

Got Bioethics?

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Dorothy lived with gusto. A lover of Irish music, she was often seen at one of her favorite pubs, singing along with a drink in her hand. She was robust, full of laughter and compassion with a well-placed curse word here and there. When told of her terminal diagnosis, she reflected back upon the richness of her life – her children and grandchildren, her travels, her friends, and simply expressed a desire to avoid “heroic measures” when the end came calling. At that point, however, she was not ready to entirely give up. The next step was surgery and, after that, a course of treatment.

Following surgery, there was an “NPO” (nothing by mouth) order pending a swallowing test. The test determined that Dorothy had a risk of aspirating food and fluids into her lungs and, therefore, the order became the status quo. There was no discussion with Dorothy about her own wishes, the actual extent of the risk and whether or not she wanted to try food and fluids notwithstanding the risk.

Dorothy was transferred to a nursing facility with the “NPO” order still in place. She had grown weaker and lost considerable weight. Thinking perhaps that things might be different in this new facility, Dorothy and her family once again brought up the issue; not only did her new physician insist on continuing the order, he loudly discussed her medical diagnosis within earshot of other patients, doing so with a cavalier attitude and lack of compassion that went far beyond simple truth-telling. The goal of getting Dorothy well enough to go home fell on deaf ears. “So, do you want an IV? Most families don’t” he said. And, that was that.

When staff members weren’t around, Dorothy, with the help of her family, tried small swallows of liquid nutrition and found that she was able to tolerate this. So, her family advocated on her behalf for a new swallowing test and all were excited when it indicated that she could tolerate fluids and some soft food! However, the physician, who likely expected that the new test would support his “NPO” order, was unwilling to change it unless Dorothy’s family had her returned to the hospital, at their own considerable expense, for a test with the original speech therapist. This time, improvement was noted and she was cleared to attempt food and fluids. Her excited family drove the test results to the nursing facility but the physician refused to give the order, saying that he would not do so as long as there was any risk of aspiration; he also made clear to the nursing staff that this patient was *not* to have anything by mouth under any circumstances.

Would Dorothy’s goal of going home have been achieved had food and fluids been allowed? Could she at least have enjoyed the psychological benefit of enjoying one last bout of self-determination? We will never know. Dorothy never left the nursing facility.

Most hospitals have a bioethics committee or consulting service and, to varying degrees, make known to physicians, staff, patients, and families that this resource is available. This is not true of many post-acute nursing facilities. But, consider how this might have been helpful in this situation?

One principle of bioethics is autonomy. This would have supported giving Dorothy the opportunity to discuss the results of the test and the risks and benefits of the physician's "NPO" recommendation then make her own decision about attempting food and fluids. If she were unable to do so, her family members who knew her best could use "substituted judgment" to make decisions for her based upon her known wishes. And, what about beneficence and non-maleficence – doing what benefits and not doing that which harms? Even if the benefit were psychological, and even if ultimately taking food by mouth would lead to a negative consequence, these corollary principles could have helped to equalize the doctor/patient relationship. And, let's not forget about the nurses and their undoubtedly mixed feelings about what they were seeing. Their voices and observations would also be part of the discussion.

Health care providers have a reasonable fear of lawsuits and, therefore, a desire for self-protection is understandable. But, here's how a bioethics committee or consultant can help. First and foremost, they are a resource for education of the medical team as well as for patients and families. Often they serve as mediators, which could have been extremely helpful in Dorothy's case. They do not give binding directives, only recommendations. However, these recommendations can support a competent patient's decision not to follow a prescribed course of treatment. Must the attending physician go along with this decision? Absolutely not. Health care facilities typically have policies for transferring care to another physician or for documentation of how a patient's decision not to comply with a physician order or recommendation will be implemented.

The time has come for bioethics resources in post-acute care. This is simply part of good medical care, particularly for seniors and individuals at the end of their life. How to make this happen is a complex question but it is one that needs to be answered. As a nurse/attorney/ethicist I hope to be part of finding that answer.

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