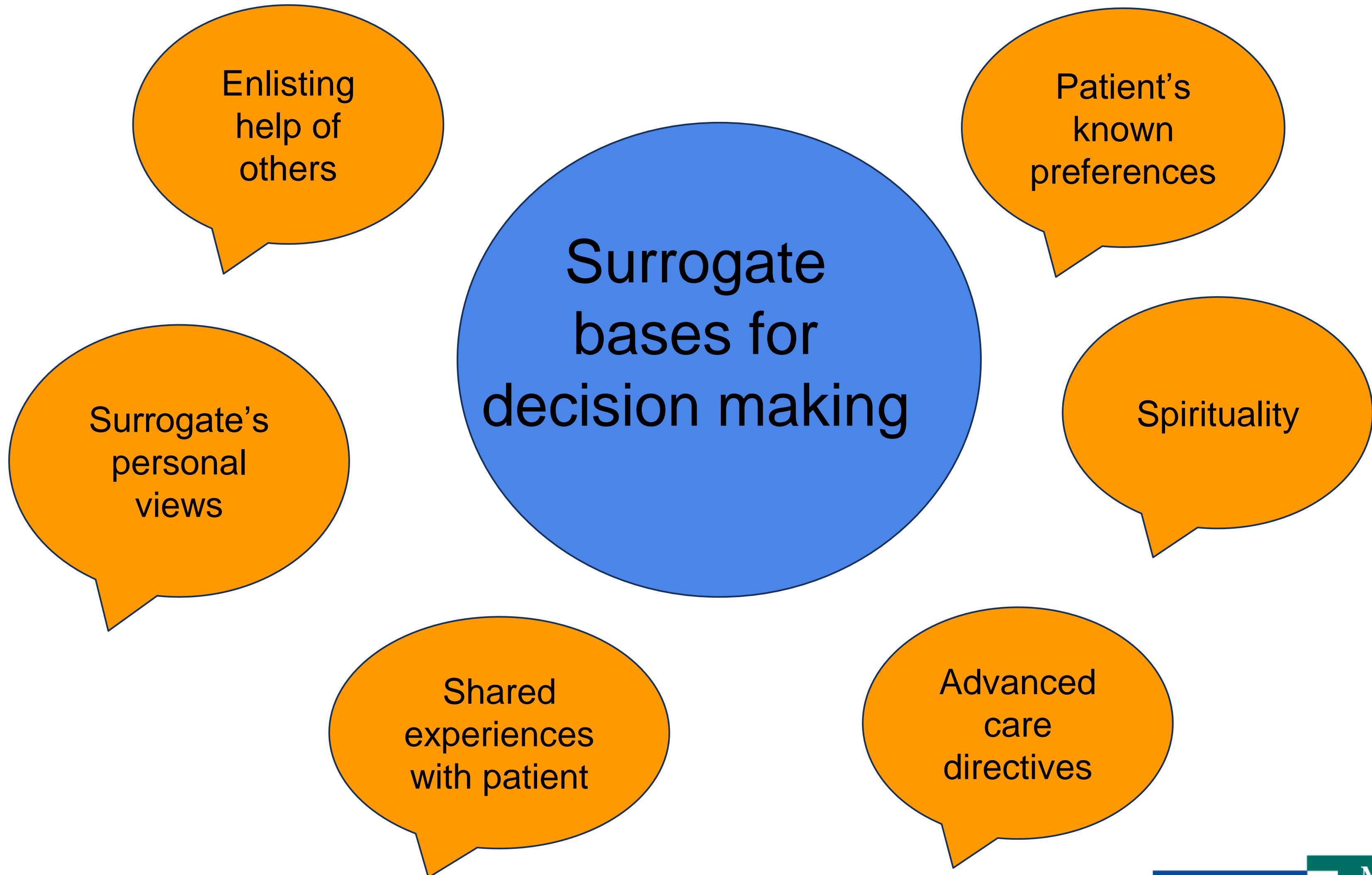
Sources surrogates use when making decisions

More than substituted judgement or best interest



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Case Study #3 James

Case Continues

- Dialysis access line was placed which James tolerated well.
- During his first hemodialysis session, James was anxious, unable to sit still, and became agitated. He attempted to pull at his line and climb out of the chair repeatedly, restraints had to be applied. Because of James' intolerance, the dialysis treatment was stopped after 10 minutes
- Shirley was updated of James' behavioral response during dialysis. She indicated that the team needed to keep trying to administer dialysis.

Case Study #3 James

Case Continues

- After another unsuccessful attempt at dialysis, the nephrology attending on service changed. The new nephrology attending happened to be James' outpatient nephrologist.
- He stated that he and James had several discussions regarding his potential need for dialysis in the future, and James had always been clear that he would not want to pursue dialysis if it came to that and had good understanding not pursuing dialysis would mean he would die.
- This information was shared with Shirley. However, Shirley continued to endorse dialysis.

Case Study #3 James

Discussion Questions

- Surrogate is desiring treatment that is difficult for the patient to tolerate
- Surrogate goes against a patient's previously expressed wishes

How would you navigate next steps?

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Case Study #3 James

A note from the Clinical Ethicist

- Consider the practical aspects of forcing treatment over a non-decisional patient's expressed preferences.
- A surrogate is obligated to suppress his or her own judgment in favor of 'channeling' what the patient would have done. The surrogate *must make the medical choice that the patient would have made and not one that the surrogate might make for himself or herself.*
- Practical suggestions for working with surrogates include:
  - Give them time to understand and accept new circumstances
  - Set "time limited trials" on particular interventions (with clear goals)
  - Consider ethnic and cultural issues
  - Negotiate intractable disputes

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Case Study #3 James

Case Resolution

- Family meeting was held with Shirley, their siblings, and the multidisciplinary team including patient's outpatient nephrologist.
- Shirley appreciated hearing from the nephrologist regarding his prior conversations with James
- Upon further goals of care discussion, Shirley decides to focus on a comfort only plan of with hospice support and to stop dialysis.

Reflection Questions

What do you think impacted decision making for the HCPOA in this case?

Would you have approached this case differently?

Take 5

What are your own personal take away points?

Takeaways

DECISIONALITY:

- Capacity is decision specific.
- Competency is global.
- Assessing capacity is not only for psychologists or psychiatrists.
- There are many tools to choose from to help inform a capacity assessment.
- 4 main tenants an individual must display for capacity:
  - Understanding
  - Appreciation
  - Reasoning
  - Expression

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Takeaways

COMMUNICATING WITH A SURROGATE:

- Provide transparency whenever possible with regards to prognosis, risks, medically appropriate or inappropriate interventions.
- Acknowledge that there can be disagreements.
- Identify the burdens of the surrogate decision maker role.
- Provide reframing when able to do so and appropriate.
- Corporate guardians often have specific guardrails in which to operate with decision making.

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Takeaways

ETHICAL ASPECTS:

- Losing capacity does not mean losing autonomy.
- Even if a surrogate is involved, include the patient in decision making as much as possible.
- The surrogate has the right to authorize medically indicated treatment over a non-decisional patient, but this right should not be considered absolute.
- The care team should be in constant conversation with the surrogate and patient (to the extent possible) to balance the competing interests of patient autonomy, nonmaleficence, and respect for persons.

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Thank you!

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