ASK THE ETHICIST

The burden of caring

by Blair Henry and Spencer Livingstone

CASE SITUATION

“I find that it is very difficult in situations where I see there is aggressive therapy being given, but it may not be in the patient’s best interest. I struggle with this. The patient is going along with it, but I do wonder if it is in their best interest. Sometimes, it seems to me that it is not to be. And that is really tough.

You think, wait a minute, there are options here. Did anyone talk with the patient about them? But there is a push to go ahead and get the person treated. And often they do die and you feel awful. You’ve been part of a very aggressive decision. You put the patient and the family through that when maybe they ought to go home or to be in a quiet place for the last few hours. We get very aggressive with these patients and it feels awful.

I had a situation last night, an older woman, and the decision was made to treat her that day. She was an inpatient and she had to be sent to get her radiation. She could barely get out of bed. She tried and vomited. And her pain was actually under control with a narcotic, so she didn’t really need treatment just for pain control. I thought we could have waited one day to allow her rest. And it was already 6 p.m. Yet, there seemed to be no other decision to be made. It was all decided. She had to be sent for treatment. It was so hard.

But I wonder, is this an ethical issue? How can I handle this in the future? I know it’s going to happen again with other patients.”

RESPONSE FROM BLAIR

Thanks for submitting this story. These situations are emotionally difficult for everyone involved, no less for health care providers as for patients and families. From my experience, radiation therapists and clinic nurses seem to see this with some regularity.

We send a lot of conflicting messages in health care: Cancer can be beaten! Patient-centred care! Good palliative care is a right! Does making a decision to stop fighting feel like a failure to patient/family health care providers? It can when no consensus exists.

Fundamentally, a capable person’s best interest is what they say it is. That being said, one’s interests can be numerous and even conflicting: to be strong for another, to be pain-free, to endure short-term pain for long-term gain, to want quality over quantity, or to seek a peaceful death. But we are not just individuals. And many of our patients may be gently coerced into treatments long after they would have personally wanted to stop, but they were doing it for others.

I think your story speaks to the issue of informed consent and how consent is a process that needs to be revisited along an illness trajectory. Your patient should have known what missing a treatment means and that she can decide to stop at any time, if she finds it overwhelming, so long as the consequences and options are clearly explained. Is there a way to check with the person about this understanding? If there is a clear understanding on the patient’s part, this is a different situation than if the person is feeling overwhelmed by the situation.

Our role as advocates for our patients supports taking some action in this situation. However, it can be perilous unless it is done sensitively and well. If the patient is being coerced by family, our stepping into the middle too quickly can create conflict that may cause unnecessary harm—harm to the relationship between the patient and the family, or harm to the relationship between you and the family. My advice is always try to avoid being triangulated into messy situations (i.e., being put in between a patient and family or patient and oncologist in cases where previously established goals of care are being followed). Sometimes stepping in is necessary, but a more process-orientated intervention can go a lot further.

The ideal is for the patient to come to her own decision that enough is enough and that her best interests involve quality of life consideration above all others. Then, the patient needs to be able to say that to all parties involved.

So, communication is the starting point. Seek clarity about what is really going on and involve the family and others where possible. Sick people can easily be susceptible to opinions. We need to be sure they receive unbiased and supportive information from us.

As a clinic and inter-professional group, colleagues should talk about these stresses and a plan for addressing this should be thought out ahead of time. I hope you can encourage your team to start this conversation.

ABOUT THE AUTHOR

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