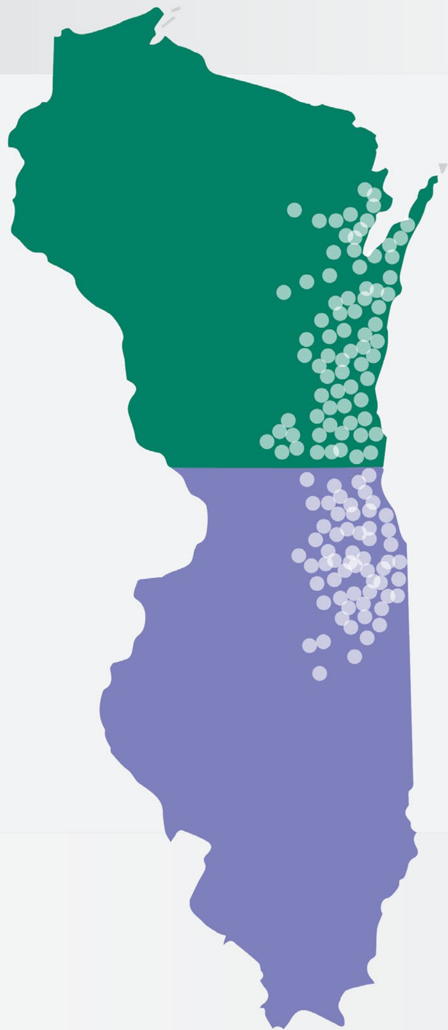

Great Lakes Palliative Care Conference

Unbefriended: A Difficult Case Presentation

Saman Misbah D.O.

No Disclosures

We are AdvocateAuroraHealth

J.A. – 72 Y.O. Presenting to the hospital from a group home with new back wound

PMHx, HPI

- History of major neurocognitive disorder, severe COPD, HTN
- History of tobacco use disorder
- “Very large multilobulated mass in left upper lobe measuring up to 20 cm” noted on CT chest.

Background

- Clinical context – Patient with significant neurocognitive disorder, concerns about capacity to make decisions
- Relevance – Moral distress noted in providers and staff caring for the patient in setting of unclear directives

Objectives

- Talk about care of “unbefriended” patients
- Understand the processes in place currently for their care
- Acknowledge the difficulty when it comes to caring for patients with this complicated background, including moral distress

Timeline

08/31

- Capacity eval done by psychologist, patient deemed to lack capacity

09/01

- Biopsy ordered, for lung mass, patient refused. “it is my cancer, I get to do what I want”
- Palliative care consulted, attempted to reach Patient’s group home coordinator, unable to do so. But were able to reach patient’s home palliative care program NP. Honoring choices document was located, patient filled this prior to hospitalization. **“I do not want to have machines keeping me alive, if I have a terminal diagnosis like cancer, I do not want chemo or radiation. I don’t want to prolong my life, if I am nearing death. If it happens that I get on a machine that helps me breath, stop it. It’s time for me to go.”**

09/07

- First Care conference involving primary team, ethics, SW and hospital CMO was done.
- Following conference, decision was made to make patient DNR, using patient’s incomplete “Honoring Choices” document.

Timeline

9/08

- Another discussion with community CM and community palliative NP reinforced their understanding that patient would have chosen DNR for himself (they had been involved in patient's care from 11/2022)
- Patient likely eligible for hospice care, however, lack of capacity and no POA chosen meant no one to sign paperwork for hospice admission.
- Patient can also not return to previous group home as he is no longer ambulatory

9/20

- Palliative care visit, patient is more cooperative and mentions this is "a nice place" and that "I don't mind being here"
- Palliative care recommends pursuing guardianship

Timeline

10/02

- Second care conference with primary team, CMO, SW and Palliative care, plan to continue treating acute issues, but no escalation of care
- Community Care decided to pursue guardianship, paperwork started

10/09

- Patient's status worsened, requiring continuous oxygen and IV hydration
- Concern for suffering, patient nodded yes when asked if he preferred comfort
- Comfort care plan was initiated

Specific aspects that were difficult

- Moral distress and other ethical challenges
- Navigating the legality of this situation
- Doing what was best for the patient in a safe and efficient manner

Definition of Unbefriended

- Lack decisional capacity to provide informed consent to the medical treatment at hand
- Have not executed an advance directive that addresses the medical treatment at hand and lack capacity to do so
- Lack family, friends or a legally authorized surrogate to assist in the medical decision making process

Adults Without Advocates and the Unrepresented: A Narrative Review of Terminology and Settings *Gerontol Geriatr Med* 2023; 9:23337214221142936. R. Brenner, L. Cole, G. L. Towsley and T. W. Farrell

Challenges with Unrepresented Patients

- Extremely vulnerable population, unable to advocate for themselves or have family/friends to do it for them
- Risk for overtreatment, this may happen in situations where it is not clinically or ethically warranted
- Undertreatment may also happen, decision made by clinicians to unilaterally hold treatment
- Delayed treatment while situation is in flux, waiting till an emergency occurs to provide treatment. This can be a cause of suffering

Five Things Clinicians Should Know When Caring For Unrepresented Patients, AMA J Ethics. 2019;21(7):E582-586.

Challenges contd.

- Laws vary from state to state when it comes to management of unrepresented patients
- Only a handful of states have formally specified decision-making processes for unrepresented patients
- But these processes vary greatly
- Need to view these laws as “floors, rather than ceilings”
- Institutions need a fair process when it comes to managing these patients

Five Things Clinicians Should Know When Caring For Unrepresented Patients, AMA J Ethics. 2019;21(7):E582-586.

.

Why not Guardianship?

- Generally, not the preferred or adequate solution to the problem
- Expensive and time consuming
- Often ineffective and not in patient's best interest

Five Things Clinicians Should Know When Caring For Unrepresented Patients, AMA J Ethics. 2019;21(7):E582-586.

Areas of improvement in our case

- What does dying mean? This can be a source of moral distress
- Unable to enroll patient in hospice, which deprived him the right for specialized end of life care
- Unable to place him, leading to increased cost of medical care.
- Room for improvement when it comes to creating policies for unbefriended patients at both statewide and hospital levels

Objectives on Repeat

- Talk about care of "unbefriended" patients
- Understand the processes in place currently for their care
- Acknowledge the difficulty when it comes to caring for patients with this complicated background, including moral distress

UNBEFRIENDED

BE FRIENDED

References

- Adults Without Advocates and the Unrepresented: A Narrative Review of Terminology and Settings *Gerontol Geriatr Med* 2023; 9:23337214221142936. R. Brenner, L. Cole, G. L. Towsley and T. W. Farrell

- *Five Things Clinicians Should Know When Caring For Unrepresented Patients, AMA J Ethics.* 2019;21(7):E582-586

- The Unbefriended Patient: An Ethical Balancing Act, *Journal of Hospital Ethics* 2023; 9(3):38-42

Questions?