The May Ethics for Lunch addressed the issue of patients either not adhering to a treatment plan or intermittently refusing aspect of the care plan, which then jeopardizes achievement of a successful outcome or leads to untoward complications and delays. The session presented four cases with different variations on this general theme: (1) a patient not following the instructions for a diagnostic test, leading to a delay in diagnosis; (2) a family member declining pain medication for an incapacitated patient; (3) a chronically ill patient with a prolonged hospitalization who sporadically refuses medications or dialysis, leading to difficulties in his management; (4) parents who do not follow the treatment plan for their daughter with mental illness.

The panel discussed a patient’s right and responsibilities when receiving care in light of core ethical principles of beneficence (acting in the patient’s best interests), non-maleficence (not harming the patient), respect for autonomy (showing respect for the patient and fostering their self-determination through informed decision-making), and justice (being fair). Among the responsibilities of patients highlighted in the presentation were requesting that the patient provide accurate and complete information about their health, being respectful and considerate of others, asking questions if there are things they do not understand, and taking responsibility for the consequences of refusing care or not following instructions.

The responsibilities of the clinicians caring for patients include determining whether the patient has decision-making capacity, clarifying the relevant medical issues and presenting information to the primary decision-maker (whether that is the patient, a parent, or a surrogate decision-maker), providing understandable care instructions, implementing choices related to health care decisions, and reviewing the situation and modifying the care plan as needed. When a patient refuses an aspect of the care plan, the health care team should strive to understand the reasons for the refusal, clarify the patient’s goals in treatment, and find opportunities to negotiate a mutual plan with the patient or primary decision-maker. The focus should be on trust-building and framing expectations that everyone can agree on. Some patients whose behavior leads to refusals or non-adherence may have a history of trauma or a pattern of maladaptive coping mechanisms, so creating behavior management plans that acknowledge these factors is important. Consistency across the interdisciplinary team (whether it is the people or the message) can also be helpful.

When negotiating a treatment plan with a patient, it is important to collaborate with them and not coerce them into decisions. Exploring the reasons for refusal may reveal untoward side effects from medications or external factors that are upsetting a patient or perhaps a general dissatisfaction with being in the hospital. Some patients who are in the hospital for long periods of time may have multiple teams care for them or have been transferred from one unit to another as their condition changes. This lack of continuity can lead to frustration and a sense that their only means of control is refusal at points in time. Finding ways to help the patient have a sense of control and is comfortable in the hospital may facilitate their acceptance of the plan. It may also help to encourage the patient to involve important people in their lives—e.g., family members who can both advocate for them to the team but also work with the team to convince the patient to adhere to the plan. Nurses often spend the most time with the patient and may be in a position to ask the patient whether there is something holding the patient back from following the care plan or something else the team could do to get the patient on board with the plan.

When conversing with patients, clinicians should try to provide more validation statements (e.g., acknowledging the patient’s emotions and perspective) than change statements (e.g., getting the patient to agree to a plan). “I” statements by the clinician, explaining how the patient’s behavior is impacting the clinician and affecting their ability to achieve the patient’s goals, may help the patient to gain a different perspective. Communication skills that help to dissipate a patient’s stress can lead to better choices being made by the patient. Negotiating with a patient can be time-consuming and energy-draining, so there may be limits to how much the team can do. Finding ways for clinicians to reduce their stress and avoid burnout can also, in the long run, lead to better outcomes for patients. Setting realistic expectations by all involved can allow everyone to feel that they have fulfilled their responsibilities and can accept the outcomes that result.