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Changes in the Hospital Culture Can Make the Difference Between Life and Death

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I have been asked by the Chayim Aruchim organization, for the benefit of the wider community, to share my observations and perspectives on end-of-life care in hospitals. While some of the content of this article may seem shocking, or at the very least, disconcerting, it is important to be aware of this information for if and when the need arises.

First, I will explain my experience and qualifications to discuss the matter. In my career as the field of Infectious Disease, I have practiced full-time as an Attending Infectious Disease physician for nearly 35 years. Nearly all of my work involves inpatient hospital consultation. Over these years, I have seen an average of approximately 25 patients per day. These patients have had a broad spectrum of severity of illness, including many hundreds, if not thousands, nearing the end of their lives. For these nearly four decades, I have worked in over a dozen hospitals, both in the New York area and currently in South Florida. Thus my experience is not limited to a particular hospital, nor a particular geographic, or political, area.

I would like to begin with an overview of a new "field of medicine" known as Palliative Care, which became a Board-recognized specialty in 2006. Palliative Care plays an important role in managing patients experiencing pain, as Palliative Care providers are trained in the use of pain medication, while other medical providers often do not possess the same degree of clinical knowledge to manage pain, which requires delicate balancing. Over the past 20 years, Palliative Care has rapidly become one of the busiest specialties in the hospital setting.

More relevant to our discussion, Palliative Care providers have assumed an important role in discussing end-of-life decisions with patients and their families. In such circumstances, ideally patients and families should have a clear understanding of the issues and the relevant medical information and then be allowed to decide how they wish to proceed. These difficult decisions generally involve the choice to either prioritize relieving as much of the apparent suffering as possible, which will sometimes even hasten death, or to decline the overemphasis on pain management and pain medications, and rather to continue all medical interventions for the patient to recover from the acute episode.

However, the reality is that of the many, many discussions I have heard between these providers and the patients and their families, very few, if any, decisions are presented in such an objective manner. Family decisions are made based on how the choices are presented, and if the options are presented by the "experts" with a certain bend, the subsequent "decisions" made by families will reflect that presentation.

Take the following hypothetical (but all too realistic) example of a Palliative Care specialist presenting to the family of a 90-year-old mother and grandmother who has been hospitalized only recently due to an acute illness:

"Your mother is 90 years old. She is suffering so much. We know that you would not want your mother to have to endure any pain and suffering. I am sure you know that she would not want it either. The kindest thing that you can do for her is to make her comfortable. The last thing we all want to do is to cause her any further suffering. The right choice would be to transfer her to hospice care, where specialists in comfort care will manage her care."

How would we expect an unassuming family member to respond to this presentation? In this example the decision has been presented as: "If you care about your mother, do this, and if you don't care about your mother, do that."

This is not merely an anecdotal observation, but a reflection of the culture in the 21st century hospital setting. As I will explain, I believe that this is a product of many changes in both society at large, as well as in the medical field in particular. Regardless of the reasons for this phenomenon, the fact that this is the prevalent way in which patients are spoken to is undeniable to anyone with actual hospital experience. And sadly, when patients and family members oppose the direction which the specialists wish them to follow, they are often met with fierce disapproval and outright antagonism.

Aside for the introduction of Palliative Care specialists into the hospital setting, another major difference in medical care over the past 20 years that I would like to highlight has been the advent of Hospitalists. Hospitalists are physicians who take care of hospitalized patients only. Until recently, each patient had his own physician who would follow their patients in the hospital. These physicians often had personal relationships with their patients, in many cases spanning decades. When their patient took ill and was hospitalized, these physicians knew that their 85-year-old patient, although now quite ill, had been actively living life just a week or two before. A physician who had a relationship with the patient would naturally work harder to get the patient back to where they were before. The importance of this relationship and understanding of the patient cannot be overstated.

In my observation, the Hospitalist who sees the patient only in his or her compromised state, simply does not have the same motivation to help the patient recover. The Hospitalist has no idea of how the patient looked just days before. Thus the medical care of the patient is compromised. The fact that the field of medicine continues to advance, and new breakthroughs in treatment are constantly being introduced, cannot overcome the importance of the motivation of the one providing that care – the doctor. The doctor's role in judging the situation and the needs of the patient and his or her family is more vital than his role in the medical intervention he provides. The intervention is merely a product of the decision of how to proceed in caring for the patient.

Again, I present a hypothetical example, this time of the patient's private physician, presenting to the same family of our 90-year-old, ill patient:

"Look, I know your mother is very sick. I have known her for 25 years. I know how resilient she is. I also know how much it means to her to see her children and grandchildren. She gets so much joy from seeing them. She may not make it, but I think it is worth a shot. Let's give it our best. If you think that she would not want to go any further than what we are doing now, let me know."

The tone of the presentation literally affects the life and death of the patient.

Another impact of the change from private physicians to Hospitalists, is in the experience versus lack thereof, of seeing patients recover from acute illness. Private physicians followed the ups and downs of a patient's experience, and they would see not just the light at the end of the tunnel, but they would see the patient actually get out of the tunnel. Hospitalists and Palliative Care specialists are trained to ease the process of dying, but lack the clinical experience of seeing patients who have recovered from serious illness when the odds seem to be against them. I remember the days when we cared for a sick patient in the ICU for weeks and the patient eventually recovered. The patient would often come a couple months later, fully-dressed, looking well, delivering a box of chocolates to thank the staff for their care and attention. I hardly see this anymore, and I often wonder if any of the Hospitalists or Palliative Care specialists have ever experienced these moving moments. I believe that such a reminder of the joy of recovery would help change their tone when advising families about how to proceed caring for their loved one.

I would like to suggest that another change in the culture of medical care is reflective of a change in general society, which now places a much greater emphasis on quality of life, even at the expense of life itself. I think it is fair to surmise that most of the Palliative Care specialists and Hospitalists are relatively young, as these are newer specialties. In today's day and age, a fully active, young individual often views old age and infirmity as an undesirable state, and this perspective may influence how they present medical choices to families. While this correlation cannot be proven, I wonder aloud if this social change has impacted the outlook of the younger generation of doctors. I quote from an AI-generated definition of hospice care: "A specialized form of end-of-life care that provides comfort, support, and medical assistance to terminally-ill patients and their families. It focuses on managing symptoms, improving quality of life, and respecting the patient's wishes during their final days." Note the focus on quality of life, and no mention of the value of life itself.

Another dynamic in the hospital which relates to end-of-life care is the "Do not resuscitate" (DNR) status of a patient. DNR is usually explained to a patient or family that this simply means that if the patient were to have a cardiac arrest, cardiopulmonary resuscitation (CPR) would not be performed. Other than that extreme situation, the patient is told that they will receive the same care regardless of the DNR status.

However, while this may be the truth on paper, I have observed a withdrawal of care and attention to DNR patients in subtle ways. For example, physicians in the hospital are generally under tremendous time pressure. Naturally, decisions must be made as to where he will expend his time and energy. A patient with a DNR order signals to a provider that this patient or family has given up to a certain extent. Again, while a particular medical provider may deny this, I have noticed this in many circumstances and in many different settings. There is no doubt that the there is a letup in the intensity of care for a DNR patient. And sadly, in such settings it is often the case that such subtle differences in care are the difference between recovery and death. As a result, I make sure to make families aware that a DNR order is not merely a status which affects resuscitation in a case of cardiac arrest, but a status which affects the entire culture of the medical team around the patient.

These are a few of my observations and perspectives that I know that people caring for loved ones want to be aware of. Sadly, these are not isolated instances but the general norm in all of the hospitals that I have worked in, as well as what I have heard from friends seeking my medical advice. This is a widespread phenomenon and an unfortunate downturn in the level of medical care provided to hospitalized patients.

I would like to conclude with two stories of such experiences, which help bring out the point of this article.

Many years ago a friend's father, a Holocaust survivor, seemed to be coming to his end at the age of 92. The family was being pushed to hospice care. After reviewing his charts, I saw some improvement in the patient and encouraged the family to wait and give him a chance. Slowly but surely he recovered, and weeks later he was back home, making Kiddush on Shabbos for his family. What this meant for him and his children!

Another anecdote happened to me just a few weeks ago. I was walking through the hallway outside of the ICU, when a woman walking in the opposite direction stopped suddenly and shouted my name. She had been a close friend of my sister growing up, and I had not seen her in over 25 years. She asked me to help her brother-in-law, who was then a patient in the ICU. He was 75-years-old, on a ventilator requiring high levels of oxygen, on dialysis for his acute kidney failure, and on medications to maintain his blood pressure. His wife signed a DNR form and the Palliative Care was called in for consultation. The medical team advised the family to strongly consider hospice care, as they felt that there was "at best a 1% chance that he would recover." In my experience, a patient transferred from the ICU to hospice care is usually dead within a couple of days. This friend asked if I could take over his Infectious Disease management and asked me to do whatever I could to help him recover. I reviewed the medical record carefully and found no explanation for why he was doing so poorly. I made some changes in his antimicrobial therapy. I explained all of this to the family and told them that although he was very sick, perhaps he could pull through. Sure enough, within the next two days, his condition had turned around completely. He got off of the ventilator and only required a small amount of supplemental oxygen. He started to regain his kidney function. A couple of days later, he began to eat and drink. One week from the time that I first saw him, he was discharged from the ICU and transferred to a regular bed in the hospital, breathing completely on his own.

Reflecting on this particular incident, I question, was it a miracle that he survived? The family thought so, as they had been told that he only had a 1% chance of survival. But I wonder, in order for the medical staff to make such a dire assessment, they would have had to have cared for 100 patients in a similar situation, tried as hard as they could to have those patients recover, and fallen short in 99 of those patients. Suffice it to say that I do not think that any of the physicians who advised this family had anything near that kind of experience.

These stories are not aberrations. They are representative of what is happening in hospitals today. I do not think that these stories would have taken place earlier on in my career. Advances in medicine do not compensate for changes in the value of life and how it takes hard work on the part of the medical team to figure out how to help extend life.

I hope that awareness of these changes will help future patients and their families make informed decisions. The decisions are literally the difference between life and death. It is the determination of the patients and their families which impact the care that the medical staff provides the patient with.

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