

The Patients We Have to See

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“There are the patients we want to see and the patients we have to see,” my attending cautioned during my medical internship. When we relate to a patient’s story, enjoy the conversation, feel capable or curious, we naturally spend more time. What happens when we struggle to connect, when a patient declines treatment, or has many complex issues that we feel incapable of addressing? *What happens when we feel helpless?* As an experienced medical oncologist observed, “*There’s a groan that is uttered when I say the word schizophrenia.*”

Dr. van Laarhoven felt exhausted, angry, and powerless as she cared for Mr. E. Her colleague asked, “Why did you try so hard for this one patient? Shouldn’t you have accepted that Mr. E. had a severe comorbidity which precluded curative cancer treatment?” I also frequently hear, “Shouldn’t we have respected his decision?”

AUTONOMY OR AVOIDANCE OF RESPONSIBILITY?

It would have been much easier to accept Mr. E’s refusal of care. Instead, Dr. van Laarhoven made multiple choices to dedicate additional effort. She could have stopped trying when Mr. E. left the hospital, when the first psychiatric evaluation failed to recognize an urgent need for hospitalization, and when the second psychiatric evaluation posed another barrier to cancer care.

Respecting Mr. E’s autonomy would require less effort. By honoring his wishes, we might also stop feeling so ineffective. We can cite our obligation to do no harm, to avoid giving toxic chemotherapy if the patient will not be adherent with care. But accepting Mr. E’s refusal did not feel good or right to the oncology fellow. Focusing solely on Mr. E’s autonomy allows us to avoid our responsibility as physicians: to ensure his understanding, incorporate psychiatric treatment, and learn about his goals. If we don’t listen to our gut and choose to try harder, we communicate that Mr. E’s life matters less.

WITHOUT A DIFFERENT APPROACH, MANY PATIENTS LIKE MR. E. WILL NOT RECEIVE EQUITABLE CANCER TREATMENT

Mr. E’s story is not uncommon. Thirteen million people in the U.S. have serious mental illness, including three million with schizophrenia [1]. Individuals with schizophrenia are less likely to receive timely, guideline-concordant cancer care, which contributes to markedly increased cancer mortality and premature death [2]. People with schizophrenia die nearly 30 years earlier

than the general population and cancer is the second-leading cause of death [3, 4].

This disparity is unrecognized and overwhelming in scope. However, with a proactive, integrated approach, we can improve cancer care delivery for this complex population. We can unlearn the pattern of helplessness by making small choices to effectively engage patients in care [5].

I am a psychiatrist and health services researcher, embedded in a cancer center, who specializes in serious mental illness and cancer. This year, our team has cared for more than 80 patients with serious mental illness and cancer. I continue to be struck by how frequently patients who initially decline treatment become engaged in care and express their gratitude and surprise that we cared enough to try.

HOW CAN WE INCREASE PATIENT UNDERSTANDING AND FACILITATE RECEIPT OF CARE?

In Massachusetts, any physician or mental health clinician can order an involuntary evaluation when concerned about risk of harm to self or others, or grave inability to care for self. This step does not mandate hospitalization or treatment, but instead means that we are worried enough that we need to assess the patient in person. What are the risks of a mandatory evaluation in the emergency department? Mr. E. could become angry at being forced to come to the hospital, which could impact the patient-clinician alliance. Mr. E. may be at increased risk for receiving cancer treatment against his wishes. The risk of not mandating that evaluation is Mr. E’s preventable death. As an experienced mental health nurse summarized, “I’m all for patient rights but someone has to say, ‘You ain’t dying on my watch.’”

My colleagues in the cancer center and community frequently ask, “What is your threshold for involuntary treatment?” I start by imagining that Mr. E. is a close friend living in another state: overwhelmed, disorganized, and emaciated, with a serious infection that is amenable to treatment. It is unclear that Mr. E. understands the risk of not having his infection treated. Despite his desire to stay out of the hospital, he comes voluntarily to see his radiation oncologist, reflecting some interest in receiving cancer treatment. To meaningfully consider his autonomy, we need to take three initial steps to (a) build patient understanding, (b) treat psychiatric symptoms

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that may impact decision-making, and (c) learn about how cancer treatment fits with the patient's values and priorities for his or her life.

First, we can use our medical knowledge and experience to educate Mr. E. and any community supports about the risk of not receiving treatment [6]. Given the symptoms of schizophrenia frequently include deficits in memory and attention, challenges with abstract reasoning, and difficulty with trust, we will likely need to explain that risk in multiple ways and break that information down into small, digestible pieces. An evaluation provides opportunity for engagement. Ideally, together with his trusted radiation oncologist, we would educate Mr. E. about the risk of not receiving chemotherapy and not treating his aspiration pneumonia.

Next, we need to treat Mr. E's psychiatric illness. He was more disorganized, scared, and delusional, and his fears were impacting his decision-making, yet he declined psychiatric treatment. Although people with psychiatric illness frequently confront additional barriers to cancer care, it can help to approach treating a psychiatric comorbidity with the same framework we use to address cardiovascular disease. With uncontrolled atrial fibrillation, we consult cardiology, control symptoms, and manage cancer treatment. Similarly, we need to consult psychiatry at cancer diagnosis, and psychiatric consultation has to be available, timely, and relevant. Even if Mr. E. declined psychiatric consultation, a mental health clinician can support the oncology team. Adjusting psychiatric medications and establishing trust may decrease the intensity of fear, improve sleep, and organize thinking.

Most importantly, we can think with the person and any family or community-based clinicians about how best to support this person and his values [7]. Mr. E. sought care from the radiation oncologist. He left the hospital because he was angry about a lawsuit, not because of a longstanding objection to chemotherapy. Maybe his cancer care could have been framed

in a way that helped him to meet his goals of maintaining his independence and thinking clearly. A person-centered approach might include a joint visit with psychiatry and radiation oncology.

PROMOTING EQUITY: THE NEED FOR INTEGRATION OF MENTAL HEALTH AND CANCER CARE

What is our obligation to Mr. E.? We need to consider the significant risk of *not* evaluating and hospitalizing patients, of not making sure that the individual, and when present, the individual's surrogate decision-maker, understands the risk of not treating the cancer. It will take more time for a patient like Mr. E. As clinicians, our gut instinct is to dedicate that extra time.

We start the day wanting to give everyone the best possible care. Yet sometimes our efforts feel futile. In the U.S., as in The Netherlands, community mental health and cancer care are delivered in siloed health systems that are not designed to address Mr. E's complex needs. The fragmentation of mental health and cancer care can contribute to misunderstanding, miscommunication, delays, and disruptions in care. Reimbursement models rarely support engaging patients outside of office visits. Rarely do we have multidisciplinary teams in place to support each other and the patient when we feel frustrated, exhausted, and powerless. However, with different approaches, we can increase access to care and begin to unlearn that sense of helplessness.

We need to be creative, persistent, and respectful as we try to understand what matters to patients. With the overall goal of promoting equity in cancer care, we can help people with serious mental illness, who have more often been the patients we ignored, get the best possible cancer care.

DISCLOSURES

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Editor's Note:

See the related article, "On the Receiving End of Autonomy and Law," by Hanneke W. M. van Laarhoven et al., on page 1143 of this issue.