

Medical Decision Making for Patients with Covid-19

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Introduction:

Many critically ill patients with COVID-19 who require mechanical ventilation are unable to effectively communicate with caregivers or with family members. As a consequence of not being able to speak or write, these individuals are unable to actively participate in their care or in decisions about their care. In addition to restrictions on who can be at the patient's bedside, the barriers to effective communication can lead to further isolation and a loss of control. In order to enhance patients' control, participation in care, and interactions with healthcare providers, caregivers, family, and friends, it is essential that communication rights of all individuals are respected and granted, regardless of their physical condition.

Communication Challenges

Barriers to effective communication have been associated with a significant increase in risk of patients experiencing a preventable adverse medical events that can increase their length of stay and unfortunately can also lead to death (Bartlett et al. 2008; Hurtig et al 2018). Being unable to communicate with one's caregivers can also contribute to a sense of isolation, disorientation and delirium.

The inability to speak can result in caregivers believing that the patients are not capable of participating in decisions about their care. Professionals may assume that the inability to speak is equated to having diminished cognitive skills or impairments. They may use simplified speech and/or speak loudly because they assume the patient may also be hearing impaired. Patients as well as healthy elders may find these behaviors to be demeaning. They feel that they are being denied autonomy and a role in medical decision making.

Medical Decision Making - Establishing Competence

In order for individuals who are unable to speak and write to participate in their care and in decision making, they need to be able to demonstrate that they understand their situation and that they can articulate their preferences when it comes to their care. Since delirium is prevalent in ICU patients it is important to assess patients with screening tools that do not rely on verbal responses.

Most often medical staff attempt to ascertain whether a patient has competence by eliciting responses to yes/no questions. Reliance on interpreting responses to yes/no questions as a way of determining competence and a patient's preferences can introduce a bias based on what questions or options the patient is presented.

Marshall & Hurtig (2019) described a case about the decision to switch a patient from oral intubation to a tracheostomy. The medical staff were trying to elicit a patient's consent to perform the tracheostomy and when the patient appeared to respond "no," they took this to mean that he did not want to remain on ventilatory support. The yes/no question format precludes the individual from easily trying to solicit the critical information necessary to make an informed decision. Luckily, presenting

the patient with alternative ways of communication revealed his intention to say, “no” because he thought the tracheostomy would be done without sedation.

At the University of Iowa Hospitals & Clinics we had provided an elderly neurosurgery patient with a communication device that allowed her to communicate with her caregivers and family while she was mechanically ventilated postoperatively. She had been introduced to the device preoperatively and was using it effectively for several days. When we rounded a few days later, the nurse indicated that she thought the patient was showing signs of delirium. This was based on the nurse’s observations that the patient was not spelling words correctly and appeared to be just randomly typing characters. Upon entering the patient’s room, we asked the patient what she was doing. She responded by typing out “My daughter lives in Australia and we use IM (instant messaging). So I was just practicing my IM skills.” This case also illustrates the dangers of misinterpretation of a patient’s status when there are barriers to communication.

Supporting Medical Decision Making

Providing a range of message options on communication boards enables non-speaking patients to solicit information related to medical decision-making and end-of-life choices.

For example:

WHAT DO YOU WANT TO DISCUSS?				MAIN PAGE
MEDICAL DECISION MAKING		MEDICAL STATUS QUESTIONS		
EMOTIONS		RELIGION / SPIRITUALITY		
YES	I DON'T KNOW/ UNDERSTAND	LATER	LETTER BOARD/ OTHER	NO

WHAT DO YOU WANT TO DISCUSS?					MEDICAL DECISION MAKING
MY DECISIONS	BREATHING TUBES & MACHINES	CPR / RESUSCITATION	DIALYSIS	FEEDING TUBES	
HEALTH CARE PROXY	COMFORT CARE	ALLOW NATURAL DEATH	FUNERAL PLANS	ORGAN DONATION	
YES	I DON'T KNOW/ UNDERSTAND	LATER	LETTER BOARD/ OTHER	NO	

Such communication boards may support patients in understanding of the implications of certain decisions and ensure that their medical care wishes are as unambiguous as possible and clearly grounded in their current situation. For example:

BREATHING TUBES & MACHINES 11				
WHAT IS A VENTILATOR?	WHAT ARE MY OPTIONS?	COULD I GO HOME WITH IT?	WILL I BE ABLE TO SPEAK?	
WHAT IS A BREATHING TUBE?	OK WITH A <u>CHRONIC</u> BREATHING TUBE	OK WITH A <u>TEMPORARY</u> BREATHING TUBE	I DON'T WANT A BREATHING TUBE AT ALL	
YES	I DON'T KNOW/ UNDERSTAND	LATER	LETTER BOARD/ OTHER	NO

MY DECISIONS 9				
WHEN DO I HAVE TO DECIDE?	CAN I CHANGE MY MIND?	I WANT TO TALK TO MY FAMILY / PROXY		
WHAT HAPPENS IF I CAN'T DECIDE?	I DON'T WANT TO MAKE THIS DECISION	I WANT MY PROXY TO DECIDE		
YES	I DON'T KNOW/ UNDERSTAND	LATER	LETTER BOARD/ OTHER	NO


Societal & Personal Challenges

Discussion surrounding critical illness and death may be uncomfortable for patients and healthcare professionals. Unfortunately, conversations about death and dying are often put off until it is too late. This may be the case in ICUs treating trauma patients as well as patients with COVID-19 who are unable to speak. What healthcare providers struggle with is how to talk to their patients about a dire prognosis and how to provide patients with communication tools that allow the patients to make their reactions and choices clear.

Supporting end of life conversations requires providing patients with

- The means to initiate “difficult conversations” related to death and dying
- The means to express a wide range of emotions
- Increased control during bedside conversations.

MEDICAL STATUS QUESTIONS 19				
WHAT IS HAPPENING TO ME?	WILL I GET BETTER?	AM I GOING TO DIE?	HAVE WE DONE ALL WE CAN?	
WHAT ARE MY OPTIONS?	WILL I BE AWAKE?	WILL IT HURT?	I WANT TO TALK WITH MY FAMILY	
YES	I DON'T KNOW/ UNDERSTAND	LATER	LETTER BOARD/ OTHER	NO

EMOTIONS 21										
ANGRY	SAD	SCARED	ANXIOUS	ALONE						
TIRED	SUFFERING	AT PEACE	PLEASE LEAVE	HOW DO YOU FEEL?						
NONE  EXTREMELY										
0	1	2	3	4	5	6	7	8	9	10
YES	I DON'T KNOW/ UNDERSTAND	LATER	LETTER BOARD/ OTHER					NO		

- The means of discussing beliefs related to mortality, afterlife, prayer and intercession of a higher power as well as wishes related to funeral/memorial service rituals (organ donation, burial, cremation, etc.).

RELIGION / SPIRITUALITY 23				
PLEASE PRAY WITH ME	I WANT TO SEE A CHAPLAIN	I WANT TO READ TEXT / SCRIPTURE	THESE ARE PERSONAL MATTERS	
I WANT TO PARTICIPATE IN A RITUAL	SIT WITH ME	I WOULD LIKE TO BE ALONE	I AM NOT RELIGIOUS/ SPIRITUAL	
YES	I DON'T KNOW/ UNDERSTAND	LATER	LETTER BOARD/ OTHER	NO

Summary

Engaging in conversations and making decisions to accept or terminate life-sustaining treatment is difficult for patients, caregivers, and their family members. Allowing the patients to have a significant role in those decisions preserves their autonomy and can also reduce the stress of the caregivers and family members. An approach to empower patients, despite potentially being unable to speak or who have reduced motor abilities, helps them to remain engaged with their caregivers and to actively participate in medical decision making, even in terminal end-of-life scenarios. Use of supportive communication materials and strategies may support these conversations.

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