Informed Consent and Ethical Best Practices in Dysphagia and Diet Consistency Decisions Part 3

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Disclosures

- Mary Casper receives a salary for employment at the American Speech-Language-Hearing Association (ASHA).
- Mary is a Contributing Faculty at the University of Saint Augustine for the Health Sciences, teaching Dysphagia.
- Mary received complimentary registration and travel expenses from SHAV for her participation as an invited speaker.
- She has no non-financial disclosures.

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How do you evaluate this clinical scenario?

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The interaction is characterized by a pragmatic of paternalism, whereby the patient's autonomy and decision-making capacity is not respected when the treatment decisions are made

This violates not only principles of ethics, but it violates the law.

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Medical ethical principles

- Autonomy
- Beneficence
- Nonmaleficence
- Justice

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PRINCIPLES OF ETHICS

AUTONOMY

Acknowledge people's right to make choices for themselves based on their own values and beliefs

BENEFICENCE

One ought to prevent and remove evil or harm; One ought to do and promote good (Beauchamp & Childress, 2009, p. 151).

NONMALEFICENCE

"One ought not to inflict evil or harm," where harm is understood as "thwarting, defeating, or setting back some party's interests"

JUSTICE

Treat others equally and fairly.

Hudson University. (2017). Principles of ethics. Retrieved from https://online.husson.edu/beneficence-nursing-ethics/

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Autonomy

01

Respect another's worth & right to make choices

02

Accept that patient may choose not to have aggressive health intervention

03

Understand that patient may value eating a little with family despite risk of choking

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Beneficence

1

Take positive action to do good for others and act to prevent or remove harm

2

Liaise with dietitian to optimize nutrition & hydration with an altered diet

3

Assess a patient's swallow function comprehensively to identify physiological impairment

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Nonmaleficence

AVOID CAUSING HARM

DO NOT RECOMMEND SURGICAL PROCEDURE THAT PATIENT WOULD BE HARMED BY

DO NOT RECOMMEND DIET RESULTING IN INADEQUATE NUTRITION

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Justice

Provide what patients need in fair & equitable manner

Consider cost of procedure

Likely benefit to patient & to all patients?

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Question

Mr Singh (65 yrs), ALS, dependent on wife

- CSE: oral feeds but coughs on liquids
- MBS: occasional aspiration of thin liquids

Refuses thickened liquids

You (SLP) advise

- A. wife to always thicken drinks in "best interest" of patient, monitor & refer to dietitian
- B. if he won't use thickened liquids you will discharge
- C. discuss with patient, agree to trial with dietitian overview

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A. wife to thicken in "best interest"

✖Contravenes patient autonomy

✓Referral to dietician is attempt to "do good" to monitor diet = beneficence

✓Referral to dietician is attempt to "avoid doing harm" to monitor for dehydration = nonmaleficence

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B. no unthickened & discharge

✘Contravenes patient autonomy

✘Contravenes nonmaleficence - potential risk of dehydration

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C. discussion & trial

✓Discussion respects patient autonomy

✓Referral to dietician is attempt to "do good" to monitor diet = beneficence

✓Referral to dietician is attempt to "avoid doing harm" to monitor for dehydration = nonmaleficence

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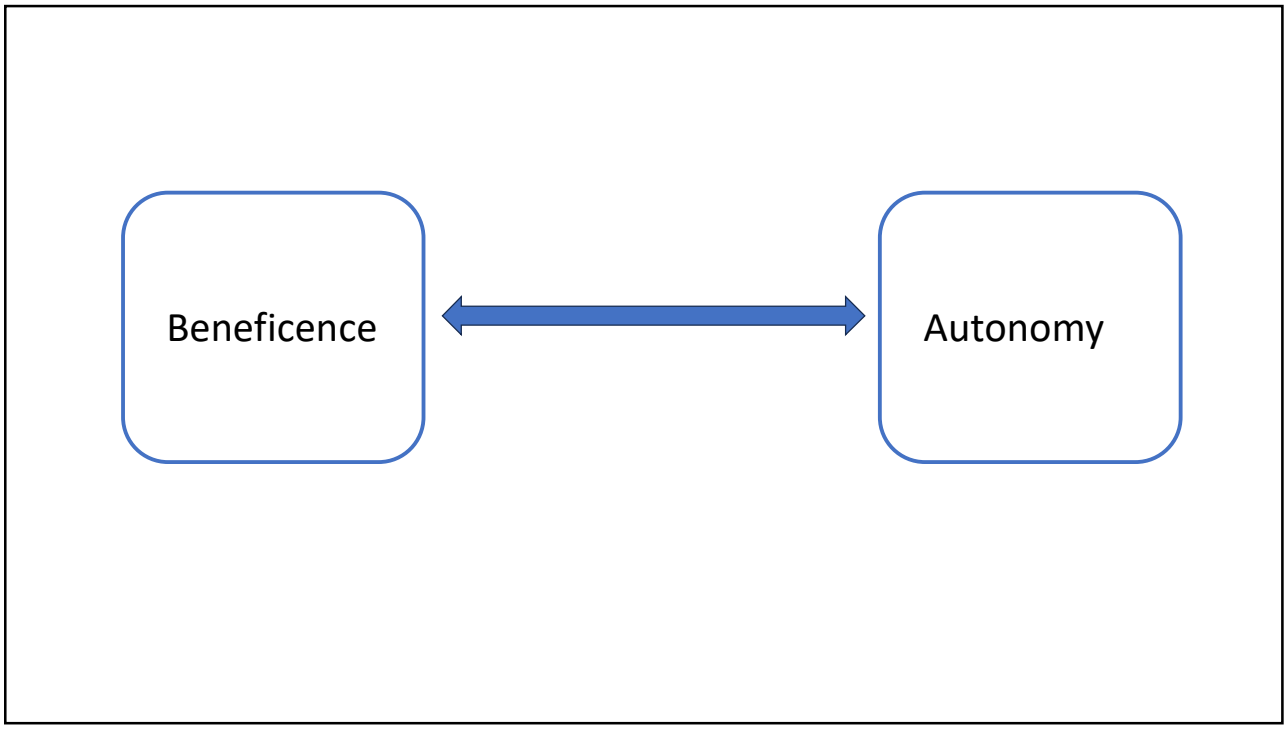

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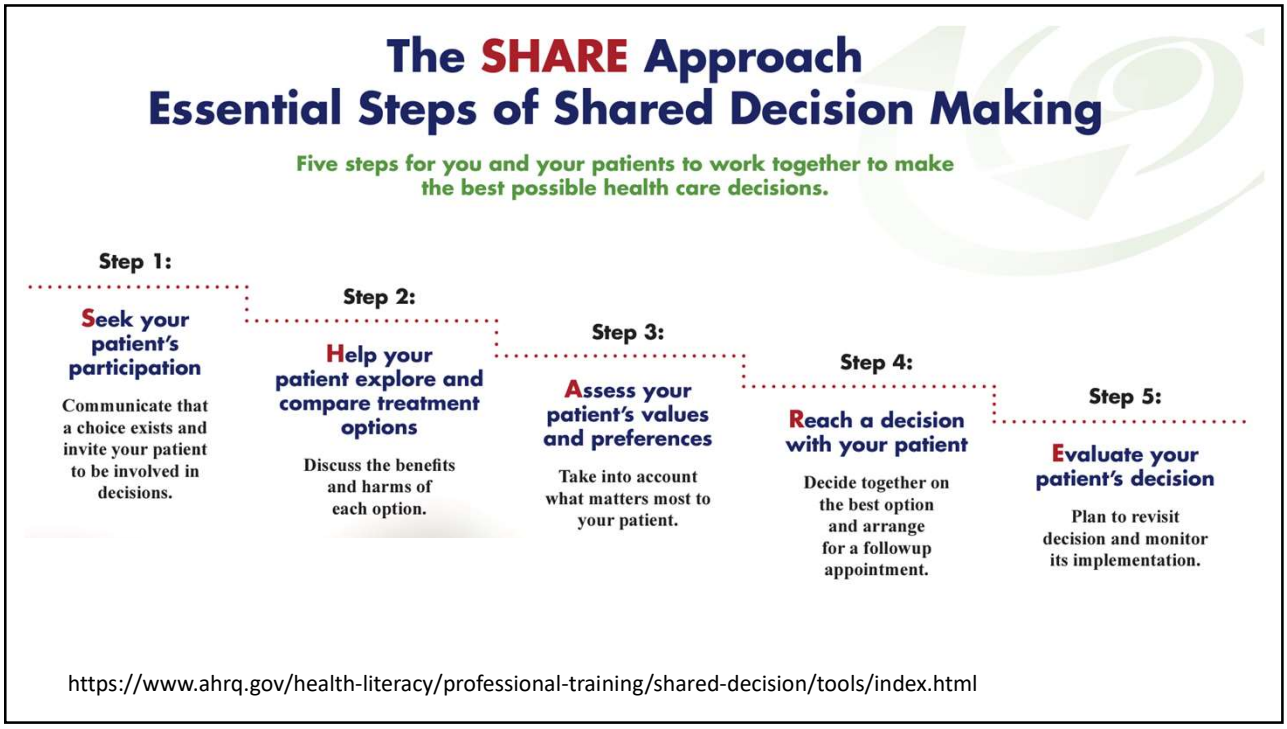

https://www.ahrq.gov/health-literacy/professional-training/shared-decision/tools/index.html

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- Students at the University of California, Irvine, are taught the "Five E's" of effective patient-centered communication from day 1 of medical school (engage, empathize, educate, enlist, and extend). Concepts such as the five E's illustrate a shift in power to the patient and the requirement that the physician adapt to that patient. (Monya)

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Tongue et al. 2005

- Ask: “How can I help you today?” Six simple, powerful words.

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History of Paternalism

- Obligations of Patients to Their Physicians
- *"The obedience of a patient to the prescriptions of his physician should be prompt and implicit. He should never permit his own crude opinions as to their fitness, to influence his attention to them. A failure in one particular may render an otherwise judicious treatment dangerous, and even fatal."*
- ~1847 *Code of Medical Ethics* of the American Medical Association
- (Monya, 2004)

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- Patients were simply recipients of the care of the doctor.
- Helpless, unable to understand, unable to participate.

- ''The relationship between the doctor and patient has a very pronounced association with the model of illness that dominates at any given time''
  - Visible symptoms only way to diagnose – patient's input or history were not relevant.

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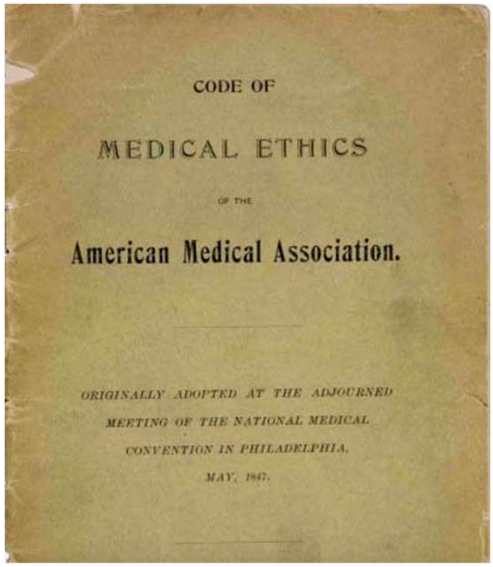

- *This remark is equally applicable to diet, drink, and exercise.*
- *As patients become convalescent they are very apt to suppose that the rules prescribed for them may be disregarded, and the consequence but too often, is a relapse.*

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A defence of medical paternalism: maximising patients' autonomy

Some patients are incapable of autonomy.

Where autonomy fails, paternalism steps in.

it is precisely this feature of the doctor-patient relationship that has suffered the harshest criticism lately with the advent of medical consumerism, self help, the patients' rights movement, and the reevaluation of professional authority in general

Komrad, M. S. (1983). A defence of medical paternalism: maximising patients' autonomy. *Journal of medical ethics*, *9*(1), 38.

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What is Consent?

Process, not paper

Components of Informed Consent

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Shared decision making

- An approach between paternalism (the doctor knows best) and basic autonomy (the patient knows best).
- Includes both beneficence (to do good) and patient authority (it's my body)
- Protects and supports patient autonomy.
- Evidence based practice vs. "fear-based practice."

- **Neither informed consent nor shared decision-making is "I shared my recommendation and the risks of not following, but the patient refused."**

Childress, J. F., & Childress, M. D. (2020). What does the evolution from informed consent to shared decision making teach us about authority in health care?. *AMA Journal of Ethics*, *22*(5), 423-429.

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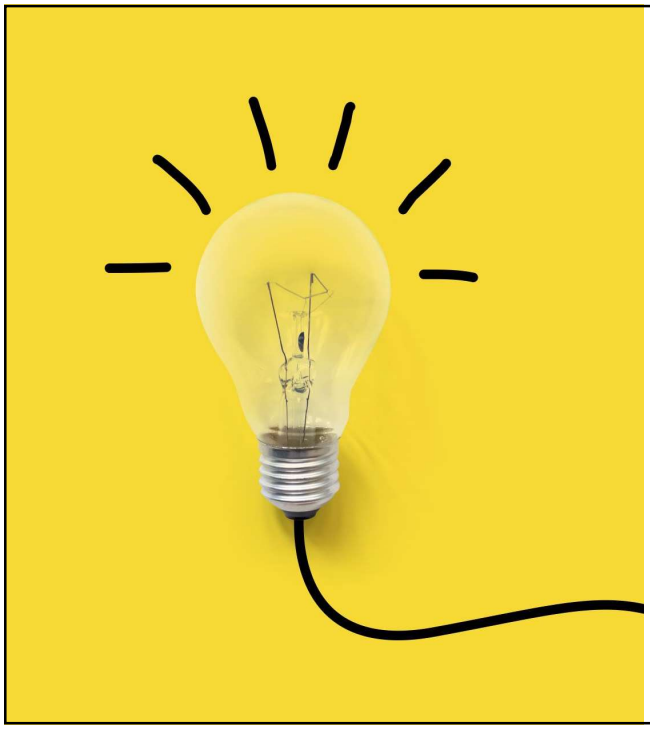

Questions to Ask

- Accurate and thorough assessment first
- Adhere to best practice
- Consideration of all management alternatives
- Sharing of information
- Who can make the decision?
- Is there any question of capacity?

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"What if" thinking

- But what if?
- The best way to avoid a lawsuit
- Problems with waivers
- Document and document

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What is the best way to avoid a lawsuit?

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Problems with "waivers"

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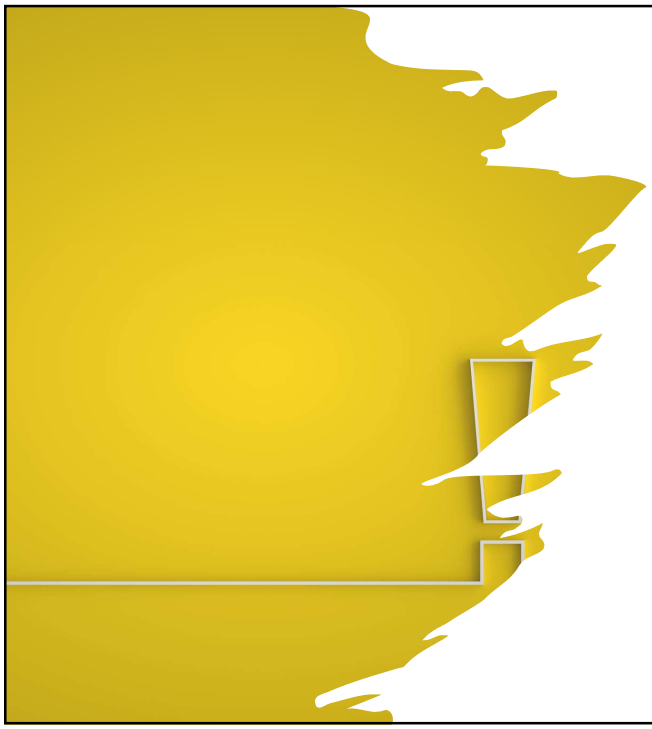

Statements about informed consent … heard in passing

- I don't have time for this.
- My supervisor would not let me do this.
- I have to protect my license.
- It would not be ethical if I did this.
- It would not be safe for the patient to eat / drink x consistency.
- But they aspirated!

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What if something goes "wrong"?

- The patient is being cared for at home with a home health SLP visiting 2 times per week. After the 10th visit by the SLP, the patient is sent back to the hospital for suspected pneumonia. At home, the patient's diet was soft & bite sized solids with thin liquids. Diagnoses include CHF, COPD, and Dementia.
- What should happen to this patient in the hospital?
- What should the home health SLP document?

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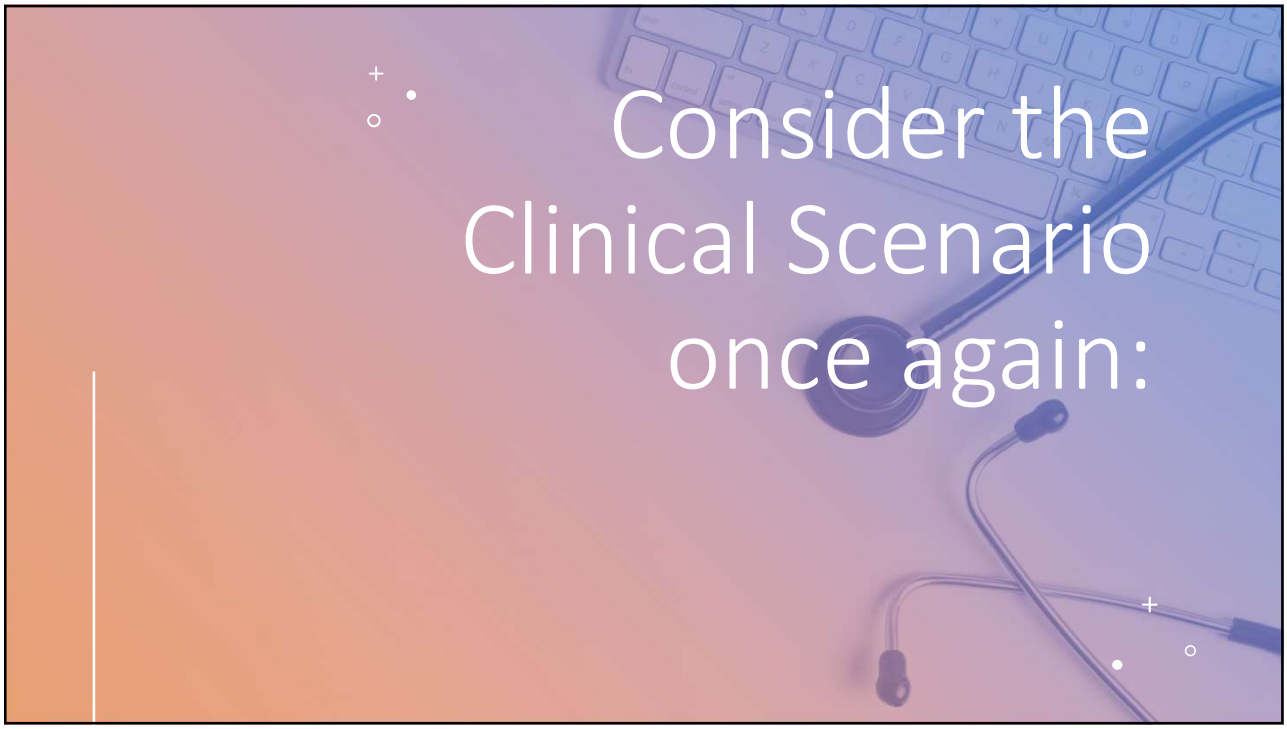

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