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Case Report

Assessing Decision-Making Capacity in a Patient with Cancer and Untreated Psychiatric Illness

Nidhi Shah*
Department of Palliative Medicine, Ichan School of Medicine, USA

***Corresponding author:** Nidhi Shah, Assistant Professor at Ichan School of Medicine, Department of Palliative Medicine, Mount Sinai Beth Israel Medical Center, First Ave @16th Street, New York, NY 10003, USA

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Abstract

Decision-making capacity at the end-of-life is an extremely challenging process complicated by heightened emotions and complex needs to respect patient autonomy. The process is often convoluted by heavy symptom burden, complex psychosocial backgrounds and concurrent undiagnosed psychiatric illnesses.

Keywords: Decision-making capacity; Confusion assessment method

Abbreviations

CAM: Confusion Assessment Method; ICU: Intensive Care Unit; MMSE: Mini Mental Status Examination; MDAS: Memorial Delirium Assessment Scale; ACE: Aid to Capacity Evaluation; HCAT: Hopkins Competency Assessment Tool; CIS: Competency Interview Schedule; OCQ: Ontario Competency Questionnaire; FCV: Fitten's Clinical Vignettes; SICIATRI: Structured Interview for Competency and Incompetency Assessment and Ranking Inventory; CCTI: Capacity to Consent to Treatment Instrument; CAI: Competency Assessment Interview

Case Report

We present a 38 year-old man with a pathological and radiological diagnosis of stage IV squamous cell carcinoma of the lung. He had a past medical history of bipolar disorder and schizophrenia diagnosed after an episode of incarceration during his youth. His medical records demonstrated noncompliance with psychiatric treatment. The course of his oncologic treatment with chemotherapy was interrupted by patient noncompliance, rebellious and compulsive behavior towards intravenous drug use and recurrent pulmonary pathologies. He received 2 cycles of chemotherapy from the time of diagnosis. He was admitted to our facility in the summer of 2014 with worsening chest pain and shortness of breath due to healthcare associated pneumonia with recurrent pneumothorax. Despite maximal medical interventions, patient's shortness of breath continued to progress. One week into the hospital course, palliative care team was consulted for management of acute symptom burden and to establish goals of care. At the very first encounter with the patient, the palliative care physicians noted the belligerent and antagonistic behavior of the patient. The course of his oncologic treatment was interrupted due to multiple medical and psychosocial complexities. The palliative care team used the Confusion Assessment Method (CAM) to screen for delirium [1]. The patient was noted to have delirium at multiple encounters. The palliative care team used various approaches suggested by Tunzi to assess for decision-making capacity [2]. The heavy symptom burden, untreated psychiatric illness, persistent refusal to various treatment options, continued inappropriate behavioral explosions with lack of rationality in patient responses categorized the patient to lack decision-making capacity. It became clear that the patient lacked insight into the entire disease process. A tremendous amount of existential distress was palpable. The clinical deterioration of his condition was rapid and inevitable. The patient lacked the verbal organization to express his choice of allowing natural death, but used aggressive and unsympathetic phrases to communicate the same.He began to express his fright of drowning and fear of being unable to breath. He could share his terror of being attached to tubes and machines, but not express his choice of allowing natural death. Grieving process was ongoing and noted by the patient's act of sharing videos of tragic and national catastrophic moments to providers entering his room.There were no formal advance directives in the patient's chart. The patient's father was identified to be the surrogate-decision maker and goals of care were directed with the patient and him. As time passed and his condition continued to deteriorate, he started to become calmer towards medical professionals, increased acceptance to medical treatments and deferred healthcare decisions to his father. The team's objective was now focused to preserve patient's autonomy and self-determination. Treatment under such clinical scenario was understood to be palliative in nature. The patient was transferred to acute hospice and palliative care unit for aggressive symptom management and comfort care. He was enrolled into hospice care and approached end-of-life in the hospice and palliative care unit of the facility.

Discussion

Definition of decision-making capacity

Assessment of decision-making capacity is the ability of patients to make their own health care decisions in a meaningful manner. Physicians assess for decision-making capacity at every patient encounter [3]. Decision-making capacity assessment includes 4 basic components such as understanding, appreciation, reasoning and the ability to express a choice. Many factors influence decision-making capacity, including but not limited to terminal medical illness, known psychiatric illness, substance abuse disorder, personal beliefs, religious beliefs, patient and family emotions and psychosocial distress.

Determination of capacity

A frequent question that arises in daily clinical practice is who will perform decision-making capacity evaluation. A study done by

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Table 1: Brief review of tools to assess capacity and primary indication for the tool.

Tools available to assess capacity	Primary Indication
MMSE	Measure cognitive status
Mac Arthur compentency assessment tool	Clinical tool to assess patient's capacities to make treatment decisions [9]
Aid to capacity evaluation	Systematically evaluate capacity when a patient is facing a medical decision [17]
Hopkins Competency Assessment Tool	Evaluating Patient's Capacity to Give Informed Consent [18]
Competency Interview Schedule	Assess the mental competence of individuals who consent or refuse psychiatric treatment [19]
Structured Interview for Competency and Incompetency Assessment and Ranking Inventory	Assess the competency for giving informed consent to treatment among psychiatric and medical patients [20]
Capacity to Consent to Treatment Instrument	Standardized psychometric instrument designed to assess the treatment consent capacity of adults [21]
Consent Capacity Instrument	Assesses ability to consent to treatments

Ganzini et al. noted that consultant physicians that perform capacity evaluations based upon request from other clinicians perceive that misunderstandings and knowledge deficits about the assessment of decision-making capacity are common [4]. Decision-making capacity can be assessed by any physician. In certain scenarios, psychiatry consultation is required which include but are not limited to known psychiatric illness [2,5]. In the critical care setting, decision-making capacity has to be evaluated with ever changing clinical patient scenario. Physicians are often interposed in situations where patients lack decision-making capacity and surrogate-decision making is not coherent with patient expressed goals of care. It is estimated that on an average 60% to 80% of critically ill patients lack decision-making capacity at some point during their hospital course in the Intensive Care Unit (ICU) [6]. As a result, intensivists have to discuss further goals of care with a patient's surrogate decision maker based on the state laws where they practice. A physician generally faces challenging situations with no prior advance directives, improbable expectations from surrogate decision makers and families based on patient scenario and trying to advocate for the patient to respect their autonomy. In such situations, it becomes an interdisciplinary form of care with thorough communication with several consultants, surrogate decision makers and patient if able to participate. Ongoing goals of care discussions with involvement from palliative care clinicians in the ICU setting help to address key elements in patient care [12]. Delirium is frequently encountered in the terminally ill patient. Almost half (42%) of the palliative care patients are delirious on evaluation and majority (45%) of the patients develop delirium through the hospital course [13]. A vast majority (80%) of ICU patients are found to be delirious on evaluation [14]. Eighty-eight percent of actively dying patients are noted to be delirious. It is important to screen for delirium to be able to assess for capacity. Delirium is notoriously known to be associated with increased mortality of patients in the hospital. The frequently used tools to assess delirium include Mini Mental Status Examination (MMSE), Memorial Delirium Assessment Scale (MDAS), Confusion Assessment Method (CAM) and MacArthur Competence Assessment Tool for Treatment (MacCAT-T) [7,8,9,13-16]. The choice of the tool depends on the ease of completion and the patient population that is being evaluated.

Competency and capacity

The terms competency and capacity have been used interchangeably, but they are not synonymous. Competency is a legal term and refers to the mental ability and cognitive capabilities required to execute a legally recognized act rationally [3]. Decisional-capacity is a medical term relating to the ability to make appropriate medical decisions in the direction of care. A review article by Leo et al. notes capacity as an individual's psychological abilities to form rational decisions, specifically the individual's ability to understand, appreciate, and manipulate information and form rational decisions.

Tools to assess decision-making capacity

There is no standard tool available to assess decision-making capacity. It is an ongoing process of understanding patient's perception of disease and its course. Applebaum identified the basis of decision making which include a patient's ability to communicate a choice, understand relevant information, appreciate the situation and its consequences, and manipulate the information rationally [10]. Various researchers have tried to make the process simple. Soriano et al. a 5 step approach with the following questions [13]: (1) What is your present condition? (2) What treatment is being recommended to you? (3) What might happen to you if you decide to accept the proposed treatment? (4) What might happen if you decide to forego the proposed treatment? (5) What alternatives are available and what are the consequences of each?

Other tools frequently used include the MMSE, Aid to Capacity Evaluation (ACE), Hopkins Competency Assessment Tool (HCAT), Competency Interview Schedule (CIS), Ontario Competency Questionnaire (OCQ), Fitten's Clinical Vignettes (FCV), Structured Interview for Competency and Incompetency Assessment and Ranking Inventory (SICIATRI), Capacity to Consent to Treatment Instrument (CCTI), Consent Capacity Instrument, Two-Part Consent Form, Competency Assessment Interview (CAI) [2] (Table 1). The choice of a tool depends on the clinician, patient scenario and urgency of evaluation. Assessment by various tools may be required in a complex case scenario to establish appropriate judgement of decision-making capacity.

Surrogate decision-making

A patient's autonomy and self-determination are crucial to the process of decision-making. If a patient is determined to lack decision-making capacity, the nature of the situation should be assessed by the health care team. With an impending decision for lifesaving or life-prolonging treatment, a physician can undertake the decision-making in view of the emergent nature of the situation and no time to locate a surrogate. This is based on the principle that the physician is acting on behalf of the patient in a manner consistent with what any reasonable person in that situation would prefer [3]. Appropriate documentation in the patient's health record of the nature of the situation is crucial

for such scenarios. In scenarios with no imminent danger to life, a surrogate decision maker should be approached. The surrogates are responsible for decision-making based on the known wishes of the patient that have been explicitly written or verbally expressed. If a surrogate is not aware about the patient wishes, a court appointed guardian may act on behalf of the patient to act in the best interest of the patient. An institutional ethics consultation is often called upon to guide in challenging patient situations in order to maintain patient autonomy and act in the best interest of the patient.

Decision-making capacity at end-of-life

Assessment of decision-making capacity is crucial to care of terminally ill patients and becomes challenging in this sub-group of patients with known mental illness and active substance abuse. Patients are often approached with medical decisions around their care towards end-of-life and most often have a decisional impairment for health care choices. Advancing illness coupled with uncontrolled symptoms can make the process of assessing for decision-making capacity extremely challenging for physicians. A study done by Kolva et al. noted that decision-making capacity was impaired in at least one domain for one third of the sample [11]. The study raises awareness for decisional impairment at the end of life and the importance of balancing for patient autonomy and protecting them from harm resulting from impaired decisional capacity. There are no gold-standard methods or instruments that can assure its valid measurements. The process is time and decision specific and needs a continuous ongoing assessment of the patient's medical condition and disease perception.

The case mentioned above highlights the importance of consideration of multiple factors to assess decisional-capacity in a terminally ill patient. The physicians felt professionally and morally responsible to strike a balance between the medical complexity, untreated psychiatric illness, heavy symptom burden and lack of insight into disease process coupled with an undiagnosed personality disorder. Establishment of surrogate decision maker is an important step to establish goals of care for a terminally ill patient with decisional impairment and with lack of formal advance directives. In addition to the various tools used by the palliative care team to assess for patient's decision-making capacity,the physicians frequently assessed for treatment of reversible medical conditions such as hypoxia, infection, metabolic abnormality. An ongoing conversation with the patient about his disease perception and insight into medical complexities was crucial to the entire process. The goal of the team remained to respect patient wishes and maintain his autonomy as he approached end-of-life.

Conclusion

Decision-making capacity is an ongoing complex process that requires an interdisciplinary team approach. Consultation from appropriate departments should be sought in challenging patient situations. The need for decision-making arises the most in decisions with imminent danger to life and compromise on patient autonomy. From a perspective of palliative care physicians, the process of decision-making is extremely crucial to safeguard patient wishes and minimize existential suffering. Thus striking a balance between a patient's refusals of life-prolonging treatment and lack of decision-making capacity at the end-of-life become a vital skill set every palliative care physician must possess.

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