

# “Of Course You Want To Die”

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## ABSTRACT

A primary care physician meets a new patient who has an intellectual disability and is suicidal in the wake of the death of her elderly parent who served as her caretaker. As their physician-patient relationship evolves, the physician comes to wonder at the health care system's failure to anticipate and take steps that would propagate a safe transition in care for adults in similar circumstances.

I glanced at my schedule and noted that my first patient of the day was in her late 50s. The chart revealed no clues about the purpose of the visit. When I walked into the examination room, my new patient was standing in its center, and she acknowledged me with a wild-eyed expression. She was hunched over and stocky, and was wearing an oversized gray and brown sweater and wrinkled black jeans. Those of us of a certain age in medicine were taught about what is now an old-fashioned term, the *lipstick sign*—you knew your patient was on the road to recovery when you walked into the room and she was wearing makeup. In the contemporary practice of medicine, we know there are other signs. It was her hair that told me she was sick. It was dirty blonde and gray, stringy, unwashed, and uncombed. I invited her to have a seat, but she remained standing.

“Welcome to our primary care practice,” I said. “Here’s what I do the first time I meet someone. I get the details of your medical history, I learn the reason you’re coming in at this particular time, and I learn more about you as a person. While we’re doing that, I’m going to document in the chart. I’m a good typist, so I’ll be able to concentrate on you as I do that. Before I begin to ask you a bunch of questions, tell me, what would you like to accomplish by the end of our visit today?”

She said, “I’m here because I want to die. I was in the Emergency Department last night, and they told me I had to see you this morning.”

*Nice.* No heads up from my Emergency Department colleagues about the patient I was about to encounter.

“What’s going on?” I asked and abandoned my laptop.

She launched into her story. Her 95-year-old mother had just died of a severe subdural hematoma. Her brother had died 4 years earlier caused by a massive pulmonary embolism. She had no other family, no partner, and no children. She’d lived with her mother her entire life in the house her mother owned. Now my patient had no one.

She had a fifth-grade education. She had never worked. She’d had a head injury when she was young and had been labeled learning disabled. She wrote down information by using a dictation app on her phone, and then she’d copy what she saw. Her mother had told her not to worry about anything, that she’d take care of her for her entire life. As my patient talked about money and where she’d live, I interjected optimistically.

“Don’t worry. You have the house. You could decide to stay there or sell it,” I said.

But, I learned, when money became tight, her mother took out a reverse mortgage. Now, after her mother’s death, in the house where my patient had lived her entire life, she was in danger of becoming homeless.

I felt overwhelmed. She had no family to help, no resources, and no discernable skills to put necessary services into place. I was shocked when I became aware of my own thoughts—that I too thought that maybe my patient would be better off dead.

I needed to take a break from this. I told my patient I’d be right back, and I stepped out of the room. The worry I felt stemmed from the knowledge that our health care and social services system might not have the necessary resources she was going to need during this precarious time. This is not a unique emotion among primary care physicians. Jonathan Weiner and his colleagues<sup>1</sup> reported that our greatest stress is caused by the complexity of the social

and financial issues that our patients face, rather than their medical needs.

I called my clinical case manager and, after a quick discussion, we decided the best next course of action would be to send her to the nearest psychiatric Emergency Department, hoping for admission. Before my patient left, I told her that she needed to come back by the end of the week on the off chance she wasn’t admitted. My emergency medicine colleagues were not convinced a hospitalization was indicated, and they sent her home.

I began to see her on a weekly basis. At the end of each appointment, she’d tell me she wanted to die, and I’d press another appointment on her to return. After each visit, she called me and left a message thanking me for my time and reiterating how badly she felt. We eventually got her to a social services center in a nearby town that addressed her psychiatric needs, and they assigned her a case manager to assist her with putting social services into place. She continued to see me at least once a week. However, instead of getting better, her suicide plan evolved from one that was passive to active, in which she began to contemplate swallowing her mother’s cardiac pills. At this, I spoke to her case manager, and we strategized different approaches. I contracted with her to bring in the pills, but she was empty-handed at the next visit. I realized that I was waiting for what seemed like the inevitable to happen.

One morning about 3 weeks into all this, I received a voice message from her.

She said, “Forgive me; it’s not your fault. Thank you for everything, but I just can’t go on like this anymore.”

I called the police and when they got to her home, she promised them she wouldn’t

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kill herself, that she'd see her psychiatrist that very day. She needed to be hospitalized, but it was complicated. If she was an inpatient in a psychiatric hospitalization, she couldn't proceed with her case for disability and all the other services she needed to survive on her own.

On another appointment, I learned that she was having difficulty affording food, and that at times she barely had enough gas to get to her psychiatrist. I paused when I learned that. *What should I do?* I reached into my wallet and pulled out what was there. I had to press it on her. I wondered at our US health care system that does not account for or adequately address the acute needs of those without a safety net.

I learned that this is not an uncommon situation. Although we often think of adult caregivers who care for their aging parents, we don't always think of the large population of caretaking parents who care for intellectually and/or physically disabled children. These caretakers are often anxious about what will happen to their sons or daughters after they die, and some even hope that their children will die before them. Intellectually disabled patients clearly range in their ability to care for themselves, and my patient was an example of one who would be able to attend to the basic activities of daily living independently. Because of her concomitant physical disability of chronic back pain, she would not be able to work. Ultimately my patient's grief process was all the more complicated by not only her mourning her mother but also contemplating the possibility of becoming homeless and having to grapple with the fear of the unknown.

My new patient had been going to specialists for management of her back pain but before coming to me did not have a primary care physician. Had she had access to a mechanism designed to provide whole-person or team-based care, it could have been realized that she was at risk. Although her mother was in her 90s, my patient had not been prepared for her mother's death and what that would mean for her own care. This outcome could have been easily predicted, and appropriate referrals could have been made

in advance to address where she would live after her mother's death and how she would be able to support herself. During her mother's final hospitalization, it might have been recognized that a potential tragedy was unfolding for my patient, and a case manager might have been expediently assigned to begin planning for her future. My patient was present at most of her mother's outpatient primary care and specialty appointments and was a constant presence at her mother's bedside during her final hospitalization. It was not clear that her mother's primary care physician fully grasped the potential tragedy that was unfolding for his patient's daughter. Had he picked up on this, he might have made recommendations for his patient's daughter. Sadly, the time available to care for patients often does not allow for adequate reflection and the kind of care that would truly have a positive impact on our patients' lives. There were several missed opportunities to intervene.

Ultimately, my patient agreed to inpatient psychiatric hospitalization. I thought of her often but didn't hear from her for weeks. And then the day came when I saw her name on my schedule.

I couldn't put my finger on why she looked different. I just felt lighter in her presence. But when I asked how she was doing, she said terrible. That she still wanted to die. But she was going to the Social Security office the next day, and she hoped it would go well. I realized that I no longer thought she'd be better off dead, that I was hopeful for her. We made another appointment for her to return.

The next morning, I came into the office and saw my voicemail blinking on my phone. One message. I tensed.

She said, "Dr. Maldonado, it was good to see you yesterday. Thank you for everything. I just wanted you to know that I had a haircut. I'll see you next week."

It hit me then—that it was the "lipstick sign" and that she was likely on the road to recovery.

However, my patient remains vulnerable in a system that has struggled to meet her needs. Three weeks after that phone call, despite an inpatient hospitalization, extensive counseling, and initiation of a

psychiatric medication regimen, one evening she lay on her mother's bed with a beloved photograph of her and swallowed a handful of pills. When a neighbor couldn't reach her, they activated 911, and she was hospitalized again. Many questions still remain, although more than 6 months have elapsed since her mother's death. Where she will live is still uncertain. Whether her case for disability will be approved is still in question. But at least she has a case manager to navigate her through a complicated system. She has a primary care physician, a psychiatrist, and a therapist. However, our health care system didn't plan for the inevitable in advance. Had it adequately done so, my patient's uncertainty, psychiatric hospitalizations, and complicated grief might have been averted.

It would be helpful to have social workers and case managers embedded in all primary care practices or a process in place for easy referrals. Primary care physicians must have the appropriate amount of time to take adequate social histories that transcend whether our patients smoke, drink, or use illicit drugs. All of us need to be skilled at eliciting the social determinants of health that have an impact on our patients' medical and psychiatric health and have easily accessible processes in place to address them. We must do better for the most vulnerable people we encounter in our health care system. ❖

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