

Choosing Life, Not Suffering: Reevaluating Hospice Care

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In his 2010 New Yorker piece titled "Letting Go," Dr. Atul Gawande discusses the case of Sara Thomas Monopoli, a 34-year-old woman with inoperable and metastatic lung cancer. Sara and her husband, Rich, chose a course of aggressive treatment in an attempt to manage her disease; sadly, despite numerous rounds of chemotherapy and experimental medications, Sara passed away within eight months of her diagnosis. Like Sara, many terminally ill patients focus entirely on the medical battle against their diseases, effectively avoiding the difficult but necessary conversations surrounding end-of-life care. Dr. Andrew Billings and Dr. Eric Krakauer of Harvard Medical School note how conditions surrounding these prolonged medical struggles are often inconsistent with the values and goals of the patients themselves. How does the patient-physician relationship need to evolve in order to reinforce patient autonomy while ensuring the quality of life (and death) the patient desires?

It is important to understand that terminally ill patients have concerns besides prolonging their lives; top priorities include avoiding suffering, being with family, and not burdening others.^[i] However, the questions that are commonly heard in the hospital revolve around medical technicalities, including the use of cardiopulmonary resuscitation, ventilators, and feeding tubes. The role of the physician is to find a balance between the prolongation of life and the preservation of its quality by individual patient standards. To address this problem, all primary care physicians should introduce advance care planning to their patients before they fall ill.^[ii] Through advance care planning, patients are made to consider end-of-life decisions, such as whether to allow CPR, tube feeding, and palliative care, and inform future care teams of their preferences.^[iii] Primary care physicians should start this conversation by discussing patients' values and preferences in order to determine what is most important to them. Currently, Dr. John Loike of Columbia University posits that most conversations about health care decisions boil down to patients asking physicians what they would do if they were in a similar position.^[iv] This conversation is inadequate. Because preferences vary widely based on cultural, religious, and personal beliefs, value discussions play an essential role in illuminating what patients desire and what they want to avoid.

After an action plan has been made, how should a physician care for a terminally ill patient? Some doctors argue for hospice care instead of the futile efforts to treat an incurable illness. However, many oncologists believe the opposite: What if this patient is the exception to the statistic and survives? Paleontologist and author Stephen Jay Gould exemplifies this medical rarity.¹ Although he was diagnosed with mesothelioma, a cancer of the protective lining of the cells that coat the internal organs, Gould refused to accept the statistic that the median survival expectancy was eight months. Instead, he chose to attack the cancer in the battle for his life. With a tenacious treatment plan, Gould made a full recovery and lived for 20 years after his diagnosis. Physicians cannot ignore that a strong will to live can be a powerful force in survival.

What is wrong with treating every patient as if he were Stephen Jay Gould? The problem is that a supermajority of patients will not be as fortunate as Gould was. It would be ethically and professionally wrong for a physician to treat his patients under the assumption that they will be the exception. Instead, it is vital that physicians be honest with their patients. Many patients want the advice of their doctor in order

to make informed, autonomous decisions about their end-of-life care. Patient autonomy is not respected by physicians who mislead patients into believing that they will be outliers to the statistics. A recent study found that 40 percent of oncologists polled had deceived patients by offering them a treatment they knew wouldn't work out of fear of crushing patients' hope.¹ At the same time, a physician who is too pessimistic about a patient's prognosis similarly fails to respect the patient's autonomy. Both cases highlight why advance care planning is so important: Although some patients may decide to pursue aggressive treatment if they are given a poor prognosis, others may find hospice to be a more suitable option.

When most people think of hospice care, they think of a patient attached to a morphine drip, drifting in and out of consciousness, waiting to die. Hospice care is stigmatized because it is assumed to be a way to let people die "naturally." In fact, the true goal of hospice care is to help people live the fullest possible lives during their illnesses. Hospice care often allows patients to live at home with their loved ones. Patients can manage their own pain and are given emergency packs to manage certain symptoms, such as nausea, fever, and anxiety. Choosing hospice care does not mean that a patient has given up her will to live; it means that she does not want to die bedridden and intubated in an intensive care unit. Moreover, it has been demonstrated that individuals in hospice care enjoy their final days more (and live longer) than individuals in an ICU. Hospice care allows for terminally ill patients to set the terms by which they live each day, according to their particular values and goals.

To preserve patient autonomy and quality of life, primary care physicians need to have honest conversations with their patients about their illnesses, options, and moral values. Such conversations should be specific to each patient, taking into account his personality and views on death and illness. As future physicians, we hope that the implementation of advance care planning will remove the stigma that surrounds hospice care and help our patients make autonomous decisions about their treatment plans.

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