Ethics for Lunch Summary – September 2018

The case presented at the September Ethics for Lunch involved a medically complex patient with an extensive psychiatric history. The patient was refusing diagnostic procedures and treatments out of his concern that his mental illness would get worse. The healthcare team was concerned that his refusals could lead to a worsening of his physical health and could ultimately be life-threatening. The patient’s psychiatric condition was not felt to be active, and the medical and psychiatric teams were of the opinion that he retained decision-making capacity. Multiple questions arose out of his refusal of necessary treatment. How do we care for an individual who is refusing needed care, knowing that the consequences will be he will get sicker? If the patient is deemed to have capacity but is not well enough to leave the hospital, how does the healthcare team manage his refusals? If he loses capacity because his condition leads to unconsciousness, is it ethically appropriate to provide treatments that will save his life, even though he was refusing them when he had capacity?

The audience and panel discussed many issues in relation to the case.

1. Assessment of decision-making capacity requires four elements:
   1. **Communicating a choice**, with some consistency or fixity in the decision made.
   2. **Understanding the information** necessary to provide informed consent/refusal, including the nature of their condition and the risks, benefits, and alternatives to the recommended treatment. This requires that the person is able to hear or otherwise receive the information and ask questions about what is being communicated to them.
   3. **Appreciating the situation** and the implications of their decision. This requires that the person internally process the medical information in light of the context and weigh it against the person’s own preferences.
   4. **Reasoning about the options** and providing an explanation of the reasons for the choice made.
2. To help ensure a person in making good decisions, it is sometimes helpful to have a family member or friend assist them in the decision-making process.
3. Just because a person has a mental illness or has a history of mental illness does not entail that they lack the capacity to make their own decisions.
4. When a person has a mental illness and prioritizes their mental health over their physical health, it is important not to dismiss or diminish their view of their best interests (e.g., when their reasons for refusal of medical interventions is due to concern that acceptance of the treatment would lead to a worsening of their mental health).
5. It is understandable that a clinician might feel uncomfortable in accepting a decision by a patient that seems to be a bad choice from a medical perspective.
6. When a patient with a history of mental illness is making a decision that clinicians may disagree with, it is important to ask how the healthcare team would react to the same decision by another patient who did not have a mental illness. Is it that the team disagrees with the values and preferences being stated by the patient when the decision seems irrational?
7. Sometimes the decisions that a person might make, whether they have a mental illness or not, may be made in order to provoke a response by another person. Such provocative behaviors can be challenging, because its seeming irrationality can lead to frustration, exhaustion from having to try to persuade the person or negotiate with them, or loss of empathy.
8. Sometimes refusals, whether of routine interventions or more serious treatments, are manipulative. The refusals can be a means of getting more attention or social interaction. Sometimes the refusals are a means of exerting control, in a healthcare system where patients may feel they have little or no control of for mentally ill patients who may feel out of control.
9. Sometimes strategies can be employed by the medical team to curb a patient’s unwanted or frustrating behavior. These include focusing the patient’s attention on the items that are most important, going into the room with a clear plan, prioritizing what questions will be asked of the patient, prioritizing which medications are most important to administer if it is anticipated the patient will refuse some of them, avoiding having the patient get over-stimulated because it could them to shut down, and engaging the patient on a personal level (while caregiving tasks are being accomplished). This latter strategy allows the patient to feel less like an object and more like a person.
10. When a patient has a psychiatric history, it can be helpful to contact their previous mental health care providers to know what their baseline is and what works best in caring for them.
11. When there is a question of whether (a history of) mental illness is impacting on decision-making capacity, four categories need to be considered:
    1. What is the **psychiatric diagnosis**? Is it currently active? For instance, in a patient with a history of bipolar disorder, are they currently manic or depressed? Is the patient showing signs of psychosis? The key question is whether the patient is under the sway of a treatable mental illness.
    2. What is the patient’s **personality**? Does the patient have a personality disorder or a particular personality type that influences how they behave and make decisions? In essence, who are they as a person? Does their personal history provide any guide to how or why they are behaving/deciding as they are in this situation? Where is the person developmentally? What is their intellect and level of education? Have they experienced trauma in their lives?
    3. Is the patient under the influence of any **motivating behaviors**—use drugs, drink alcohol, have a sexual addiction, etc. The key factor here is what does the person do, and is the desire or compulsion for that behavior influencing how they approach the decision at hand.
    4. What is the person’s **environment**? What are they surrounded by? Are they isolated? Who are their supports? Are they able to make connections with other people?
12. If a patient is reliant on others (due to the need for medical or psychiatric care), the team should seek opportunities to allow the person to have whatever control they can in the situation. This can enhance their sense of autonomy and help them navigate choices, particularly in cases that involve quality of life or dignity concerns when the patient’s voice becomes all the more important.
13. The health care team should also recognize when a patient is making decisions out of emotion in the moment (for instance, they are angry and refuse treatments because of the anger). These non-rational, rash or impulsive decisions borne of emotion might change once the emotion has settled down. Having a trusting relationship with a clinician can be a foundation for psychotherapeutic interventions to curb overwhelming emotions, so the patient can make more reasoned decisions and not let their emotions get the best of them.
14. Trauma informed care can be important in how patients are approached, how clinicians speak to them, whether it is permissible to touch them, etc., so as to not trigger the patient into uncontrollable emotions.
15. When a patient’s behavior is frustrating or taxing for the healthcare team, it may lead to avoidance in wanting to care the patient (e.g., rotating responsibilities so that one clinician is not burdened with the caregiving). This may be helpful for the health care team to manage the situation but may not be optimal for the patient in developing consistent attachments and trusting relationships.
16. When decisions are being made in light of quality of life considerations, it is important that clinicians do not impose their own values on the patient (e.g., the clinicians sense the patient has a poor quality of life and therefore certain treatments should not be offered, but the patient actually feels they have a good quality of life). When quality of life is a central concern, it is also important, however, that clinicians do not forget the need for empathy and trying to understand the patient’s perspective and imagine what it is like to be in the patient’s shoes.
17. In advance care planning, it is important to determine who will speak for the patient if they lose capacity to make their own decisions. Once a person is designated as a health care agent, it is also important to determine how the patient would want that person to make decisions:
    1. Would the patient want the surrogate decision-maker to make decisions solely on the wishes stated by the patient?
    2. Would the patient prefer to defer all decision-making to the surrogate decision-maker and have them choose what they thought was best, even if it differed from what the patient stated when conscious?
    3. Would the patient prefer some mix of shared decision-making, combining their preferences and wishes with their surrogate decision-maker’s wishes in order to come up with a decision?
18. Decision-making capacity can occur on a sliding scale. Simple decisions that do not involve significant risk may be straightforward enough for the person to understand and rationally manipulate the information to come to a decision. Complex decisions that involve complicated procedures and/or entail high risk may be more difficult to understand or weigh the pros and cons, so clinicians want to ensure the patient really has capacity to make these more momentous decisions. Concern with the sliding scale notion of decision-making capacity, however, is that clinicians may declare a patient to have capacity for simple decisions that a patient agrees to in concert with the team’s recommendations but then declare the patient not to have capacity when the patient disagrees with the team’s recommendation for more serious decisions.
19. Patients are assumed to have decision-making capacity until proven otherwise.
20. In many clinical situations when there is refusal of recommended treatment, not just in the interface with mental health, clinicians have to grapple with their obligations of beneficence (recommending and advocating for what they think is best for the patient) and respect for autonomy (allowing the patient with decision-making capacity to make their own decisions).

References:

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