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Perspective Open Access

When Technology Exceeds Our Humanity...

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Perspective

What is a good life? Or a good death? Even after 30 years of nursing, I would not even attempt to answer such a deep, personal question. Given the technological advances, it is not surprising that patients think they can cheat death. As famed medical ethicist John Fletcher stated: "The issue is not one of death. The issue is what kind of death, an agonized or peaceful one" In my practice setting, I see many patients tenaciously fighting their condition. However, there comes a time when the ravages of disease prove insurmountable for even the strongest willed patient. Coupled with the fact that less than 1/3 of Americans discuss advance planning, with the number only slightly higher for those individuals with serious, chronic diseases. This is very telling that patients and families alike do not like to discuss these ohso-important matters. This leads to overly aggressive care in the last weeks of life that most likely goes against the patient's wishes. Providers make it harder for patients to accept changes and make decisions when they are unaware of the disease's trajectory. There are many factors to consider when bringing up advance directives including patient and family readiness to accept information, and level of trust and confidence in the provider. They may never get to that acceptance point, much like the stages of dying coined by Elisabeth Kubler-Ross [1,2].

The subject of death or dying remains largely shrouded in taboo and superstitions, especially when it comes to end of life decisions. In my experience, it is the patient who is sometimes left out of this important discussion. When is enough, enough? Ancient philosophers valued death over violation of personal principles which says to me that the patient is the driver of this journey. It is up to the interdisciplinary medical team to communicate clearly by outlining realistic options while fleshing out their quality of life goals. I am fortunate to work in a setting that values end of life care so much that a select group, myself included, had an intensive training program on how to begin such conversations. I thought I was skilled at these difficult conversations, but this training opened my eyes in having a transparent discussion regarding goals of treatment. And in doing so, without figuratively hitting the patient over the head with the brutal truthfulness of their

condition. There is a noted lack in both nursing and medical school regarding end of life care except for the mechanics of the process. Given that people are living longer, it is vital that this is included as essential curriculum [3].

Don't be mistaken that it is only the patient and/or family unwilling to discuss end of life care. Studies show time and time again that providers are reluctant to broach the subject or even acknowledge that the patient is nearing death. One such study conducted by the Center to Advance Palliative Care (CAPC) found that palliative care screening could result in a 6 billion dollar savings. Going further, a team of oncology patients participated in a pilot project to be screened for palliative care consults. At the end of the six months, the oncologists, who previously stated their patients "are not there yet", voiced that they did not know how they effectively practiced before the project. In my opinion, it is wrong on many levels to offer life sustaining treatment options without discussing goals, expectations and defined endpoints. I have witnessed and been a victim of this particular brand of moral distress. It is having these difficult conversations that can make a meaningful difference in this final journey. That can be accomplished by education about end of life communication, and ensuring availability of these specialized services. This is certainly a priority as people age and has increased care needs. In the end, people want to know their lives matter. It is up to us, as skilled medical providers, to ensure that their legacy is honoured [4].

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