

ETHICS CASE

Influence of Psychiatric Symptoms on Decisional Capacity in Treatment Refusal

Commentary by Joshua M. Baruth, MD, PhD, and Maria I. Lapid, MD

Abstract

How psychiatric symptoms affect patients' decision making in practice can inform how we think—theoretically and conceptually—about what it means for those patients to have decision-making capacity. Assessment of a patient's decisional capacity allows those with adequate capacity to make choices regarding treatment and protects those who lack capacity from potential harm caused by impaired decision making. In analyzing a case in which a patient with stage II breast cancer refuses further treatment, we review the conceptual model of informed consent and approaches to assessing decision-making capacity that are in accordance with the American Medical Association *Code of Medical Ethics* as well as tools to assess decisional capacity.

Case

Dr. A is the oncologist for Catherine, a 55-year-old woman with newly diagnosed stage II breast cancer. When Dr. A asks about Catherine's past medical history during her initial consultation, Catherine mentions that she has often felt so tired over the past two years that she could barely get out of bed. "It just didn't seem worth it to wake up," she explains. "So I'd just sleep all day because I didn't want to do anything. It's not like anyone would really miss me, anyway." Dr. A asks if Catherine feels that way now, and she shrugs, "Sometimes. It comes and goes. It was bad after my husband died two years ago, but I guess I feel okay now." Dr. A also notices in Catherine's health record that her weight has fluctuated up to thirty pounds in both directions. When asked about this, Catherine says, "I don't really remember why—probably different diets." Catherine reports that she has never talked about her mood with a clinician. She adds, "Everybody used to say I was just moody."

During treatment, Catherine experiences side effects so severe that she cannot go to work and reports difficulty with activities of daily living, as she lives alone and lacks immediate family or close friends. As Dr. A evaluates her initial response to treatment, he sees that her tumor burden has actually increased slightly, and he informs Catherine that she might have to undergo more aggressive therapy. At this, Catherine shakes her head and says, "I won't do it." When pressed further, Catherine says, "It isn't worth it to me. I've thought a lot about my life over the past weeks, and there just isn't any reason to

keep going, especially since my husband died." Dr. A asks Catherine to consider people or activities she still enjoys, to which Catherine retorts, "That's exactly what I did. I couldn't think of any." Dr. A then asks about her struggling to come to terms with her cancer and suffering during treatment. Catherine says sarcastically, "Well, it's no picnic. But honestly, Dr. A, I'm okay with things ending here. I've lived my life, and, at this point, I'm tired of suffering. I just want to be with my husband. I miss him all the time."

Uncertain about Catherine's mental health, particularly given her history, Dr. A consults Catherine's primary care physician, Dr. B. Dr. B recalls, "There were times over the years when she seemed a little withdrawn, but nothing ever jumped out at me." He confirms that her husband, who was her main social support, died two years ago and says that he has not seen her since then. "She and I had a pretty good relationship, though," Dr. B adds. "I'm sure I can convince her to consent to further treatment. I can't imagine having *nothing* to live for."

Wanting additional and more up-to-date information, Dr. A refers Catherine to a psychiatrist, Dr. C, who diagnoses Catherine with complicated grief and prescribes antidepressants. However, Catherine does not fill the prescription. When Dr. A calls to ask her about this, Catherine says, "Look, I understand what's at stake here, and I've made up my mind. Please don't make this harder for me." She expresses understanding of the risks and benefits of refusing further treatment for her cancer.

Dr. A wonders if Catherine's grief has compromised her capacity to give an informed refusal. He also wonders just how far her current feelings are from her baseline mood, how much distress her cancer experience has caused her, and the degree to which this could be influencing her decision making. Lastly, Dr. A considers Dr. B's offer to try to "convince" her and wonders whether further attempts at persuading her might not be respectful of her decision and values. What should Dr. A do?

Commentary

Determinations of medical decision-making capacity are intended to uphold patients' rights to make their own medical decisions but at the same time protect them from their decisions when their capacity is compromised. It should be noted that capacity is attached to a particular medical decision (e.g., consent to treatment, participation in research) at a particular time [1]. A person lacking capacity for one medical decision may have capacity for other decisions [2]. Assessing capacity can be subjective and confusing for clinicians, particularly when patients refuse a recommended treatment or the treatment involves substantial risk.

The presence of adequate decision-making capacity is a mandatory criterion of the informed consent process. For informed consent to be valid, three elements must be present: *provision of information*, *voluntariness*, and *competence* [3]. Provision of

information requires that a patient receive adequate information regarding the nature and purpose of a treatment or procedure as well as the risks, benefits, and alternatives of each option, including no treatment. Voluntariness requires a decision to be made voluntarily and free from coercion. Competence is a legal determination of mental capacity that includes those abilities evaluated by clinicians in assessing decisional capacity. The legal standards for evaluating capacity are generally based on patients' ability to: (1) understand the relevant information about their condition and proposed treatment; (2) appreciate the nature of their situation, including their underlying values and the potential consequences of their choice; (3) reason about the potential risks and benefits of their choices; and (4) express their choice [4, 5]. This assessment process is in accordance with the American Medical Association *Code of Medical Ethics' "Opinions on Consent, Communication & Decision Making"* [6]. In this article, we discuss the case in the context of this guidance and the conceptual model for informed consent and approaches to assessing decision-making capacity.

Influence of Psychiatric History and Current Diagnosis

As we see in this vignette, Catherine is experiencing complicated grief following the death of her husband two years prior as well as a recent diagnosis of stage II breast cancer. Complicated grief is an older term for grief in which significant incapacitation persists for over six months following a loss [7]. In the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders*, it is now included in a proposed psychiatric syndrome called persistent complex bereavement disorder (PCBD), although the emphasis remains on distress or functional impairment so severe that is outside of sociocultural norms of [bereavement](#) [8].

Catherine presents a clinical picture consistent with depressive symptomatology occurring initially in the context of grief, since her husband died almost two years prior to her cancer diagnosis. After her husband's death she experienced fatigue, inability to get out of bed, feeling it was not worthwhile to wake up, excessive sleepiness, lack of motivation, severe weight fluctuations, and moodiness. Although Catherine reports these symptoms are now intermittent, they clearly are in excess of normal grief given their duration (two years) and severity. Her depressive symptoms have worsened during the progression of her cancer, to the extent that she now expresses increasing feelings of worthlessness, finding no reason to live, anhedonia, and desire for death suggestive of passive suicidality. It is important in this case to recognize the presence of major depression, the serious risk of suicide, and the need to treat appropriately.

Depression can impair medical decision making, and Catherine's severe depression, significant functional impairment, and possible passive suicidality put her at risk of making treatment decisions that she would not otherwise make if she were not depressed. One important ethical consideration, then, is whether it is ever justifiable to consider a patient's refusal of treatment to be indicative of lack of decisional capacity

based on a patient's symptoms of mental illness. What is the relationship between psychiatric symptoms and medical decision-making capacity, and is it ever appropriate to take into consideration a patient's psychiatric diagnosis when determining capacity? And what if the patient is refusing treatment? Historically, it has been a common perception that people with mental illness have a reduced ability to provide informed consent [9]. Severe depression can manifest as impairment of information processing and reasoning that can significantly affect decision making [10]. Compromised ability for decision-making capacity has also been associated with disorders like dementia and delirium [11], intellectual disability [12, 13], psychosis [14, 15], and bipolar disorder [16-18]. Additionally, reduced decision-making capacity has been associated with patients admitted involuntarily or patients refusing treatment [15]. Not surprisingly, there has been controversy regarding the appropriateness of including people with mental illness in medical research [19, 20].

Yet, studies have shown that decision-making capacity is preserved in the majority of psychiatric patients [15], including those with mild to moderate depression [21-23]. Diagnostic categories alone (i.e., Alzheimer's, depression, schizophrenia) do not equate with presence or absence of decision-making capacity [1]. For example, in schizophrenia, capacity is correlated only modestly with psychotic symptoms but more strongly with cognitive dysfunction [24].

Therefore, based on the bioethical literature, it would be inappropriate to let a prior or current psychiatric diagnosis determine Catherine's medical decision-making capacity. Accordingly, her capacity should be determined in the context of her current decision and underlying values. Determining that she has some understanding and ability to communicate her decision may be straightforward. In the vignette, Catherine says: "Look, I understand what's at stake here, and I've made up my mind." However, it may be a bit more difficult to adequately assess her ability to reason and appreciate her underlying values. Is Catherine able to use reason in the context of a psychiatric diagnosis for complicated grief? Is she able to identify her underlying values while experiencing significant distress related to her husband's death and her own cancer diagnosis?

One instrument to assist clinicians in evaluating decisional capacity is the MacArthur Competence Assessment Tool for Treatment (MacCAT-T), a semistructured interview that requires the clinician to provide patients relevant information about the medical condition; the proposed treatment options; and the risks, benefits, and alternatives of each treatment option. After [provision of information](#), the clinician is further guided by a set of questions to test patients' understanding and appreciation of the information presented to them, their reasoning ability in going through the different treatment options and making a selection, and their ability to communicate a choice [25]. The MacCAT-T has been used to measure decisional capacity in people who are severely depressed [26], so use of this instrument in Catherine's case would provide valuable

information regarding her unique situation and decision. Importantly, it has been shown that physicians often fail to correctly recognize incapacity, sometimes as much as 58 percent of the time [2], which further highlights the importance of using formal assessments like the MacCAT-T as well as consulting relatives and other members of the health care team.

Determination of Best Interest and Capacity

Another important ethical question highlighted by this vignette is who is best positioned to [assess decisional capacity](#) and the patient's best interest. A psychiatrist is most commonly consulted to assess decisional capacity, but any licensed physician can make the determination [27]. It is important for physicians to consider that their determination is not just clinical, but ethical [28, 29], and should not be based solely on objective measures [29]. The belief system and morals of physicians should not unjustly influence their decisions about capacity. It has been proposed that the influence of these factors can potentially be reduced by physicians' recognizing their own biases, seeking second and contrasting opinions, and reporting the results of different conclusions [29].

Discussions with family and the multidisciplinary health care team are key in determining patient values that inform medical decision making. For example, including physicians previously involved in the patient's care and the hospital ethics service can be important in understanding a patient's belief system and decision-making history, which information can support conclusions regarding capacity if prior medical decisions are in agreement with the decision being made currently. Not only can information from family and other health care professionals be used to support conclusions when determining capacity, but it can be useful to a surrogate or proxy decision maker when a patient is deemed to lack decisional capacity. Through substituted judgment based on knowledge of the patient's wishes or preferences, a surrogate decision maker upholds the ethical principle of respect for autonomy [30]. If the patient's wishes are unknown, or when necessary to prevent suffering, the surrogate makes decisions based on what he or she thinks is in the best interest of the patient [30]. For example, a surrogate may rely on knowledge of a patient's spiritual commitment and its role in past medical decisions in judging what is in the best interest of the patient.

Influencing a Patient's Decision

Another important ethical consideration for this vignette is whether it is ever appropriate for a physician to attempt to influence the patient's decision. One of the essential elements of informed consent is a lack of coercion, assuming the patient has capacity to make a decision independently. In cases in which the patient's decision may not appear to some to be in his or her best interest, despite seeming to have adequate decisional capacity, there are approaches physicians can use to assist the patient in an unbiased way without disrespecting his or her autonomy. First, if the patient does not recognize the importance of a capacity assessment, the physician should encourage the patient to

perform to the best of his or her ability on the evaluation [2]. Furthermore, a patient's capacity can be restored by treating reversible disorders that affect cognition (e.g., metabolic delirium, mania) and reassessing capacity later.

For those who require assistance with decision making due to impairments in decisional capacity, information provided to the patient can be simplified with alternate forms of communication (e.g., visual aids) [31]. In a prior study, one of the authors (MIL) and colleagues found that implementing an educational intervention improved decisional capacity in severely depressed patients [26]. Similarly, Carpenter and colleagues [24] showed that patients with schizophrenia improved understanding and capacity as measured by a study-specific version of the MacCAT-T following education. Other investigations also showed that education can assist psychiatric patients in achieving capacity to consent [32, 33].

Additionally, the impact of a decision should be considered. For example, vastly different outcomes result from refusing a life-saving treatment that could result in death and refusing a low-risk treatment that may or may not have negative consequences. Accordingly, with decisions involving greater risk, a physician should consider more than a single, objective assessment of capacity and incorporate more information based on prior decisions or what others consider a reasonable decision [34]. When grief, guilt, or personal loss distorts cognition, a psychiatrist would have the necessary expertise to assess how a patient's decision might be different when these emotions are not present [29]. However, when deviating from assessing capacity purely objectively, there is always the potential for paternalism. An approach to assessing capacity should be adopted that best fits the patient's needs, respects the patient's autonomy and values, and limits unnecessary physician influence [35].

In Catherine's case, it is imperative to communicate the importance of the capacity assessment and encourage her to optimize the process by treating her depression. Additionally, an approach to decision making that considers her established values and past decisions, without the undue influence of her current grief and personal loss, would be respectful of her best interest and autonomy.

Conclusion

When evaluating decisional capacity, it is essential for physicians to obtain a mental status examination and formal assessment of cognitive function. This procedure should be followed by assessment of the patient's: (1) understanding; (2) appreciation of his or her situation, including underlying values and potential consequences; (3) reasoning about the potential risks and benefits; and (4) ability to communicate a choice. Using a structured capacity assessment tool may provide valuable information concerning the patient's situation and decision. It is not appropriate to let a prior or current psychiatric diagnosis solely determine decisional capacity. However, if a patient is currently suffering

from a mood disorder, is potentially suicidal, or has any another condition that could potentially compromise his or her capacity, the patient should be referred to a psychiatrist for a formal consultation.

Decisional capacity can be optimized by treating reversible disorders that affect cognition. Information provided to patients can be simplified and educational efforts or alternative forms of communication should be implemented when needed. When patients have impaired decisional capacity, information from relatives, friends, or other physicians about their underlying values or spiritual beliefs, as well as their prior medical preferences and decisions, can be used to help assess whether medical decisions being made on their behalf are in alignment with what they value and what is important to them. Finally, a formal ethics consultation is an option, especially in more uncertain cases. For those with adequate decisional capacity, it is ethically acceptable to refuse treatment and, accordingly, for physicians to respect patients' autonomy.

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