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Truthful Prognostication: How to Talk to Patients about Devastating Diagnoses and End of Life

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OUTLINE

- Review the Ethical Principles involved with bad news
- Truth-telling and the Principle of Beneficence
- Goals of Care Discussions and Palliative Care
- Ethics of Clinical Trials
- Advance Directives
- MOST
- Surrogacy Issues

Goal: to facilitate dignified end of life experiences for your patients and/or their families.



CLINICAL ETHICAL PRINCIPLES

- Principle of Respect for Persons
  - Informed consent and capacity
  - Surrogate decision-making
- Beneficence:
  - Maximize therapeutic benefits, minimize risks/harms
  - Weighing therapeutic options
- Non-Maleficence
  - Do not intentionally harm or neglect
  - Duty to warn



CLINICAL ETHICAL PRINCIPLES

- Justice
  - Distributive justice and healthcare access
  - Costs of therapies
  - Health disparities issues
  - Resource allocation considerations
  - Priority-Setting for scarce resources



THE PRINCIPLE OF AUTONOMY

Respect for an *autonomous* patient's right to self-determination based on his/her values, beliefs and preferences.

Does not deal with non-autonomous patients



THE PRINCIPLE OF RESPECT FOR PERSONS

- Dual obligation to respect autonomous patients' wishes, and to protect non-autonomous patients.
- Crafted as a guiding ethical principle in The Belmont Report, and deals with vulnerable patient populations.
- Clinical ethicists prefer it because it establishes WHEN a patient is autonomous.



COMPETENCY V. CAPACITY

- Competency: legal status for emancipated adults; court determination; it does not change over short periods of time. Minimal and low standard.
- Decision-making capacity: medical determination that can change over short periods of time due to changes in medical and mental health status. May need to be a higher standard for some decisions.
- Many competent patients lack capacity; some incompetent patients have capacity to assent or consent.





INFORMED CONSENT

- Disclosure of procedures, risks and benefits: reasonable person standard; *material risks* a reasonable person would want to know
- Decision-Making Capacity and Competency: Legally competent patient must
  meet the U-ARE criteria
- Voluntariness.
  Patient's decision
  must be free of coercive
  influences.





U-ARE CRITERIA FOR CAPACITY

- Understanding = comprehension of information disclosed in the informed consent process [U]
- Appreciation = ability to apply that understanding realistically to one's own situation [A]
- Rationality = ability to reason with the information and process treatment information and one's preferences in a logical manner [R]
- Expressing a choice = ability to state a clear preference [E]



IS THERE A "STANDARD" FOR CAPACITY

The more serious the expected harm to the patient from acting on a choice:

No single standard adequate for all decisions

The standard depends on gravity of risks/harms involved

- the higher should be the standard of decision making capacity
- the greater should be the certainty that the standard is satisfied.

TRUTH





TRUTH-TELLING: BENEFICENCE

- The myth of “therapeutic privilege”
- Truth-telling as part of informed consent
- ~90% diagnosed with one of the four most common types of cancer are informed of their diagnosis (Neurology News, 2015)
- ~45 % with Alzheimer’s or their caregivers report the same in a survey commissioned by the Alzheimer’s Association (Ibid)

- Withholding the truth creates moral distress



TRUTH-TELLING ABOUT LOSS OF AUTONOMY

- Ensure that you discuss Advance directives with patients if loss of autonomy is inevitable.
- Naming surrogates, end of life preferences regarding nutrition and hydration; DNR and other preferences.
- Information about Death with Dignity States and establishing residency

But…Breaking Bad News is hard to do…













THE "SPIKES" MODEL: STEP 1 (S)
SETTING UP THE INTERVIEW

- Arrange for some privacy. (Separate room; curtains.)
- Allow patient to dress or be covered
- Have tissues ready
- Involve significant others.
- Sit down.
- Make connection with the patient. (e.g. eye contact; touch)
- Manage interruptions. (Set your pager on silent or ask a colleague to respond to your pages.)



THE "SPIKES" MODEL: STEP 2 (P) PERCEPTIONS OF THE PATIENT

"Before you tell, ask."

- Ask what patient already understands and appreciates:
- "What have you been told about your medical situation so far?" or "What is your understanding of the reasons we did the MRI?".
- Based on this information you can correct misinformation and tailor the bad news to what the patient understands.



THE "SPIKES" MODEL: STEP 3 (I)
OBTAIN PATIENT INVITATION

- While a majority of patients express a desire for full information about their diagnosis, prognosis, and details of their illness, some patients do not.

- "How would you like me to give the information about the test results? Would you like me to give you all the information or sketch out the results and spend more time discussing the treatment plan?".

- If patients do not want to know details, offer to answer any questions they may have in the future or to talk to a relative or friend.



THE "SPIKES" MODEL: STEP 4 (K)
GIVE KNOWLEDGE AND INFORMATION

- Warn the patient that *bad news is coming*: "Unfortunately I've got some bad news to tell you"
- Do not use technical words or jargon.
- Avoid excessive bluntness.
- Give information in small chunks and check periodically as to the patient's understanding.
- When prognosis is poor, avoid using phrases such as: "There is nothing more we can do for you."
- Discuss palliative care options as a care plan



THE "SPIKES" MODEL: STEP 5 (E) ADDRESS EMOTIONS WITH EMPATHY

- Patients' emotional reactions vary: silence, crying, anger.
- Observe the emotion.
- Use open questions to query the patient as to what s/he is thinking or feeling.

- Example: "I'm sorry to say that the tests confirm there is something very wrong." [Patient cries]. "I know that this isn't what you wanted to hear. I wish the news were better."



THE "SPIKES" MODEL: STEP 6 (S)
STRATEGIZE AND SUMMARY OF OPTIONS

- Reduce anxiety with a clear care plan of action
- Before discussing care plan, ask if pt. is ready
- Present all available treatment options
- Discuss palliative care, nutrition/hydration
- Share responsibility for decision-making
- Do a teach back: Check for U-ARE
- Discuss VSED (Voluntary Stopping Eating and Drinking) and other EOL preferences
- Be prepared to discuss Death with Dignity laws



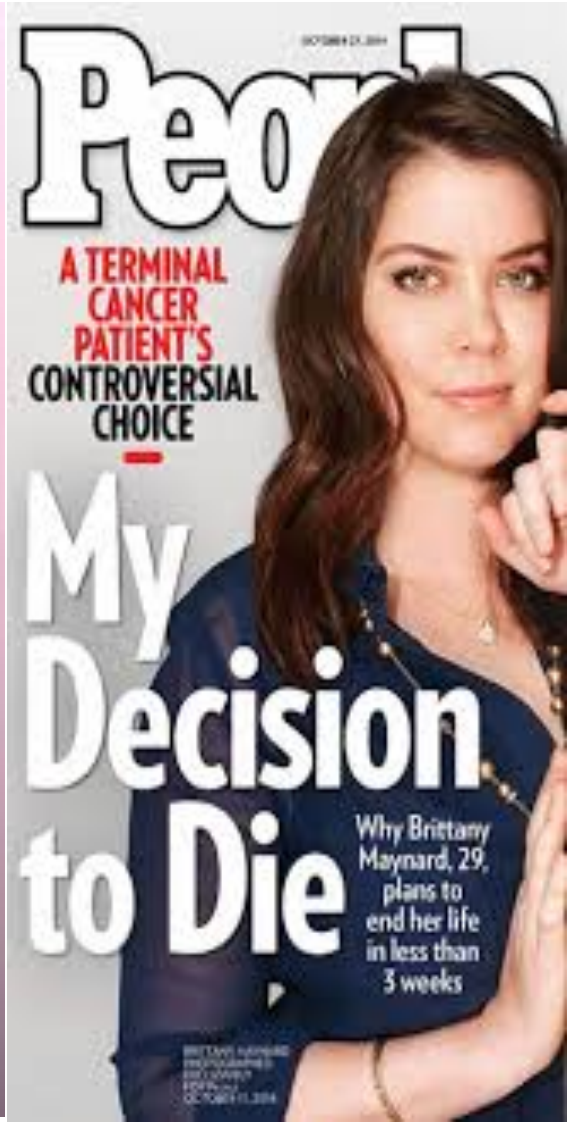
ADVANCE CARE PLANNING

- Patients with no family or competent family members
- Patients for whom there is likely to be disagreement among potential surrogates
- Patients for whom the likely surrogate would make different decisions than what the patient would want
- MOLST/POLST: Medical/Physician Orders for Life-Sustaining Treatments (www.polst.org)
- As part of the ACA, initial legislation sought for reimbursement for EOL discussions; didn't pass. Creates the false rhetoric of "death panels"



BRITANNY MAYNARD





JANET ADKINS, ALZHEIMER'S PATIENT (1990)

- Janet Adkins, a 54-year-old Portland, Oregon, woman with Alzheimer's disease was Dr. Jack Kevorkian's first patient in which he used the "suicide machine" in his1968 Volkswagen van in Groveland Oaks Park near Holly, Michigan.





SUE RODRIGUEZ: ALS PATIENT (1991-4)

- After being diagnosed with the terminal disease ALS in 1991, Rodriguez took her fight to the Supreme Court of Canada. She failed to get euthanasia and assisted suicide, and quietly received PAS in 1994. In Jan, 2015, the Supreme Court of Canada unanimously ruled to allow PAS.





DEATH WITH DIGNITY STATES

- Oregon (1997). How to Die in Oregon (2011)
- http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/index.aspx
- Washington (2008) http://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct
- Vermont (2013)
- California (pending 2015)
- Montana and New Mexico: decriminalized PAS
- Canada (2015)



BENEFICENT CARE PLANS

IS THE BENEFIT REALLY WORTH THE RISK?



BALANCING POTENTIAL CLINICAL HARMS

- Side-effects of treatment
- May worsen quality of life
- May hasten death
- Costs of some treatments
- Experimental protocols
- Innovative therapies



INNOVATIVE THERAPY

- Novel procedures or treatment that may offer greater benefit than standard treatment
- Innovative therapy is non-validated practice
- "Significant" innovative therapy should be prospective research.
- Innovative therapy does not require IRB approval if:
  - No standard of care exists
  - Pt. not a candidate for the standard of care
  - Pt. is refusing the standard of care



THERAPEUTIC MISCONCEPTIONS

- Special problems with informed consent arise when both providers and patients have therapeutic misconceptions.
- Inexperienced prescribers may be overly optimistic about outcomes.
- Experienced prescribers may encounter enthusiastic patients who do not understand and appreciate the risks associated treatments
- Patients may not understand and appreciate that they may live an extended life with poorer quality than had they chosen to do nothing.



Palliative Care

- **1969**: *On Death and Dying* (500+ qualitative interviews). 5 stages of death; hospice care plea.
- **1972**: Elisabeth Kubler-Ross testifies for the U.S. Senate Special Committee on Aging.
- Early resistance to palliative care (1980s and 1990s) due to misconceptions
- Should not be confused with hospice care (px of <6 months)
- Can accompany any and all aggressive medical treatments.



Palliative Care

- Steady growth in palliative care since 2000
- Millions still do not have access to it, and access varies by state and region
- In 2008, KY was one of the states with the lowest prevalence rates (37%) receiving a D grade nationally. By 2011, that improved to a C grade (55%) when 50% of U.S. states receive a B grade (61-80%).
- UK only got palliative care in 2009 (at least a decade behind benchmarks)

Source: http://reportcard.capc.org/pdf/state-by-state-report-card.pdf



IT'S NOT HOW LONG LIFE IS BUT THE QUALITY OF OUR LIFE THAT IS IMPORTANT.

- ROGER DAWSON







DISTRIBUTIVE JUSTICE AND ECONOMIC BURDENS OF TREATMENT



WHAT IS A LIFE WORTH?

"Suppose the treatment cost a million dollars. Would it be worth it then? Ten million? Is there any limit to how much you would want your insurer to pay for a drug that adds six months to someone's life? If there is any point at which you say, 'No, an extra six months isn't worth that much,' then you think that health care should be rationed."

- Singer, P. Why We Must Ration Health Care. *New York Times*, 2009



SHARED DECISION-MAKING



Beneficent Care for Incapacitated

- In the case of an incapacitated patient, the **Principle of Autonomy** is disabled, and the **Principle of Respect for Persons** obligates us to protect the patient by ensuring there is authentic surrogate decisions

- **The Principles of Beneficence/Non-Maleficence** is requires that incapacitated patients be protected from making decisions that are harmful or that they would not make, if they had capacity.



KAREN ANN QUINLAN, PVS (1975-85)

- **Karen Ann Quinlan** (1954 –1985) .
- re **Quinlan** (70 N.J. 10, 355 A.2d 647 (NJ **1976**)



- NJ Supreme Court ruled in the surrogates' favor: to remove the ventilator, citing the irreversible nature of her vegetative state.
- She lived in a PVS until 1985.
- First case in which the courts suggest hospital "ethics committees" and launched the era of patients' right to self-determination.



NANCY CRUZAN, PVS (1990)

- ***Cruzan v. Director, Missouri Department of Health***, 497 U.S. 261 (1990). Court recognized the constitutional right of a competent person to refuse life-sustaining therapy; equated artificial nutrition and hydration with other life-sustaining therapies; ruled that each state could set evidentiary standards for withdrawal based on "clear and convincing evidence" of a patient's wishes. Creation of AD was the outcome.







Federal and State Law

Patient Self-Determination Act (1990)

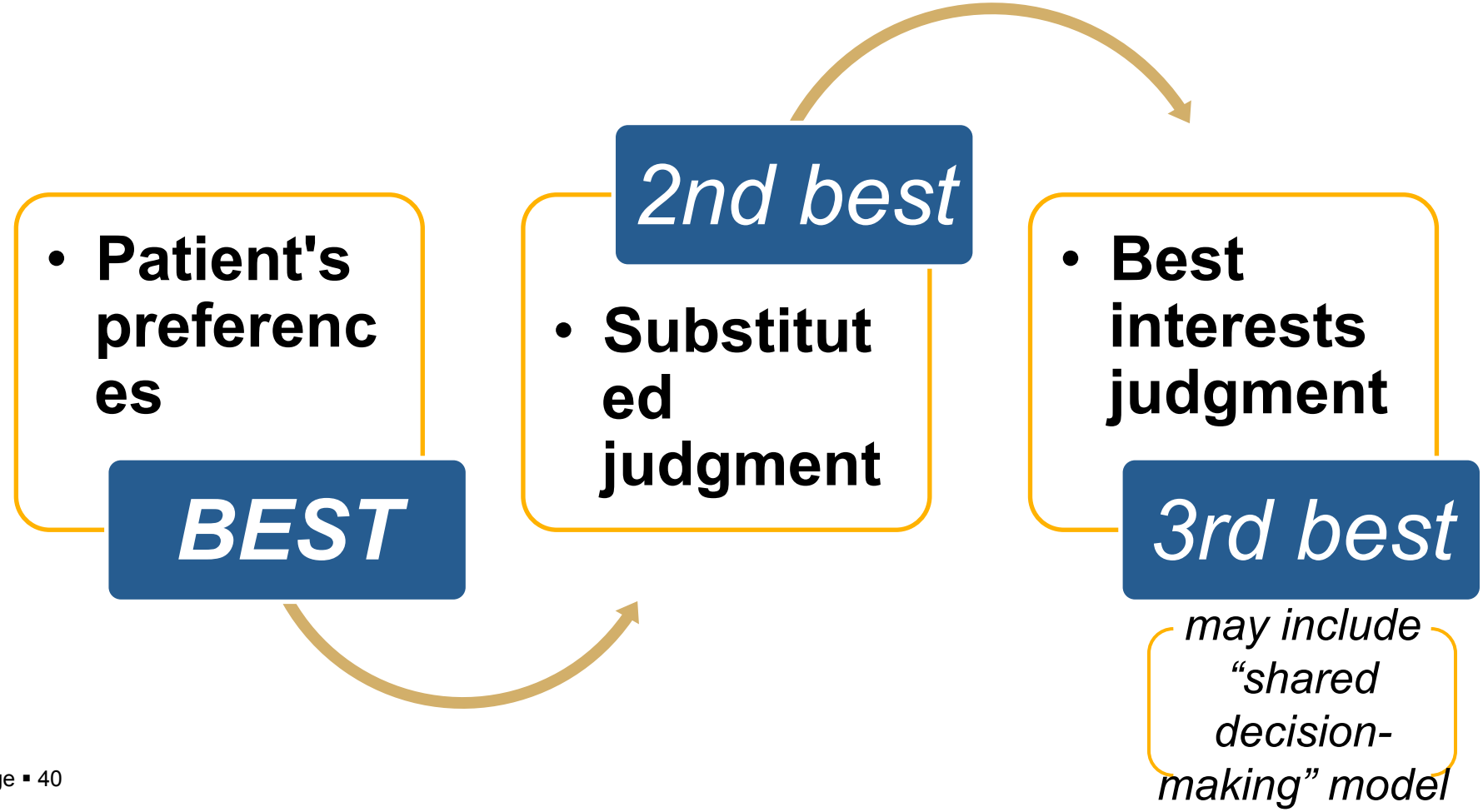
Must provide written information about Advance Directives

State Living Will laws generally instruct in 4 areas:

- Surrogacy designation
- Refuse or request life prolonging treatment
- Refuse or request artificial feeding or hydration (tube feeding)
- Express wishes regarding organ donation



SURROGATE DECISIONS



TERRI SCHIAVO, PVS (1990-2005)







Medical Issues in Schiavo

- In 1990, 26-year old Terri Schiavo experienced cardiac arrest
- Sustained severe brain damage
- Diagnosed with Persistent Vegitative State
- Nutrition achieved through percutaneous endoscopic gastrostomy tube (was removed and reinserted twice, through 10 year period)
- History of bulimia makes “feeding Terri” an eerie theme in both life and death



Legal/Ethical Issues in Schiavo

- What makes a surrogate a surrogate?
- Court grants husband legal surrogate
- Marital status remains in question for public
- The absence of an advance directive leads to “Persistent Legislative State”
- Schiavo case involved 14 appeals and numerous motions, petitions and hearings in FLA courts; 5 suits in federal court; federal legislation and 4 denials to hear case from SCOTUS.



Conclusions

- Patients want to know to the truth about their end of life options
- Patients don't want to be isolated, abandoned or misled (Kubler-Ross, 1969)
- Failure to truthfully prognosticate leads people to "die deaths they deplore in locations they despise" (Christakis, 1999)
- Patients need to control their end of life destinies.

QUESTIONS?

