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Narratives in Oncology

On the Receiving End of Autonomy and Law

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Disclosures of potential conflicts of interest may be found at the end of this article.

By the end of the week, I was exhausted. I had spent hours and hours on the telephone in an attempt to get "Mr. E" admitted to the hospital. From an oncological perspective, his case was relatively straightforward: this 55-year-old male suffered from a T3N0M0 squamous carcinoma of the proximal esophagus. Because of its proximal location, we discussed long-course chemoradiation with curative intent (50.4 Gy; 1.8 Gy in 28 fractions combined with carboplatin [area under the curve 2] and paclitaxel [50 mg/m^2] each week during 6 weeks), and Mr. E was very motivated to start treatment [1]. At the same time, however, Mr. E had developed an elevated mood with psychotic features and was voluntarily admitted to the psychiatric medical unit (PMU). The symptoms were possibly related to the recent discontinuation of his abundant alcohol use or his hypothyroidism, which we treated during the admission. Alternatively, the deterioration of his physical health could have just uncovered a longer existing psychiatric disorder. Leptomeningeal metastases were excluded. During his presence on the ward, he was showing unpleasant behavior. He challenged every type of healthcare advice and threatened professional caregivers with all kinds of law suits, but he did manage to stay just between the lines. However, after 2 weeks, he decided to leave because we did not approve of him going to his lawyer to file a lawsuit against a telephone company. At that time, we could not hospitalize him involuntarily because, according to the Mental Health Act in The Netherlands, involuntary admission requires suspicion of a psychiatric disorder that could lead to severe danger to himself or others and that could only be diverted by hospitalization, as ascertained by an independent psychiatrist. We crossed our fingers and made a plan with his general practitioner, hoping that Mr. E would manage to sufficiently adapt to undergo the treatment for his tumor in a safe way.

Unfortunately, within 2 weeks after Mr. E had left the PMU, his clinical condition rapidly deteriorated. Because of considerable weight loss, he was started on drip feeding. As he was unable to handle the drip feeding himself, homecare nurses were called in for assistance. However, Mr. E turned down their advice, did not let them care for his drip feeding, and was certainly not willing to go to a nursing home or hospital to be looked after. He had prepared his tube with a small plastic bag that was filled with the remnants of drip feeding, overgrown by fungus. Alarmed by his poor physical condition and growing psychotic delusions, the homecare nurses requested us to take action. We contacted the municipal psychiatric crisis team to make a home visit to give an independent evaluation of the situation, which is required in order to admit a patient involuntarily under the Dutch Mental Health Act. Even though there clearly was a risk for his health, the danger was not considered sufficiently acute and severe to issue a temporary treatment order for him by law.

I felt powerless. Of course, I realized I should count my blessings—living in a country where the autonomy of people is protected by law. However, at the same time, it also went against my standards of taking good clinical care to simply watch the deterioration of Mr. E due to his diminishing ability to control his rebellious behavior, while knowing this would jeopardize the potentially curative treatment of his esophageal cancer that he actually wanted to undergo.

The Dutch Mental Health Act regulates the legal status of patients admitted for inpatient mental health care and describes, among other regulations, procedures for involuntary admissions and patients' rights. Point of departure of the act is respect for a patient's autonomy, which is primarily understood in terms of the biomedical principle laid down by Beauchamp and Childress [2]: patients have the right to refuse any interference with their physical or mental integrity, which includes the right to refrain from hospital admission and treatment. This way of understanding autonomy accentuates the right of "negative freedom," [3] that is, individuals should be able to act without coercion or interference from others. This restricted view of autonomy, however, also has its downsides, and runs the risk of neglecting patients who withdraw from health care due to lack of mental capacity in relation to their care arrangements [4]. In response to the prevailing interpretation of the principle of autonomy, (health) ethics has made a plea for an approach that does not (solely or mainly) emphasize the right to self-determination of the individual but (also) considers the way people shape their lives through interaction with others. In addition, the legal framework is not considered as an endpoint, but as the starting point of the discussion [5].

The situation of Mr. E would have been so much simpler if he would have completely declined medical treatment for his cancer. Basically, he just did not want to be admitted because he denied his psychiatric condition and had his own views about what he needed to do to be "healthy enough" to start chemotherapy and radiation. Adequate physical fitness and sufficient nutritional intake were necessary to complete this

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curative, though toxic, treatment, but nobody could foresee at what point he would cross the line to acutely endanger himself. Although his preparation was certainly not optimal, it was still not bad enough to disallow his chance of a curative treatment.

The next day, however, 24 hours before the planned start of chemoradiation, Mr. E was seen by the radiation oncologist. He noted that the patient was dyspneic and the laboratory results (that came in after Mr. E had left the hospital) showed an elevated C-reactive protein of 167 mg/L. We suspected an aspiration pneumonia. Foreseeing that the start of chemoradiation the next day would be impossible if he stayed at home and "cared" for himself, we deliberated extensively with the crisis team, who evaluated the patient again to see if we could admit him involuntarily by law. However, the crisis team judged that Mr. E had full decision-making capacity with respect to his somatic situation, and the acuteness of the danger to his life remained insufficient to take such an extreme measure as to deprive him of his freedom.

Now I felt not only powerless but also frustrated and angry. We had tried so hard to inform the crisis team that at that very moment Mr. E could be suffering from an aspiration pneumonia—and now, without even taking his body temperature, they decided there was no acute danger? And how could the crisis team decide that Mr. E had full decision-making capacity with respect to his somatic situation simply based on the statement that he knew that without chemotherapy his treatment would not be curative? Given his current clinical condition, Mr. E could clearly not oversee the prerequisites for curative treatment.

So the day after, when Mr. E came to the hospital for his first radiation dose, we again asked the crisis team to evaluate Mr. E. Weighing all the pro's and con's, including the expectation that his mental and his physical state were not going to improve when continuing along the same path, this time the decision was made that there were sufficient criteria to admit him against his will by law. In this way, he would be given a chance to be treated for his psychiatric condition, which would (hopefully) improve his capability to undergo treatment for esophageal cancer.

Relieved, we planned the first chemotherapy course for the next day. However, Mr. E was furious. He felt betrayed by the admission and blamed the Department of Medical Oncology for everything that had gone wrong. In fact, he even suspected that the infusion bags of carboplatin and paclitaxel were mixed with poison. My heart sank; did we do the right thing by admitting Mr. E to the hospital? Although we had admitted Mr. E by force, this did not imply that we could treat Mr. E by force. In fact, Mr. E's brother and current legal representative had assured us that he agreed with the forced admission, but he had also let us know that he would have difficulty with chemoradiation treatment against Mr. E's consent. Indeed, the whole multidisciplinary team felt that forced treatment would be a bridge too far. Chemoradiation is an intensive treatment with an insecure outcome and the decision to start such a treatment should be shared by both the physician and the patient.

Fortunately, the next day, after a long conversation with the radiation oncologist whom Mr. E trusted, Mr. E accepted the administration of chemotherapy. Nevertheless, administering treatment remained a challenge. Chemotherapy was administered at the PMU while a nurse from the oncology department was present to safely give him chemotherapy and nurses from the psychiatric department were present to control his behavior. At the first course, the patient insisted that the radiation oncologists should check all drugs and stay with him during infusion to be sure he would not be poisoned. Things got out of hand when he became physically aggressive, in one instance because the nurses would not let him buy candy for the anorectic patients in the ward. We had to move him to the closed ward and started to treat him with an antipsychotic mood stabilizer against his will. Every day we feared he would escape on his way to the Department of Radiotherapy. Unfortunately, the tight chemoradiation schedule did not allow us to wait until his mental status had improved as a result of the antipsychotic treatment.

Finally, we managed to complete the full chemoradiation schedule. With great relief, I presented the case of Mr. E during the weekly case discussions of our department. Directly afterward, one of the medical oncology fellows asked: "Why did you try so hard for this patient? Why did you invest so much time from yourself and from the whole multidisciplinary team in this single patient? Are you really convinced that you did the right thing? Shouldn't you simply have accepted that Mr. E had a severe comorbidity that precluded curative treatment?" I hesitated. Why was I not prepared to accept that we would not be able to treat Mr. E's esophageal cancer? Indeed, for treatment of esophageal cancer, as for many cancers, it is well known that several comorbidities are associated with increased mortality and may result in the decision not to treat patients with curative intent [6, 7]. Why could I not give up on this patient? Perhaps I felt a personal sympathy for this patient? Well, actually, I did not. Mr. E accused me of being a poisoner, and even though I knew that this accusation was rooted in his psychotic delusion, it did not enhance my sympathy for Mr. E. Maybe I felt uncomfortable starting the conversation about a grim prognosis, especially because of his relatively young age? Since many oncologists experience this discomfort, this could well be true [8, 9]. However, even so, this was not the complete story. Indeed, I felt I was not struggling with a patient potentially dying of cancer because of a comorbidity precluding treatment with curative intent, but rather with a patient potentially dying of cancer because of a nonsomatic comorbidity. And even more so, this was a treatable comorbidity if we had just had the time. Accurate treatment of his psychiatric disorder could lead to an improvement of his ability to make (wiser) decisions and to engage in his treatment in a much better way.

It is well-recognized that mental illness is associated with a substantially higher case fatality rate from cancer, even though the incidence of cancer is no greater than in the general population [10]. Although poor outcome may in part be explained by more advanced stages at diagnosis [11], psychiatric patients also receive significantly less surgery, radiotherapy, and chemotherapy, suggesting that cancer survival disparities of psychiatric patients are related to inequitable access to appropriate care [10, 12, 12]. Their behavior, rejecting and repelling people that want to care for them, certainly contributes to this. Also, one could imagine that physicians experience more resistance to treat patients with psychiatric comorbidity due to countertransference [14]. Therefore, rather than the inevitable effect of a comorbid condition on outcome, the reduced outcome of

psychiatric patients should be regarded as potentially amenable to intervention. As recently described by Rosenbaum: "as more clinicians modify their approach to treat mentally ill patients successfully, the default inches away from 'I can't help this patient' to 'Of course I can' " [15].

Therefore, as a multidisciplinary team, we decided not to give up on Mr. E. Thanks to intensive collaborative efforts, we managed to guide Mr. E through the complete chemoradiation trajectory and improve his psychotic delusions, all while staying within the limits of the law. The chemoradiation treatment was complicated by a fistula at the level of the tumor, which slowly improved spontaneously in the 2 months thereafter. Thanks to the forced admission of medication, his manic psychotic episode faded. Mr. E was proud that he had completed treatment. The long-term outcome of his esophageal cancer, of the treatment complications, and of his psychiatric disease remains uncertain. Nevertheless, I believe we did the right thing.

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Editor's Note:

See the related commentary, "The Patients We Have to See," by Kelly E. Irwin, on page 1020 of this issue.