

Consent, Dementia, and Surrogate Decision-making: Ethical Challenges in the Context of Homeless Health Care

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A Year Like This...

The Case of LR

85yo Spanish-speaking male

HPI: Diarrhea 3-4x daily, new-onset iron-deficiency anemia, 5-lb unintentional weight loss (baseline wt was 113#)

Asymptomatic/not bothered by diarrhea

PMH: Alzheimer's dementia, chronic obstructive pulmonary disease, coronary artery disease, and dyslipidemia

Social History

From Puerto Rico

Formerly homeless- has moved from transitional shelter to long-term supportive housing

Has a home attendant 4 hours day/ 5 days/week

Former smoker, quit in the past 3 months without assistance

Initial Work-up

Labs: normal, except iron-deficiency anemia

Stool studies negative for infection

Barium enema: mass concerning for rectosigmoid neoplasm

Colonoscopy is recommended.

Discussion

What are the medical issues arising in this case?

What ethical issues does it present?

How ought we to proceed?

What are the consent requirements, absent an emergency?

How much weight loss, or how severe the anemia, to constitute “an emergency?”

Discussion

Terminology

- “Unbefriended patient”
- “Unrepresented patient”
- “Isolated patient”
- “Adult orphans”

LR: Barriers to Diagnosis

Advanced dementia

Prevents meaningful discussion of diagnostic and treatment options

Unable to provide informed consent

Has not appointed a healthcare proxy

LR: Barriers to Diagnosis

Lack of Healthcare proxy

Unable to identify/contact any relatives

No progress re: family, treatment plan, or consent despite multiple attempts with native Spanish speaker.

Discussion

Is there an ethical dilemma here?

Who should decide how to proceed when there is no clear guidance about who should make decisions?

Should we focus on consent or goals of care?

Discussion

LR: Deciding How to Decide

Caseworkers from supportive housing

Ethics Committee → SW group as “proxy”

Palliative care → Ethics panel

Recommended non-invasive work-up with contrasted CT of abdomen & pelvis

Recommended pursuing guardianship

Adult Protective Services recommended hospital admission to be declared incompetent and proceed with work-up

Discussion

What is the difference between competence and decision-making capacity?

Does it matter in determining how best to proceed?

What is in the patient's best interests?

Who gets to/has to decide?

Who might be in the best position to decide?

Four pathways for surrogate decisions

- Directed decision making- specify decisions in advance in writing, such as a living will
- Delegated decision making- specify a healthcare power of attorney
- Devolved decision making- if no one is specified, family members by default become healthcare proxy
- Displaced decision making- court-appointed guardianship or surrogate

Alternate Approach

Two-physician consent for diagnostic sigmoidoscopy

Bx consistent with rectal cancer

Risk of tumor growth with resulting obstruction or bowel rupture

Curative surgery deemed not an option

Consideration of chemo vs radiation, but need consent from guardian/proxy

On-going Issues

APS cannot help with guardianship

Housing organization cannot afford legal fees

Does not qualify for palliative care

Patient states he is fine, does not have cancer, and would not want care for anything. Patient wants home attendant or Director of Social Services to make decisions.