Ethical Considerations in Surrogate Decision Making: An Acute Inpatient Perspective

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Objectives

- Discuss challenges associated with Ethical Decision Making
- Explore the impact of cultural differences and implicit bias
- Discuss collaboration between Social Work, Case Management, and inpatient Palliative Care Team
- Reflect on the impact of the COVID pandemic on delivery of palliative care in the inpatient setting

Glossary of Terms

HCP- Health Care Proxy
POA- Power of Attorney
NOK- Next of Kin
SDM- Surrogate Decision Maker
EOL- End of Life
AUD-Alcohol Use Disorder
SUD- Substance Use Disorder

Palliative Care in the Inpatient Setting

We are a consultative service, composed of a team of Nurse Practitioners, with off site Physician support that:

- provide support and enhance patient and caregiver coping
- Perform medical translation
- Assist with care coordination
- Support patients and their loved ones in medical decision making
- Provide symptom management recommendations

Palliative Care in the Inpatient Setting

Our team is often consulted in the setting of:

- Catastrophic neurologic injury
- End stage and multisystem organ failure
- Advanced or Metastatic Cancer
- Complex family dynamics
- Uncontrolled or complex symptom management

Ethical Decision Making

Beneficence: obligation to act for the benefit of the patient, avoid harm and promote welfare

Nonmaleficence: weighing benefits and burdens

Autonomy: all persons have intrinsic and unconditional worth, and therefore, should have the power to make rational decisions and moral choices, and each should be allowed to exercise his or her capacity for self-determination

Justice: fair, equitable, and appropriate distribution of health-care resources determined by justified norms

Ethical Decision Making: Challenges for patients lacking capacity AND without an identified SDM

- What is Capacity and how is it assessed?
- Choice Architecture
- Legal Issues and Massachusetts Law/Institutional Workarounds
- Health Care Proxy (HCP) vs guardian vs Power of Attorney (POA) vs Next of Kin (NOK)
- Discharge planning
- Special Circumstances

"The ability to utilize information about an illness and proposed treatment options to make a choice that is congruent with one's own values and preferences"

4 Component Assessment Model:

1. Understanding
2. Appreciation
3. Reasoning
4. Expression of a Choice

Capacity

Influences:

- Language barriers
- Health Literacy
- Cultural considerations
- Distrust
- Medications
- Mental Health issues
- Delirium
- Communication skills of provider
- Distressing symptoms
- Psychosocial dynamics

Choice Architecture

"...the practice of influencing choice by organizing the context in which people make decisions...and the concept that the manner in which the choice is presented does not limit the choices available, but can be used to steer conversation..."

Two Primary Components:

Structuring-what to present

Describing-how to present

Legal Issues

- MA State Law and Institutional Workarounds
- Uncertainty/"Gray Areas"
- Family Dynamics and Disclosure
- Circle of Support Dynamics
- Guardianship Types
- HCP vs Medical Power of Attorney

Role Rights, Responsibilities and Scope

- Health Care Proxy
- Power of Attorney
- Guardianship (standard and expanded)
- Parents and Next of Kin

Discharge Planning

- Validity/Ability of NOK and/or SDM to consent (SNF/LTAC placement, hospice)
- MOLST completion
- Code status
- Changes in patient status that preclude return to prior facility
- Insurance barriers

Special Circumstances

- Brain Death
- Organ Donation
- NOK/SDM living abroad

Cultural Differences and Implicit Bias:

Impact on medical decision making in the acute inpatient setting

- Cultural Considerations
- Population demographics

- Language barriers
- Religious concerns
- Categories/Secondary Culture
- Implicit Bias:

  Self Awareness
  Assumptions

- Ism's & Stereotyping

- White Knight Syndrome
- Detaching from Outcomes

Cultural Considerations: SEMC demographics

- Large geographic catchment area
- Chinese, Russian, Vietnamese, Spanish, Portuguese and Haitian Creole speakers
- Mixed socioeconomic status
- Low to moderate health literacy and medical sophistication
- Moderate to high percentage of AUD and SUD
- High percentage of moderate to severe end stage organ failure

Cultural Considerations: Language barriers

- Language translation onsite for Chinese, Russian, Portuguese and Spanish speakers
- Video and phone interpretation for other languages
- Quality of Conversation
- Other unacknowledged biases

Cultural Considerations: Religious Concerns

- Catholic Priests and inclusive Chaplains onsite 7 days per week, on call overnight
- Community resources for other denominations
- Religious guidelines
- Gender and Family Role expectations

Cultural Considerations: How patients identify

- LGBTQIA+
- Religious Affiliation or Spiritual Practices
- Political Affiliation
- Race and/or Ethnicity
- Subcultures
- Personality Trait

Implicit Bias: Self Awareness

"Prejudice or stereotyping that is present but not consciously held or recognized"

- Requires radical honesty with oneself about provoked emotions, assumptions and comfort levels, the influence of prior interactions and willingness to combat bias

Findings from the Joint Commission

- Non-white patients receive fewer cardiovascular interventions and fewer renal transplants
- Black women are more likely to die after being diagnosed with breast cancer
- Non-white patients are less likely to be prescribed pain medications (non-narcotic and narcotic)
- Black men are less likely to receive chemotherapy and radiation therapy for prostate cancer and more likely to have testicle(s) removed
- Patients of color are more likely to be blamed for being too passive about their health care

https://www.jointcommission.org/resources/news-and-multimedia/newsletters/newsletters/quick-safety/quick-safety-issue-23-implicit-bias-in-health-care/

Project Implicit Research - Harvard University

The Implicit Association Test (IAT) measures the strength of associations between concepts and evaluations or stereotypes to reveal an individual's hidden or subconscious biases. This test was first published in 1998 by Project Implicit, and has since been continuously updated and enhanced. Project Implicit was founded by Tony Greenwald of the University of Washington, Mahzarin Banaji of Harvard University, and Brian Nosek of the University of Virginia. Project Implicit is a non-profit organization aimed at educating the public about hidden biases and providing a "virtual laboratory" for collecting data on the Internet.

Take the test here

Source: implicit.harvard.edu | About the IAT | About Us

Implicit Bias: Assumptions

- Health literacy
- Willingness and ability to manage disease or engage in discussions
- Coping
- Denial
- Existing social supports
- Beliefs, wishes and needs

Implicit Bias: Isms and Stereotypes

- Racism, sexism, ageism
- Gender identity, sexual expression, ethnicity and religion

Examples:

-Bikers are violent and dumb

-Asians are deferential

-Christian Scientists will refuse medical treatment

-Addicts are manipulative

Implicit Bias: White Knight Syndrome

- Internally focused - "my" experience, feeds some emotional need or desired power dynamic in provider, more telling, less asking
- Insidious and subtle or blatant
- Supersedes the patients autonomy

Implicit Bias: Detach from the outcome

- Strong sense of the "right thing to do"
- Triggers strong emotional response
- Buffer between team and family ("Can't you make them…")
- Steering or nudging is not our role or the goal
- Again, the "mutual explorer" role

Implicit Bias: Due diligence

- Refers back to assumptions
- Requires digging or investigation, or revisiting topic multiple times
- Reminder that we never know everything and that much of the patient remains out of our view

Collaboration between Palliative Care, Social Work and RN Case Management to support effective EOL discussions with SDM

- *The structure at SEMC*
- *Who are you?*
- *Opportunities*
- *Reflections*

Collaboration: SEMC

St. Elizabeth's Medical Center
A STEWARD FAMILY HOSPITAL
Steward

- PC is contracted, not employed by Steward
- CM was employing SW but narrow role as discharge planners
- High burnout rate, high attrition, frequent short term travelers
- Transitioning to smaller SW department and RNCM as discharge planners
- Rotation from floor to floor, usually covering multiple floors
- Lack of clarity about roles and responsibilities

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Collaboration: Who Are You?

How many RN's?

How many SW's?

How many SW's are more than 5 years out from program completion?

How many practice in acute inpatient environments?

How often are you involved in family meetings regarding goals of care?

How many have adequate, onsite PC programs?

Collaboration: Invitation to Share

We want to hear from you!

1. Tell us about your experiences at your current or prior worksite
2. Let's try for 3 mins per person with 5 mins for audience reflections or questions

Impact of COVID pandemic on planning and delivering PC services: An ICU Pilot

Our team compiled the following data between 3/17/20 and 4/21/21

- **102** patients consulted
- **46** patients consulted between 3/17/20 and 5/27/20
- **64** of those had **family meetings** to determine goals of care
- **57** passed, **40** of those had GOC shifted to focus on comfort
- **37 of 40** had family meetings to determine goals of care
- **40** patients spoke **language other than English**

COVID 19 ICU Pilot

- Primary communication with families
- Daily or twice daily updates by phone, often conference calls
- Care coordination between teams
- Average daily census in first 60 days: 24
- Average LOS: 14-21 days
- Twice weekly staff debriefings at change of shift

COVID 19 ICU Pilot: Lessons Learned

- Reinforced need for ongoing, regular communication between teams and families
- Highlighted benefits of PC
- Remote communication is not as good as face to face communication, especially with non-English speakers
- PC can be an integral part of Critical Care team

COVID 19 ICU Pilot: Unique Challenges

- Assessing health literacy and psychosocial dynamics
- Multiple members of a single family in ICU at a time
- Families had difficulty grasping gravity of illness
- Battling misinformation, distrust and fear
- Emotional burden on family not being able to see patients
- Infrastructure issues (PPE, AV devices, restrictions on Interpreters and Spiritual Care teams members, lack of private space)

COVID 19 ICU Pilot: Unique Challenges

- High volume, high stakes, high intensity bearing witness
- Inadequate staffing
- Unclear policies on visiting, EOL
- Unable to offload patient support to families
- Long hours

COVID 19 ICU Pilot: On the fly initiatives

- Advocated for iPADs mounted on rolling stands to FaceTime
- Created bio's and pictures to hang on patient doors
- Hosted formal staff support and debriefing as well as daily 1:1 "check in rounds"
- Collaborated with Facing Cancer Together to offer grief support group to bereaved

COVID 19 ICU Pilot: Silver Linings

- **Strong morale** and sense of community\cohesion
- **Supported integration** of PC into Critical Care team
- Positioned PC to provide **staff support**
- **Improved** providers and staffs **understanding** of PC
- **Organic growth** of PC team

Questions and Answers: 15 mins

Good Shepherd Inpatient Palliative Care Team at SEMC

Chelsea Shenker, Program Director
Jennifer Bowman,
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Decision Making Capacity

Capacity vs. Competency

Capacity: a functional determination about whether a patient is capable of making a medical decision, within a given situation
Physician/clinician determination based on the clinical picture
Pertains only to the current situation/specific decision
Takes into consideration the severity and complexity of the decision, factoring in the possible consequences (risks/benefits) to the patient
Some people may have capacity to make some medical decisions (ex- PO abx or a minor procedure) but not other decisions (ex- undergoing surgery or chemo)

Competency: "the ability of an individual to participate in legal proceedings"
Legal competence is presumed and a hearing with presentation of evidence is required to disprove an individual's competence
Legal determination made by a judge in a court, and since it's never determined by medical providers, so we won't use this term in the rest of our discussion

Reference: https://www.ncbi.nlm.nih.gov/books/NBK532862/

Why is decision making capacity important?

All appropriate patients should be able to make informed decisions (consent) for themselves (patient autonomy)

Which one of the following is not required to say that a patient has decision-making capacity?

a) able to reason, to weigh treatment options
b) can express a choice among treatment options
c) is oriented to person, place and time
d) understands the significance of information relative to personal circumstances

To demonstrate decision making capacity a patient must be able to:

Receive info: must be awake, but not necessarily oriented x4

Understand, evaluate, and process information

Do they recall conversations about the treatment and do they have the ability to process probable outcomes (ex- be able to relate what they have been told and what it means). This can be affected by problems w/ memory, attention span, and intelligence

Ability to reason/ rationally evaluate the burdens, risks, benefits, and alternatives to the proposed health care. This can be affected by psychosis, depression, anxiety, delirium, and dementia

Communicate a treatment choice (implies ability to communicate meaning that an unconscious patient can't make decision), and this decision needs to be consistent/stable enough for the treatment to be implemented

Who makes decisions if a patient lacks decision-making capacity?

A surrogate (ex: patient appointed HCP, patient representative, or a guardian) or in absence of HCP or guardian, next of kin surrogate decision maker (NOK-SDM).

Reference: https://www.mypcnow.org/fast-fact/decision-making-capacity/

Palliative Care COVID Response Plan in the ICU

March 31, 2020

Intent:

Adapt the Palliative Care service (PC) to meet the needs of the patients, families, and staff at SEMC during the COVID pandemic..

Proactively meet increased demand for family communication for consulted COVID ICU patients.

Utilize State pandemic waivers that allow virtual and telephonic methods of conducting patient care.

Assist the ICU in ensuring SEMC pandemic rules are abided without interruption to patient and family care/communication.

Establish a consistent process to orient families to ICU and set expectations for communication as visiting is prohibited.

Ensure consistent messaging passed directly from Attending to Palliative Care (PC) team to family.

Provide twice daily updates to the family (with modification as needed and additional outreach for changes in condition).

Confirm HCP/medical decision makers to the extent possible (Case Management is partnering with us to achieve this).

The usual function of the PC service will continue without interruption (consults for non-ICU and non-COVID patients).

The PC service will be staffed at the same level as during non pandemic times.

Purpose:

Reduce HIPPA violation risk given higher volume of calls from family members by identifying family point person(s).

Leverage communication expertise to reduce workload on ICU Attendings, Residents and Nurses to optimize care of critically ill patients.

Minimize miscommunication and misunderstanding stemming from multiple sources of information to families to the extent possible.

Provide psychosocial and spiritual support to families in concert with Chaplaincy and Case Management.

Prepare families for foreseeable potential outcomes and possibility of difficult decision making.

Participate in and facilitate Advance Directive form/order completion (HCP, DNR/MOSLT)

Process:

All COVID patients are referred for PC consultation.. If not intubated, the patient can determine the level of support desired.

PC assesses HCP/decision makers (with Social Work assistance prn) and provides staff with a list of all known parties that are permitted communication by HCP.

PC contacts family, orients them to the ICU process.

Attendings brief PC twice daily, and as needed, with important changes in condition.

PC provides M-F coverage for consulted COVID patients. On weekends, a designated Resident (to be designated and supervised by Attending,) will communicate with families with (telephone) backup by PC for complex GOC discussions and EOL support. PC and designated Resident will ensure thorough sign out at the start and end of each weekend.

PC coordinates virtual family meetings as needed in cooperation with Attending. PC may provide family follow up as needed to make referrals for bereavement support.

This plan will be re-evaluated, at a minimum, on a monthly basis by PC and ICU to ensure it is meeting needs and remains appropriate given the dynamic state of the pandemic.

SPIKES: an adapted format for Goals of Care Meetings

Setting:	Who is included
	Where: private, quiet, adequate seating and size, potential interrupters (eg when is the room next booked, can we put a sign on the door), tissues, water and lighting, muting phones.
	Opener: setting expectations for meeting
Perception:	What does patient and family understand about their illness\treatments
	Medical literacy\sophistication
	Issues around trust
	Psychosocial dynamics
Invitation:	Would you like to know more query assesses readiness\willingness
	Shifts power dynamic
Knowledge:	Correct\Add to understanding
	Medical updates
	Diagnostic or treatment education
Emotion:	Expect emotional response

Summarize\Strategize:	Review or teach back of plan
	Set a timeline for decision making
	Identify additional resources