The Differential Diagnosis (DDx) of Refusal of Care

Dr. Mark Hughes & Dr. Joseph Carrese
Teaching Ethics

Chapter 6

The Forgotten Text
Vivian V. Altiery De Jesús
Early in the morning a group of surgery residents gathered to take a lecture regarding the Difficult Patient and Challenges faced with Colleagues. Throughout the discussion, a probe-question was placed in the table "What is the differential diagnosis of Refusal of Care?". Basically, that is one of the main problems, seldom we see a situation where a patient is labeled "difficult" because they don’t agree with their physician (¬.¬).

After the resident chatted back and forth with both lecturers, differential diagnosis (DDx) were produced.

1. Misunderstanding/Misinformation
2. Ignorance/Poor health literacy
3. Discomfort/Pain
4. Fear
5. Bad outcome of family/friend/Self in the past
6. Adverse risk
7. Lack of Capacity

Yeap! All of them alone and combined, practically you have from 7 to 5,040 combinations of why a patient may be refusing treatment (considering only this seven categories) (.@.@) .... The good news is that healthcare workers only need to master a single technique…effective communication (^_^). Easier said than done. Ironically, by
the time I was on my third year I had 26 years of communication experience (take away a few months, although high-pitched crying was highly effective in my early days).

Regardless of my communication experience on a daily basis (‘_‘), I encountered many combinations of the differential diagnosis. The Google-Symptom (sorry for the rest of Internet Browsers), which could fall on the poor health literacy category, provoked an inner face palm (‘_‘). I recall one patient that challenged every recommendation based on Internet findings (‘_‘)...I think that I did not encounter many Google Diagnoses due to the poor signal on the Island after the Hurricane. I remember the slight frustration at having a constant resistance (_deposit). How many times either my family or I had to turn on the generator and study at the weirdest hours (‘_‘), or just go to the yard or roof and study maximizing the sunlight....(Those were deep connection with nature (...)). Plus, it was not my humble roof-yard opinion (deposit) and two years of lecture training, I had a few residents and one attending pulling the strings too. Nonetheless (_deposit), it seemed that no matter what explanation or how much time is spent, Google seemed to always be on the lead (deposit). Just a deep breath, recall your ”difficult patient lecture” (_deposit) and move on (‘_‘) ... acknowledge the patient’s knowledge and you know the rest.

Eventually, the patient followed the recommendations, but I think the team labelled him difficult due to the extra-time we had to pour against his Google bullet list every single day. Fear, discomfort, and any previous bad outcome experiences are
challenging and delicate (°<>°). Most people had experience at least one fearful experience, especially in childhood. Most of the time is the caregiver that provides reassurance and helps the person overcome their fear(^_^). In the clinical setting, it is very difficult to persuade because the healthcare worker cannot say "Don't worry I swear that everything will be ok" (¬¬). Because in reality, I don't know if everything is going to be 'ok' (﹏). To start with, is the "ok status" the same for the patient and me? (×_×) Furthermore, fear creates misunderstanding, and mitigating them takes time. The relation deeply depends in the communication and ability to build trust in the relationship.

There is one diagnosis that we did not discuss, but it has followed me since the second half of my third-year clerkship. It was my Internal Medicine-Floor Rotation. "Fifty-three-year-old female otherwise healthy prior admission she came due to a Hemoglobin around 4-5. Differential Diagnosis?"

"Cancer (ಠωಠ)" – I said.

"Where are we in first year?" - I still don't get why an MS1 is so unworthy (°﹏°). Someone was in a foul mood today (¬¬). Later, I learned that for this particular attending when asked DDx you had to pistol like the Wild West all differential diagnosis (°апример°) =εїз .... the usual Family Feud approach was unacceptable(¬_¬).

“Anemia?” – offered my fellow combatant.
“Are you asking Me?! Which one and why?” – This was going to be interesting and challenging (¬_¬). Well welcome to bootcamp (へへ). Not my favorite learning approach but adaptable¬¬(¬¬), practically my high school was a tailored military driven curriculum, which allowed me to learn discipline and structure beyond academics.

“Who will take this case?” – I was snapped out of my thoughts, practically everyone had poured DDx̿̿̿̿̿̿̿̿̿̿̿̿̿̿̿̿̿̿̿̿̿̿̿̿̿̿̿̿, but apparently there were more(⊙_⊙), and my two hamsters were running at full capacity<(¬_¬)>.

“I will.”

The medical history shouted GI cancer: weight loss, stool shape change, rectal bleeding, the anemia, her age, her family history…deep down she suspected it too.

“What is the plan?” - the patient asked me.

“I would have to speak with my superiors, but the next step will be to have a few tests.”

“Tests searching for what.” - The question was more of a statement than a question.

Her eyes said it all, she knew what we were suspecting. I felt time slow down… Test searching for cancer? Test searching for cancer (do it more secure, woman.zip). We suspect you may have cancer, CANCER CANCER CANCER CANCER. You cannot blurt out that she has cancer, what if she doesn’t (⊙_⊙)´. The attending didn’t look convinced about Cancer. Well, our attending didn’t look convinced of anything¬¬(⊙_⊙)/… Hurry up!

Remaining two more seconds quiet would be worse than blurring cancer (>>.<<).
“One of the possibilities is that you may have cancer. We need test to make sure you don’t have it.” – looking back the wording I choose, were bias(~_~;). Later during my MBE seminar, Practicum, and Pediatric Oncology Rotation at Bloomberg Children Hospital, I learned to adapt a more neutral language. Instead of “make sure you don’t have it” a more neutral approach would be “We need to test to know whether or not you may have cancer”.

She nodded. “If that is what you are thinking I would like to leave the hospital.” – she said calmly. I did not expect any of this, her calm reaction nor her desire to leave the hospital without ruling out cancer (・_・;). Perhaps it was the way I frame my answer?

“Why?” – I asked her.

“My father died of cancer.” – she responded. “And it was awful.”

“I am sorry for your loss. However, knowing at an early stage could help in the management”.

She shook her head. “I know but then after the test what would happen?”

“We are searching for other causes too. But in the case that the test is positive for cancer, we would discuss possible therapeutic treatment”.

“Exactly. Test will lead to more test, and treatment.” – There was something going on, but she was calm and secure about her decision.

“Are you worried about the procedure, about the experience?”
“No, I know that it would be hard but better than my father, due to technological advancement.” – Now I was lost(ºº), this refusal was not due to Google, and apparently neither by previous bad experience (with staff). She did not seem fearful either.

“Why would you prefer to leave the hospital?”

“Actually, I would like to be healthy, I do exercise, try to eat healthy, I don’t smoke nor excessively drink. I have never done drugs. But I don’t have health insurance.

Regardless if I know today or tomorrow if I have cancer, it would not change a thing because I cannot afford it”.

I was not prepared for this (+_+). However, everything moved like a reflex muscle, from the standardized practice with the “and if” situations. “If you would like, we could connect you with a social worker. But right now, we are worried about your health”. It was not the same, it did not feel the same (•_•). Perhaps because I realized that this was a real case, maybe because in the middle of the natural disaster, things wouldn’t work as efficiently(¬¬). Do not give false hope, but do not kill hope either. Easier said than done. What would I gain in spelling the detrimental side of the story, I knew, she knew it, everyone in Puerto Rico knew it…things were not like before? \(~\_\~)/ We had two options, sit down and wait or start walking forward. I remind myself to keep the most neutral face possible.

She gave a deep sigh. “Alright, I will try.”
Here is another DDx for the “difficult patient”: sometimes, there are things that are beyond the physician’s and patient’s control. There are other socio-economic factors that are playing in the background and strongly stir the decisions and perceptions. The physicians’ responsibility is trying to mitigate and aid (either by direct action or by referring to the correct resources) the obstacle that may label a patient “difficult”. It is our responsibility, as physicians, to practice the Principle of Justice…excusing oneself behind the “difficulty” label cannot be a waiver to our duties.