Vulnerable and Unrepresented: Ethical and Legal Pathways to Patient Care

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Objectives

1

Explore ethical considerations surrounding unrepresented patients and practical approaches for consideration.

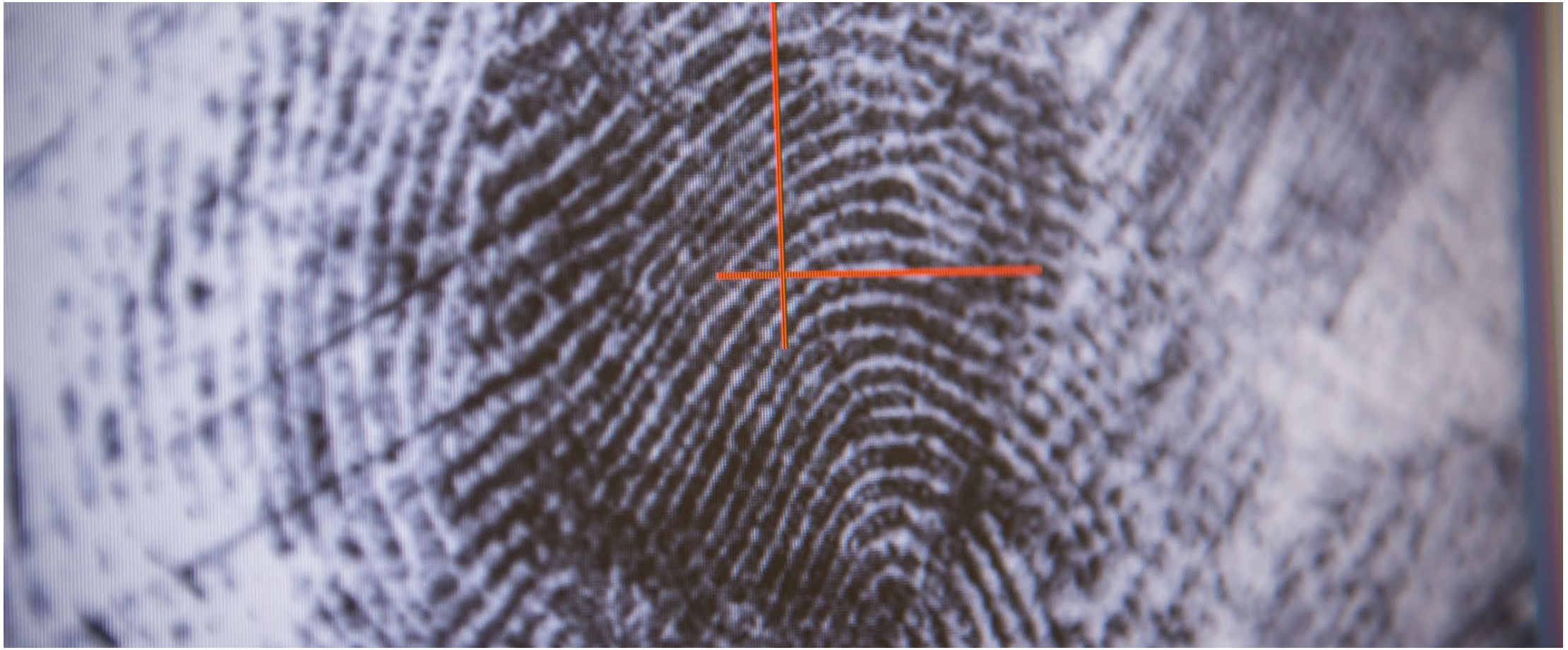
2

Identify possible legal and ethical options to facilities with unrepresented patients.

3

Review the documentation expectations to mitigate loss and protect patient rights.

Context and Importance



Scope of Issue

Definition

Why is it Important?

Why is it a growing Concern?

Taylor M. (2025) Why caring for unrepresented patients is a growing issue. Becker's Clinical Leadership. 2/27/2025

Legal Considerations

Family Health Care Decisions Act (FHCDA)

- Framework for Medical Decision-Making
- Who can make decisions
- Capacity Decision-Making
- Routine v. Major Treatment v. Life Sustaining Treatment

Intent: Balance patient rights with medical necessity

Patients Without Capacity and Surrogate

- Assess patient's wishes and preferences
- Routine medical treatment- Attending practitioner
- Major medical treatment- Consult and concur
- Withdraw/Withhold life sustaining treatment- Court or Consult and Concur, Imminent death

Legal Pathways for Unrepresented Patients

- Ethics Committees
- Guardianship
- Emergency Treatment and Implied Consent

Ethical Considerations

Complexities in Ethical Decision-Making

Rule-based ethics (policies, laws, advance directives)

Interest-based ethics (best interest standard)

Value-based ethics (patient's known or presumed values, dignity in care)

Key Ethical Issues

- Inconsistent definitions and terms for “unrepresented”
- Timing of decisions
- Rotation physicians with differing goals of care
- Determining “Best Interest”
- Moral distress

Ozar D. (2019). Who are “unrepresented” patients and what counts as “important”medical decisions for them? AMA Jour of Ethics. 21(7):E611-616

Conflicts of Interest

INSTITUTIONAL CONFLICTS

PHYSICIAN AND PRACTITIONER CONFLICTS

LEGAL AND ETHICAL SAFEGUARDS MUST BE IN PLACE

Unique Challenges for HCPs

- Uncertainty
- Distress/Emotional Toll
- Delays in Decision-Making
- Burden without Clarity
- Liability Risks
- Prolonged Stay
- Inconsistency in Ethics Committees
- Limited Legal Guardianship
- Communication and Documentation

First Step: Capacity Determination

Capacity v. Competency

FHCDA

Clinical Assessment-
2-Step Determination

Special Credentialing

Notification

Right to Object

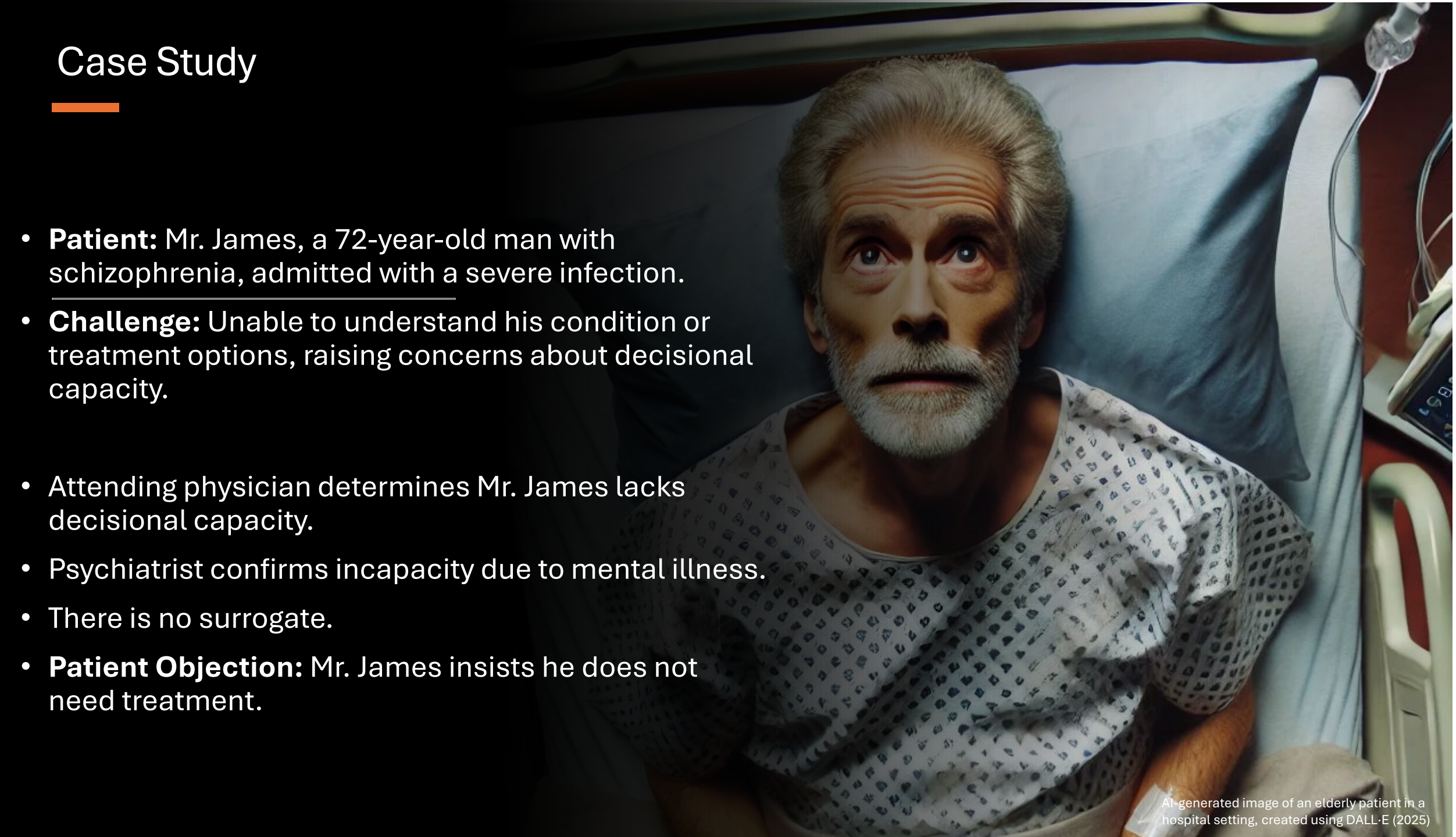
Assess for Wishes and Preferences

- Previous Medical Records
- Team Consultation
- Background
- Past Decision-Making
- Best Interest Standard

Case Study

- **Patient:** Mr. James, a 72-year-old man with schizophrenia, admitted with a severe infection.
- **Challenge:** Unable to understand his condition or treatment options, raising concerns about decisional capacity.

- Attending physician determines Mr. James lacks decisional capacity.
- Psychiatrist confirms incapacity due to mental illness.
- There is no surrogate.
- **Patient Objection:** Mr. James insists he does not need treatment.



AI-generated image of an elderly patient in a hospital setting, created using DALL·E (2025)

Practical Approaches

5 Ethical Goals to Protect Decision-Making

- “Protect highly vulnerable patients
- Demonstrate respect for persons
- Provide appropriate medical care
- Safeguard against unacceptable discrimination
- Avoid undue influence of competing obligations and conflicting interests”

Pope TM, Bennett J, et al. (2020). Making medical treatment decisions for unrepresented patients in the ICU. American Thoracic Society Documents. 201(10):1182-1192

Standardized Protocols

CONSISTENCY

COMPLIANCE

PATIENT RIGHTS

IMPROVED COORDINATION OF CARE

STREAMLINE PROCESSES

Documentation

- Capacity Determination
- Efforts to Find Surrogate
- Assessment of Values and Preferences
- Ethics Committee (consult legal)
- Treatment Decisions and Rationales
- Ongoing Reassessments

Institutional Policies

Develop Policies Around Supporting Unrepresented Patients

Consider Impacts of Policies on Vulnerable Populations

Implement Proactive Identification

Strengthen Community Partnerships

Develop Hospital-Based Volunteer Surrogate Programs

Massachusetts Success Story

Massachusetts Case Study

1,200 people ready for discharge in Massachusetts were stuck in hospital beds each day

1,792 patients awaited discharge statewide.

1,200 additional days before discharge for individuals who are hospitalized and have lost decision-making capacity without having appointed an HCA, and require appointment of a guardian

$3,529 is the average cost in Massachusetts for every day that a patient stays in an acute care hospital because of a discharge delay

- Volunteer Recruitment and Training
- Patient Matching Process
- Documentation and Implementation
- Toolkit: **How to Create a Volunteer Health Care Agent Matching Program** (2024)

Website: [Health Care Agent Matching Program | Massachusetts Coalition for Serious Illness Care]

Every patient deserves compassionate, ethical, and just care—regardless of their circumstances. When a person has no voice, it is our responsibility to listen. When they have no advocate, it is our duty to stand in their place with integrity. The way we treat the most vulnerable among us defines who we are as healthcare professionals and as a society.

Thank you

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