

INTRODUCTORY LECTURES

Advanced Care Planning - Empowering Patients for a Peaceful Death

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Abstract

In the early 1900's, Americans had a life expectancy of about 50 years. Childhood mortality was very high and an adult who lived into their sixties was considered to be doing pretty well. Prior to the advent of different types of antibiotics, people would die quickly of infectious disease or accidents and medicine only really focused on caring and comfort. Since then, there has been a shift in medicine's focus. New science, technology and communications have shifted the way Americans treat incurable diseases and have promoted the idea of aggressive fighting as well as to keep patients alive at any costs. The internet has allowed easy access for patients to do on-line research and to know the treatments for diseases and the availability of trials. This has promoted the idea that every disease or cancer is curable if the patient does exactly as the internet says. It has hindered the idea of compassionate care and dying with dignity so that a patient can stay alive at all costs, even in a vegetative state. In the last two decades, there has been a significant expansion of palliative and supportive care services in the United States. This has including the development of a specialty for palliative care medicine with a board certification in hospice and palliative medicine. A challenge to the field has been the reluctance of physicians to request palliative care consults in a very timely manner as well as relinquish care of their patients. A common occurrence in the United States, at many cancer centers, is the treatment of chemotherapy and radiation up until the day before a patient dies. At this point, the physician ends up throwing up his or her hands with nothing left to offer the patient or its family. However, what we have been finding is that presently there are now many oncologists who are willing to refer patients to palliative care for specific management of difficult pain control issues. At the Moffitt Cancer Center, we have a Palliative Care consulting service along with a Palliative Care Fellowship program where we work with cancer teams to provide resources to them when they are running into difficulties with their patients. Typically, we step in when first line treatments have failed, symptoms have shown no signs of decrease, or when the primary teams have exhausted their standard management options. Our hope is for the primary care teams to be able to manage basic symptoms themselves and only call on the Palliative Care team when they have surpassed their comfort zone. For example, the Palliative Care team would step in if a patient's dosage of medication was out of a primary team's spectrum. Other uses of the Palliative Care team include having the end of life discussion with the patients to find out what their expectations are of their treatment, what their concerns are and what their requests are. Normally treating primary teams are very uncomfortable in having this discussion with their patients due to the feeling that they are giving up hope or the fact that they are letting patients know that the end of the road is near. The Palliative Care team can then be called upon to come in and transfer the care from the primary team to the "death team". At Moffitt we have instituted a number of strategies to make this transition acceptable and more beneficial for the patients. One of the strategies that we used is an Advanced Care Plan. By having a consultation at the time when the patient is diagnosed, we are able to speak with them about what it is that they see in terms of what would be acceptable to them. We use the Project Grace Advance Care Plan which was developed by a physician and is very simple to understand. With this tool, we are able to bring up the discussion while trying to focus in on the patient's spirituality and the coping mechanism as the cancer patient. This allows the conversation of end of life treatment preferences and what the patient's typical desire is for life sustaining measures.

Keywords: Life expectancy - cancer not always curable - palliative care teams - Project Grace Advance Care Plan

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Introduction

In the early 1900's, Americans had a life expectancy of about 50 years. Childhood mortality was very high and an adult who lived into their sixties was considered to be in excellent health. Prior to the advent of different types

of antibiotics, people would die quickly of infectious disease or accidents and medicine only really focused on caring and comfort. Since then, there has been a shift in medicine's focus. New science, technology and communications have shifted the way Americans treat incurable diseases and have promoted the idea of

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aggressive fighting to keep patients alive at any costs. The internet has allowed easy access for patients to do on-line research and to know the treatments for diseases and the availability of trials. This has promoted the idea that every disease or cancer is curable if the patient does exactly as the internet says. It has hindered the idea of compassionate care and dying with dignity, a patient can stay alive at all costs, even in a vegetative state. These new changes have influenced the dynamics of all medicine but especially pain and palliative care.

The idea of the family physician is dead. Due to changing times, patients in the United States jump from doctor to doctor, sometimes seeing a physician only once. This makes it difficult for a doctor to understand a patient's situation and history or really know their beliefs and wishes. Another problem we find is that many physicians have no formal training in delivering bad news or in having a conversation regarding end of life care. These issues can cause problems for doctors when they have to bring up that discussion. Part of our work is to advocate that patients have this discussion with their physicians at a time when they are healthy; however this does not typically happen because who wants to talk about death when it is, in fact, the last thing on their minds? With the changing times, there has become a need for a separate doctor, different than the family doctor, who is trained in the "breaking of bad news" and able to offer the patient that comfort and ability to organize their wishes and get the results that are so important to them.

In the last two decades, there has been a significant expansion of palliative and supportive care services in the United States. This has included the development of a specialty for palliative care medicine with a board certification in hospice and palliative medicine. A challenge to the field has been the reluctance of physicians to request palliative care consults in a very timely manner as well as relinquish care of their patients.

Even though hospices have been operating in the U.S. for three decades, they remain widely misunderstood; however, they are the perfect example of quality end-of-life care (Gleckman, 2010). Many doctors are always uncomfortable in bringing up the idea of Hospice to their patients due to the fact that no one wants to rob a patient of their hope; by bringing up hospice care it is often felt to be a death sentence. In 2008, more than one-third of patients are enrolled in hospice for a week or less. In certain organizations, the numbers of short stays are increasing, perhaps because these requirements may be making already reluctant doctors even less willing to refer to hospice until their patients are actively dying (Gleckman, 2010). However, that should not be the case.

Hospice care is one way to deal with death in a compassionate way, but another common occurrence in the United States, at many cancer centers, is the treatment of patients with chemotherapy and radiation up until the day before a patient dies. At this point, the physician has nothing left to offer the patient or family. What we have been finding is that presently there are now more oncologists who are willing and able to refer patients to palliative care for specific management of difficult pain control issues, of complex pain syndromes, or for patients

having atypical nerve pain of different complexities in their treatment strategies. We can co-manage these patients with these physicians to work towards a better outcome for the patient.

At the Moffitt Cancer Center, we have a Palliative Care consulting service along with a Palliative Care Fellowship program where we work with disease based cancer teams to provide resources to them when they have challenges with their patients. Typically, we step in when first line treatments have failed, symptoms have shown no signs of decrease, or when the primary teams have exhausted their standard management options. Our hope is for the primary care teams to be able to manage basic symptoms themselves and call on the Palliative Care team when they have surpassed their comfort zone.

The Palliative Care team typically is the team to have the end of life discussion with the patients and family to find out what their expectations are for their treatment, what their concerns are and what their requests are. Normally treating primary teams are very uncomfortable in having this discussion with their patients due to the feeling that they are giving up hope or the fact that they are letting patients know that the end of the road is near. One of the strategies that we use is an Advanced Care Plan. By having a consultation at the time when the patient is diagnosed, we are able to speak with the patient and family about what are their goals of treatment. We use the Project Grace Advance Care Plan which was developed by a physician and is very simple to understand. With this tool, we are able to bring up the discussion of the benefits and burdens of each treatment for the patient. We are also able to evaluate whether the benefits and burdens are compatible with the patients and their family's goals. This document provides a framework on which we can initiate the discussion with the patient. When counseling a patient it is important to determine first and foremost what their goals for healthcare are as they near end of life. As health care professionals, we must validate to the patient that these goals may change as the patient's illness progresses. Other times the family, as a unit, will be working on these goals. We have found that the proper management of symptoms in these patients may help them prioritize these goals. We stress to the patient that to honor these goals an effective mechanism needs to be in place such as the advance directive.

Unfortunately, there haven't been many studies to show the scientific benefit of using these documents. Teno et al (2003) examined 688 living wills as part of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) study. They found that 50% of the orders not to attempt cardiopulmonary resuscitation were not contained in the medical chart, rendering it obsolete as the doctor had no idea that the order had been made. Furthermore, 87% of those living wills that do make it to the chart are written in vague medical language making it unclear as to what the patient actually wants. Only 13.3% go beyond general statements and 3.2% refer to current medical conditions.

Advance care planning with a community and organizational approach to advance care planning were studied in a project entitled the "La Crosse Advance

Directive Study” (LADS), which retrospectively reviewed all adult deaths in all local healthcare organizations for an 11-month period in 1995 and 1996. The objectives of the study were to determine the prevalence and type of end-of life planning and its correlation with treatment decisions. Data were collected from medical records, from death certificates, and from interviews with attending physicians and healthcare proxies. While other studies have documented low rates of advance directive completion, the LADS results stand in stark contrast.

Of the 540 deaths included in the study, the prevalence of written advance directives was 85%, with the most of these (95%) found in the medical record. Median time between the recording of the completed advance directive and death was 1.2 years, clear evidence of planning in advance of a medical crisis. And unlike other studies, which have found poor correlation between advance directive preferences and actual treatment decisions, we found that patient preferences to forgo life-sustaining treatment were honored by consistent medical orders reflecting these preferences.

While there are still lessons to be learned and improvements to be made, the results of the LADS provide strong evidence that certain strategies are likely to have a significant impact on the ability of healthcare systems to assist patients in choosing end-of-life preferences and the willingness of health professionals to respect them (Gundersen Lutheran Medical Foundation, 2007). Personally, I have had the opportunity to witness the benefits of having the Advance Directive done prior to a patient’s demise. While treating patients in the palliative care setting, many family members are very relieved that they are very clear on what their loved one wanted and that they can follow those wishes because they are spelled out in a simple form. In my opinion, there is much less burden placed on the family member when this discussion is held.

The Pain and Palliative field is evolving at an extremely high- paced path. New methods for the comfort of patients are being put into place to make sure that a patient’s last wishes are fulfilled as well as to ease the discomfort of family and friends and the relationship with the patient and his or her doctor. By utilizing, the advance care directives as well as the palliative care team, the overall dying process is made easier for those involved and takes the pressure off of oncologists and other physicians who may not feel comfortable with the idea of bringing up the topic of death or the idea of Hospice care. The main purpose of this new field and its treatments is to provide personalized and professional care as well as to bring back a certain dignity to dying.

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