

ETHICS CASE

Ethical Management of Patients with Cancer and Mental Illness

Case and Commentary by Laurel J. Lyckholm, MD, and Arwa K. Aburizik, MD, MS

Abstract

Patients with co-existing cancer and mental illness must be given special attention due to the vulnerability that is created by their compromised psychological ability to comprehend the meaning of their cancer diagnosis, treatment, and prognosis. They are at increased risk for mortality due to many factors arising from their mental illness. To provide them with care that is just and compassionate, clinicians must be empathic and imaginative. Using a case and brief application of theories of justice involving vulnerable populations, we explore practical and ethical issues surrounding the care of patients with mental illness and cancer, arguing that society must provide the resources needed to provide comparable cancer care to those who are more vulnerable.

Case

TM, a 56-year-old man with schizophrenia, presented to his primary care physician with intermittent difficulty swallowing. He did not elaborate on exacerbating or alleviating features or associated symptoms. His review of systems was negative.

TM lived locally in an adult home. He was unwilling to consistently perform activities of daily living, such as bathing and dressing. The nursing staff of the adult home provided his medications. TM's younger sister was his next of kin and had health care power of attorney. She attended appointments with him and assisted him in making decisions regarding his health care. Specifically, she aided in explaining clinical information to him in a manner that he seemed to better understand. She would not consent to procedures or therapies to which he was opposed.

Physical exam revealed a thin and disheveled man. He was alert and oriented. He had no outward signs of perceptual disturbances such as delusions or hallucinations. The remainder of the exam was unremarkable. A chest radiograph revealed a 3.8-cm lung mass. The patient was referred for a CT-guided biopsy of the lesion. Although he was initially reluctant, he ultimately agreed to the procedure after further counseling and discussion, and his sister supported his decision and provided consent. The biopsy confirmed the diagnosis of squamous cell carcinoma. Further staging did not reveal locally extensive or metastatic disease. Therefore the cancer was considered to be Stage

Ib (T2aNOMO). He was referred to the surgical oncology service for possible resection of the mass.

During the initial surgical consultation, the patient stated that he did not believe he had cancer and would not consent to any surgical procedures. However, during a subsequent visit, the patient acknowledged the diagnosis and stated that he would consider surgery. After lengthy deliberation about the case, the members of the surgical oncology team opted against surgical intervention based on their feeling that the patient did not reliably demonstrate a good understanding of the diagnosis and might therefore have a higher risk of complications postoperatively. They stated that they did not feel it was safe to operate but offered no further explanation. TM completed radiation therapy, and a six-week post-treatment CT scan revealed stable disease, although with possible residual tumor.

Commentary

People with mental illness face significant health challenges that extend beyond the obvious effects of their psychiatric symptoms, adversely influencing their physical health and access to medical care [1, 2]. The Centers for Disease Control and Prevention (CDC) [3] reports a lower use of medical care and lower adherence to treatment for chronic disease among patients with mental illness. A variety of affective, psychological, and cognitive symptoms can interfere with healthy lifestyle decisions, motivation to seek care for physical complaints, and the ability to trust and effectively engage with health care clinicians. Depression, fatigue, asthenia, despair, hopelessness, and distorted perceptions of reality, such as hallucinations and delusions, are among symptoms that can increase the challenge of accessing health care [4].

People with mental illness also face multiple challenges as they navigate relationships within the health care system, make clinical decisions, and otherwise participate in their medical and psychiatric care. Studies show that clinicians can have negative attitudes toward or biases against people with mental illness [5-7], making it difficult for those patients to identify clinicians who will understand their specific needs, advocate for them, and assist them in navigating the system. Clinicians might lack training and skill in detecting somatic signs and symptoms in the context of psychiatric illness. In addition to the factors mentioned, time and resource constraints render this group of patients vulnerable to disparities of health care uptake and reception [8-10].

Mental illness complicates care for patients with cancer. Several studies report a significantly higher rate of mortality in psychiatric patients overall compared to the general population [11-13], and one study has shown a higher rate of mortality for psychiatric patients with cancer even though the incidence of cancer in psychiatric patients is no greater than in the general population [11]. One possible explanation includes reduced access to screening [14, 15], leading to delayed diagnosis and a more

advanced stage at presentation. In addition, people with mental illness have more limited access to cancer care and a lower likelihood of receiving specialized interventions [11].

What might explain these [treatment disparities](#)? They might be attributable to clinicians' concerns about patients' ability to physically, emotionally, or mentally tolerate procedures or comply with complex care instructions. For example, one study found that Medicare patients with coexisting mental illness who received elective surgical procedures had longer length-of-stay and worse postoperative outcomes, including higher risk of 30-day and 1-year mortality, than those without mental illness [16]. Or treatment disparities might result from the presence of contraindications to specialized interventions due to cognitive, psychological, or social factors. For example, patients taking chemotherapy for cancer might understand that the chemotherapy will help the tumor shrink and enable them to live longer and also that chemotherapy is toxic, but they can have limited ability to connect side effects with the treatment or to access resources if they are experiencing serious toxicity, which could be life-threatening [17]. The oncologist might feel that certain chemotherapy or other cancer treatments, while superior in their survival or palliative benefits, present too much risk in a patient who may have waxing and waning insight. While family members and others may assist the patient in making medical decisions, they might not always be present to assist the patient in managing the side effects and toxicity of treatment. Another example might be of a patient who becomes ill from the side effects of therapy and stops taking his or her psychiatric medications or who errs in dosing oral chemotherapy and other supportive medications, such as anti-emetics and analgesics, which could be harmful or dangerous.

In what follows, we describe decision making in mental illness and in patients with co-existing mental illness and cancer. We then discuss how and why provision of cancer care can be different and challenging for people with mental illness and offer recommendations for ethical care in light of the case.

Decision Making in Mental Illness

Autonomy can be seen as empowering in that it can strengthen one's self-respect and control over one's life [18]. One way in which autonomy can be diminished is through mental illness, which is an example of a controlling influence occurring internally [19]. Mental illness can cloud one's judgment, making it difficult to reach decisions about one's cancer care that are in harmony with one's beliefs and values.

If a person's autonomy is truly compromised, then a surrogate decision maker should decide for the patient on the basis of substituted judgment or the best interest standard. Substituted judgment involves knowing what the patient would want if he or she were able to make a decision, based on his or her known values [20]. The best interest standard is based on what most people in a similar situation would want and what would be in their best interest assuming there is no information about the patient's wishes

[20]. Ideally, application of both standards involves significant investment by people who both know and care about the patient. This includes family members, treating psychiatrists, and other health care professionals who have been involved in the patient's care. It also involves understanding the patient's goals and values, even if he or she is not able to fully articulate them. In that case, friends and family can provide narratives that include life choices and previous health care and other significant decisions that the person has made [21].

[Decision-making capacity](#) involves three essential components: comprehending, evaluating, and choosing among realistic options. People with mental illness facing medical decisions should be presumed to have decision-making capacity unless there is evidence to the contrary that warrants further assessment, as in TM's case. Patients with mental illness should not be deemed to lack decision-making capacity until they have been formally evaluated [22]. Discussion between mental health and cancer clinicians should be mandatory.

Patients with psychiatric illness can retain their decision-making capacity or at least be able to participate in assisted decision making. Jonsen, Siegler, and Winslade write:

Psychiatric diagnoses such as schizophrenia, depression, or dementia do not, in themselves, rule out the possibility that a patient has mental capacity to make particular decisions. Many persons with mental disease retain the ability to make reasonable decisions about particular medical choices that face them [23].

Decision making is on a spectrum as wide as that of mental illness. Some patients retain the ability to understand the information provided to them and are able to communicate choices, appreciate the situation and its consequences, and manipulate information rationally in order to make decisions. In addition, since capacity is a clinical standard that applies to a particular decision at a given moment, the evaluation of capacity must be assessed in the context of the decision at hand [22, 24]. For example, a patient may be able to decide that he does not want aggressive life support, but he might not be able to understand the concept of radiation and chemotherapy or the purpose of a cancer-directed surgery.

Decision Making and Treatment Disparities in Cancer Patients with Mental Illness

Decision making. Patients with psychoses such as manic or major depressive episodes may have significant challenges in making informed decisions due to indifference, ambivalence, or indecisiveness [25]. Furthermore, psychotic illness may prevent patients from understanding the nature and purpose of a medical intervention. They may be unable to choose or communicate their consent. Much like TM, some patients with mental illness do not understand or accept that they are ill or need treatment [25].

Some cancer-related conditions, especially those that affect the central nervous system (CNS)—such as lymphoma, primary brain tumors, and metastatic cancer—may also impair judgment, understanding, and communication [26]. For example, a patient with CNS lymphoma and significant cerebral edema may be unable to understand his or her condition, the reason for it, the goals of therapy, or the therapy itself, which is often quite intricate. The decisions involved in undergoing toxic or high-risk treatment—including chemotherapy, radiation, and surgery—are complex and challenging to understand even when a person is unencumbered by mental illness.

Treatment disparities. The case of TM is also illustrative of potential disparities in cancer care for patients with mental illness; based on the foregoing discussion of decision making, we offer steps that might be taken in caring for such a patient with mental illness and cancer (see table 1). One might ask if there was a justifiable basis for the decision made by the surgical service to forego primary resection, which would be the standard of care for this patient with stage I squamous cell lung cancer [27]. One might also ask if enough care was taken to explain as well as possible to the patient and his sister the patient's situation, the diagnosis, the staging, and standard treatment for stage I squamous cell lung cancer, as well as the prognosis of the cancer and how veering from standard treatment might negatively affect the prognosis. While the surgeons did not demonstrate any specific evidence of personal bias against the patient, they did not seem to demonstrate significant rigor in their consideration of his case. They met with the patient and his sister once regarding their recommendation, but they did not perform further psychological testing or contact his psychiatrist or anyone else who might aid further in decision making.

Table 1. Considerations for providing ethical care to mentally ill patients with cancer

Decision Making
Patients should be presumed to have decision-making capacity unless evidence suggests otherwise. Patients with mental illness may be able to make appropriate, independent decisions. Caretakers must be involved in the care and decision making at all levels.
Treatment
Mental illness does not rule out aggressive treatments. Treatment must be even more carefully considered and the patient more carefully monitored. Antipsychotic and other medications should be reviewed for side effects, toxicity, and interactions with chemotherapy and palliative medicines such as anti-emetics.
Care Team
The patient's mental health team should be involved, and treatment of the mental illness should be optimized. Comorbidities Depression commonly accompanies the diagnosis of cancer.

How can such disparities in cancer care be rectified? Health literacy is an important aspect of cancer care. Patients with mental illness have variable levels of health literacy [28]. They may be unable to comprehend their diagnosis, its impact on their life, what various treatments entail, and their prognosis. For patients with limited ability to understand their diagnosis and prognosis, it is especially important to ensure that they are provided information in a way that is more comprehensible to them [29] as well as to critically evaluate their candidacy for treatment. More specifically, those providing care for such vulnerable patients must be extraordinarily thoughtful and empathic in order to provide equivalent and compassionate care [30], which are primary goals of medicine and a just society in general.

The standard of care, simply stated, would be that which provides the patient with the highest quality, patient-centered care that benefits him most from the standpoint of what is known of his individual preferences and values or what is in his best interest if these preferences and values are unknown. Well-known ethical theories of [justice](#) complement this idea, including liberation theology [31], of which a central thesis is the “preferential option for the poor”—to prioritize service to poor people in order to ensure that those with the least resources are provided a standard of care at the very least

equivalent to that of those with more resources—which Paul Farmer and others have applied specifically to the provision of medical care [32]. John Rawls’s theory of justice proposes that persons living under a “veil of ignorance” of their place in society should be the decision makers for others [33]. He writes that “this ensures that no one is advantaged or disadvantaged in the choice of principles by the outcome of natural chance or the contingency of social circumstances” [34]. He advocates distributing social and economic inequalities “to the greatest benefit of the least advantaged” members of society [35]. Both of these theories seek to provide advantages to the most disadvantaged in order to provide care that is equivalent to that provided to others less disadvantaged.

Conclusion

In summary, patients with co-existing cancer and mental illness must be given special attention due to the vulnerability that arises from their possible inability to fully comprehend the meaning of their cancer diagnosis, treatment, and prognosis. They are at increased risk for mortality due to many factors arising from their disability [11-13]. To deliver care that is just and compassionate, clinicians must be empathic, imaginative, and nonjudgmental. The principle of “equivalence of care,” which refers to approximating the quality of care given to non-prisoners and prisoners can be applied in a similar way to the care of the mentally ill [36]. Society as a whole and the health care system must provide the extra resources needed to approximate the cancer care provided to those less vulnerable.

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Laurel J. Lyckholm, MD, is a clinical professor of hematology, oncology, and blood and marrow transplantation at the University of Iowa Carver College of Medicine in Iowa City, where she is also a primary faculty member in the Program in Bioethics and Humanities and a consultant on the University of Iowa Hospitals and Clinics Ethics Consult Service. Dr. Lyckholm's research and clinical interests are directed toward improving cancer and palliative care for the most vulnerable of our citizens.

Arwa K. Aburizik, MD, MS, is a clinical assistant professor of hematology, oncology, and blood and marrow transplantation, and psychiatry at the University of Iowa Carver College of Medicine in Iowa City. She specializes in caring for medically ill patients with psychiatric comorbidity and has a special focus on psycho-oncology.

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