How Do We Define “Difficult” Patients?

Receiving a referral for a patient who is described as being difficult is not uncommon for me, particularly after many years of working in what some might call “non-mainstream” areas. However, I sometimes wonder what “difficult” means when I read this descriptor. The issue came up again recently when I received a referral with this label attached.

When the patient’s appointment time arrived, I walked down to the waiting room to greet her. She was accompanied by a patient representative and a staff member who often assists with patients classified as difficult. What I saw before me, slouched in a chair, was a slight woman with crumpled clothing and greying hair trying its best to escape a bun on the top of her head. Her arms were crossed over her chest and her large belly seemed out of place in contrast to her thin legs. I introduced myself and helped her out of the chair. She did not loosen her grip on my left hand and we walked together into my office, holding hands like two people who knew each other well, although the exact opposite was true.

It took a while for me to take a history from the patient. English was not her first language and, at times, her responses to my questions seemed tangential. I gave up asking the questions and, instead, asked her what was going on in her life. Some of the story she told me was rambling and seemingly off topic, but the gist of it was familiar to me: a woman with limited choices because of a poor family socioeconomic history (i.e., poverty, lack of education) and the vagaries of circumstance in a relationship where alcohol and violence play a synergistic role. Now, after the patient was diagnosed with stage III rectal cancer, she was making plans to “get rid of him,” likely not for the first time, when she was good and ready. She said she was safe and not living in fear, and her clenched fists and upturned chin revealed her conviction.

She made me smile at times during our conversation with the accuracy of some of her questions: “Why do men think that sex is the same as love?” and “Why can’t you speak German?” (I’ll pause here to say to the men reading this column that I do not, for a moment, think that ALL men equate sex with love—but some surely do, and this comes from many years of working with men with sexual problems. As for you readers who speak German, I am just too old to learn another language!) At times, her eyes glistened with intelligence as we talked but, at other times, they roamed around my office, which admittedly was not the neatest it has ever been.

After a 30-minute discussion, we came up with a plan for her immediate future. She agreed to have her partner join us at our next meeting so that I could tell both of them what was safe for them to do sexually while she undergoes treatment and what was off limits. At the next meeting, I focused on him as I talked about these issues, and I saw out of the corner of my eye the patient giving me a thumbs up. I felt really validated in that instant. The two of them left my office a short while later, escorted by a staff member so that they could find the location of her next appointment for the day.

Since this interaction, I have thought a lot about how we label patients—difficult, odd, challenging, nonadherent, demanding—and I wonder if this is more about us and our need to get things done on our terms, in our timeframe, and according to our rules. Why do our patients have to meet our needs? The image I have of her in my mind is not someone who is difficult, but rather someone who is doing the best she can in her own life and is not willing to bend to fit our expectations.

She may not fit the picture of someone with agency, the ability to be a self-advocate, but that is exactly who she is and I admire her for that and much more. I just wish that others could see beyond the messy clothes and unruly hair and her reluctance to do things our way and then change the label or, better yet, not label at all.

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Digital Object Identifier: 10.1188/13.ONF.531