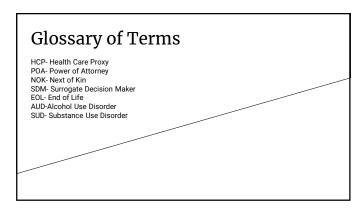
## Ethical Considerations in Surrogate Decision Making: An Acute Inpatient Perspective

Alixis Van Horn, MSN, APRN-C, ACHPN Inpatient Palliative Care Nurse Practitioner Good Shepherd Community Care @ St. Elizabeth's Hospital Good Shepherd Community Care

## Objectives

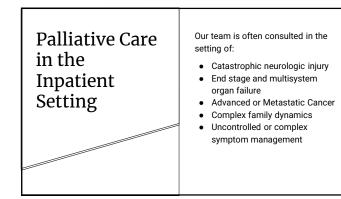
- Discuss challenges associated with Ethical Decision Making
   Explore the impact of cultural differences and implicit bias
   Discuss collaboration between Social Work, Case Management, and inpatient Palliative Care Team
   Deflort on the impact of the COVID pandemic on delivoration
- Reflect on the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

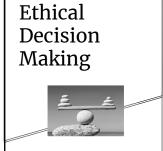




We are a <u>consultative</u> service, composed of a team of Nurse Practitioners, with off site Physician support that:

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





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

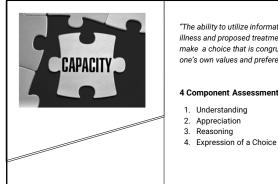
Nonmaleficence: weighing benefits and burdens

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

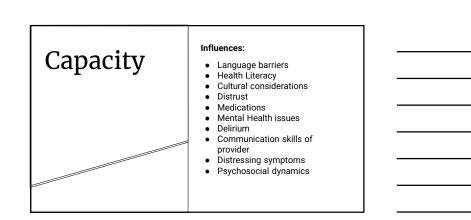
**Ethical Decision** Making: Challenges for patients lacking capacity AND without an identified SDM

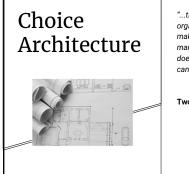
- What is Capacity and how is it assessed?
- Choice Architecture Legal Issues and
- Massachusetts Law/Institutional Workarounds
- Health Care Proxy (HCP) vs guardian vs Power of Attorney
- (POA) vs Next of Kin (NOK) • Discharge planning
- Special Circumstances



"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:





"...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:

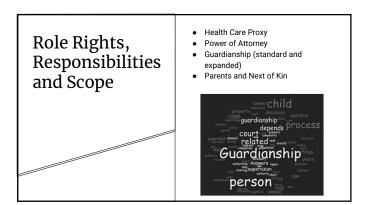
Structuring-what to present

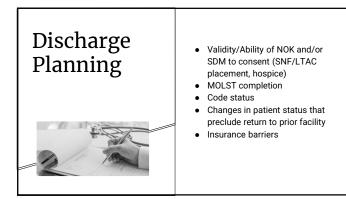
Describing-how to present

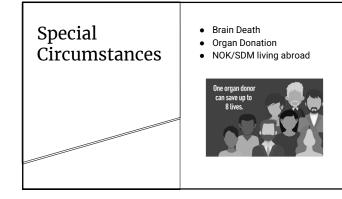


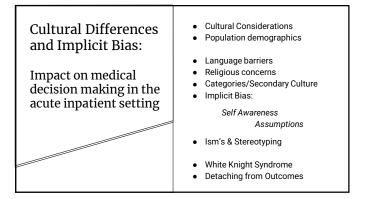
- MA State Law and Institutional

- HCP vs Medical Power of Attorney





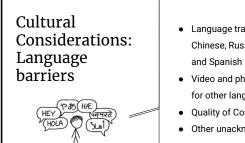




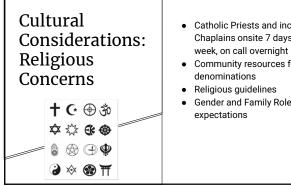
#### Cultural **Considerations**: SEMC demographics



- 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



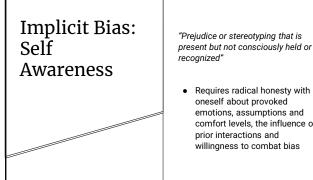
- Language translation onsite for Chinese, Russian, Portuguese and Spanish speakers
- Video and phone interpretation for other languages
- Quality of Conversation
- Other unacknowledged biases



- Catholic Priests and inclusive Chaplains onsite 7 days per
- Community resources for other
- Religious guidelines
- Gender and Family Role

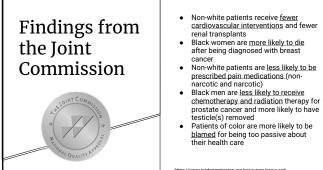
## Cultural **Considerations**: How patients identify • •

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



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

emotions, assumptions and comfort levels, the influence of willingness to combat bias



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

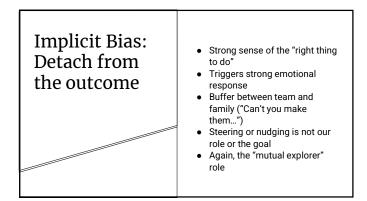
Source: implicit.harvard.edu | About the IAT | About Us

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



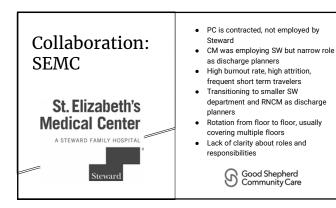
## Implicit Bias: Due diligence

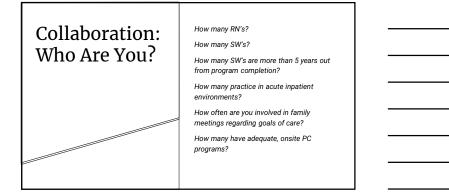


- Refers back to assumptions
- Requires digging or investigation, or revisiting topic multiple times
- Reminder that we never know everything and that much of the patient remains out of our view



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





## Collaboration: Invitation to Share



#### We want to hear from you!

- 1. Tell us about your experiences at your current or prior worksite
- 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 consulted46 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
- shifted to focus on comfort
  37 of 40 had family meetings to determine goals of care
- 40 patients spoke language other than English

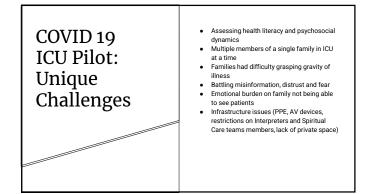
# COVID 19 ICU Pilot

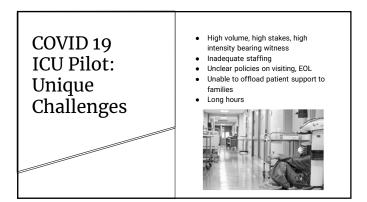
- Primary communication with families
- Daily or twice daily updates by phone, often conference calls
- Care coordination between teamsAverage daily census in first 60
- days: 24 • Average LOS: 14-21 days
- Average Los. 14-21 days
   Twice weekly staff debriefings at change of shift



- Reinforced need for ongoing, regular communication between teams and families
- Highlighted benefits of PCRemote communication is not as
- good as face to facecommunication, especially withnon-English speakersPC can be an integral part of

Critical Care team

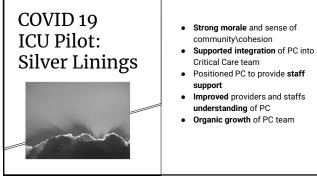




## COVID 19 ICU Pilot: On the fly initiatives



- 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



- Strong morale and sense of
- Improved providers and staffs



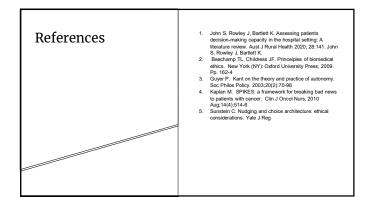




Alixis Van Horn, MSN, APRN-C, ACHPN

Erin Ivatts, MSN, APRN-C, ACPHN







## **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 decisionmaking 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 interrupter (eg when is the room next booked, can we put a sign on the door), tissues, water and lighting, muting phones.	rs
	Opener: setting expectations for meeting	
Perception:	What does patient and family understand about their illness\treatmen	its
	Medical literacy\sophistication	
	lssues around trust	
	Psychosocial dynamics	
Invitation:	Would you like to know more query assesses readiness\willingness	
	Shifts power dynamic	
-	Correct\Add to understanding	
	Medical updates	
	Diagnostic or treatment education	
Emotion:	Expect emotional response	
Summarize	trategize: Review or teach back of plan	
	Set a timeline for decision making	

Identify additional resources