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Healing And Transformation: My Experience In Palliative Care

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Abstract:

I spent the month of November pursuing an elective in palliative care. Although I was surrounded by death and dying, the elective was not depressing and hopeless. This was because death was transformed in the palliative care setting: it was no longer seen as an enemy to be defeated, but rather viewed as the natural end of life. Hope was thereby redefined from living as long as possible to living a contented, meaningful life in the time one has left. I learned that treating physical, psychological, social and spiritual distress in a comprehensive manner is critical in helping people live their last days in peace and comfort, and to ease their journey to the next realm.

I had a wonderful and enriching experience that allowed me to recall, renew and deepen my love for healing.

Healing and transformation: my experience in palliative care

I was apprehensive about beginning my palliative care elective in November. Fellow medical students and physicians were not very reassuring. The typical response was, “Palliative care? I could never do that…way too depressing.”

Would I be able to handle caring for terminally ill patients? Although I was a fourth year student, and had spent over a year on the wards caring for patients, I had largely been separated and buffered from death and the dying process. If a code occurred, I was either told to leave the room or was one of the many bystanders doing my best to observe without getting in the way. Sick patients who were not acutely ill were sent away to nursing facilities, and I never heard about them again. Death and dying were not openly mentioned in the wards. We said, “His [or her] prognosis is uncertain.” When patients asked existential questions regarding the meaning of life and death, or simply wanted prayer, we ran to get the chaplain. Hospice was viewed with fear and distrust: Accepting palliative care meant failure; it meant giving up hope. “She is being sent to hospice!” colleagues would say, incredulously, when that decision was made by other physicians. “You only go there to die!”

My palliative care rotation was anything but a bleak and hopeless experience. I quickly learned that my original apprehension was due to certain misconceptions. I discovered that palliative care was not only for people who were close to dying. Many patients were quite active, and availed themselves of palliative care services for pain and symptom management, as well as psychosocial support.

One of my favorite patients, Mrs. Johnson, is a good example of a young woman who used palliative care resources for symptom control. Only 34, she had been suffering from osteopetrosis for nearly three decades. Her fragile bones fractured easily, causing her severe pain. Over the past few years, her bone marrow had also become affected, leaving her susceptible to developing anemia and infections. Despite such hardships, Mrs. Johnson was a lively and friendly person. She was actively working and married. She used palliative care services for treatment of her frequent infections and for adjustment of her pain management regimen. She impressed us with her humor and her patience: When we asked about her large collection of beautiful silk pajamas, she stated, “I’m in the hospital a lot. I need to be comfortable!”

I learned that symptom management in the palliative care setting included much more than relief of physical symptoms. It became clear to me that psychological, social and spiritual suffering interacted in a complex fashion with physical distress. One must address all symptoms in a comprehensive manner in order to keep patients comfortable. One of my patients, Mr. Sanford, made this clear.

A large, 83-year-old gentleman with colon cancer, Mr. Sanford one day became very delirious and combative. He struck out at staff, ripped off his oxygen mask and tried to pull out his urinary catheter. He remained agitated despite receiving lorezapam and haloperidol, potent antipsychotic medications. Just when we thought that we might have to administer some pentobarbital to sedate him, his son arrived with the family dog, Sandy. Upon seeing the shaggy white poodle, Mr. Sanford started sobbing. He settled down after a few minutes, and fell asleep comfortably with Sandy nuzzled under his arm. I was surprised to see the powerful healing effect that this small, friendly pet had on Mr. Sanford. I had never believed that non-medical approaches could produce such dramatic results so rapidly. Sandy had quickly calmed Mr. Sanford; he thus had averted the need for a drug with potentially serious side effects such as respiratory depression and slowing of the heart. Unlike many medical interventions, Mr. Sanford’s poodle had relieved his distress without adding new and troubling symptoms

Although many patients used palliative care services for symptom management, one could scarcely deny the presence of death. Death was ever present. We always started our weekly meetings in hospice by listing the names of those who died during the previous week, and we offered them a short prayer. Yet, death became transformed in this special setting; death was not the enemy, to be fought and destroyed at all costs, as it often seemed to be in the hospital. Rather, death was viewed as the natural end to life. I learned that after a certain point, delaying death with futile medical treatments did not extend life in any meaningful sense; it only extended the dying process.

I vividly recall Mr. Smith, a 76 year old man with end stage esophageal cancer whom we admitted because of increasing weakness and delirium. His family said that Mr. Smith had not been recognizing family members for the past week. He was also hallucinating: he had lengthy conversations with his wife, who had died months ago. Mr. Smith's cognitive status fluctuated greatly during his stay at hospice, he was at times very confused, but he could also be very lucid. He told me during a clear moment, "I am not afraid to die. I've done everything I want to do. My wife died in March, and I am ready to join her."

Unlike the hospital setting, where I was mostly shielded from the dying process, during my palliative care elective I became accustomed to end of life experiences. I learned to recognize the symptoms of impending death, such as altered respiratory patterns, terminal delirium, and coolness of extremities. I learned that although physicians are not great at making prognoses regarding death, we can estimate by offering phrases such as "hours to days," "days to weeks",, "weeks to months" and "months to years." Such estimates reduced major prognostic errors, and also allowed patients and their families the ability to plan their remaining time.

I recall Mr. Roberts, the husband of a 53-year-old woman dying from ovarian cancer. Our estimate that his wife would die in "hours to days" allowed him to gather family members from different states together for a final good-bye.

On the other hand, there was Mrs. Smith, a 68-year-old woman with breast cancer. She was admitted with severe left hip and groin pain, which we discovered resulted from a left hip fracture due to a metastasis of her cancer. She used her prognosis of "months to years" to set personal goals: In the short term, she hoped to transfer herself from bed to chair, and in the long term, she hoped to walk with the aid of a walker.

As death was transformed in the palliative care setting, so also was hope. I discovered that hope was not surrendered in this setting – it was redefined from extending the quantity of life to improving the quality of life. Patients shifted their goals from wishing for an unrealistic cure to being comfortable physically, mentally and spiritually.

I saw my patient Mrs. Harris undergo such a transformation. A 68 year old homemaker with breast cancer and metastasis to her lung and brain, she had had multiple medical procedures during the past two years, including the removal of a lung, resection of a brain tumor, and radiation therapy. She now suffered from bouts of excruciating pain due to herpes zoster infection (shingles) of her left forehead.

She originally told me that she wanted to live until she saw her nine-year-old granddaughter married. At the same time, she said the past two years had greatly exhausted her: "Sometimes, I'm not sure what I'm fighting for, and if fighting is worth it." When our physician told her that she would not live another fifteen or so years to see the marriage of her granddaughter, she was not surprised. "Despite all those treatments, I know I still have the cancer in me," she said. She tearfully told us that she greatly worried about completely loosing control, and being a burden to her family. "I do not want to be hooked up to all those machines, and become completely helpless." At this point, she refused further "extreme treatment" including all surgeries and radiation. She redefined her goals to spending as much time with her granddaughter as possible. "I would like to go shopping with her!" she said, with a smile.

Mrs. Harris also mentioned that she had become increasingly religious in the past few months. “God did not interest me before, but I find that I am relying on prayer more and more.”

Her experience was not unique; I found that many of my patients were concerned with spiritual matters.

Mrs. Smith, my patient with breast cancer and bone metastases, found much strength reading the bible everyday. She said it helped her raise nine children, and it would help her now.

Mr. Vernon, my 83-year-old patient with terminal lung cancer, was admitted with respiratory distress due to malignant fluid in his lungs. I noticed that on certain occasions, prayer helped relieve his difficulties in breathing as effectively as morphine.

Indeed, I realized that spirituality was a key component to the holistic perspective advocated by palliative care: surrendering to a Higher Power brought much comfort to our patients and their families. Many spent time in the meditation/prayer room, reading holy texts, praying, meditating, or just relaxing. I realized that spirituality imbues our lives with meaning. It transforms death from annihilation to a gateway: a gateway to the Great Beyond, a place where we live an altered existence in the presence of The Divine.

Conclusion

My brief time working in palliative care has enriched my own life enormously. This rotation just happened to coincide with the Islamic holy month of Ramadan, during which Muslims avoid food and water from sunrise to sunset. I always find that fasting is a time of peace and renewal. This Ramadan was especially uplifting, as I was able to recall my love for healing. I realized that healing involves much more than a physical cure. It encompasses more in its reach than treatment with medication and surgery. It involves rest and comfort. It calls for relief from physical symptoms such as pain, nausea and constipation, but also psychological symptoms such as depression and anxiety. It entails visits from family members and loved ones. It may require prayer and meditation.

Finally, I realized that a part of healing is to recognize when to let go: although I experienced much more of death and dying during my palliative care rotation than at any other time in medical school, I did not feel in the hospice setting that we had failed our patients who died. We must recognize that at a certain point, treating physical disease becomes impossible. Yet, we can always attempt to relieve mental distress and spiritual suffering. We helped our patients who were dying live their last days in peace and comfort, and I hope we helped ease their journey into the next realm.

Note: I have changed the names of the patients and family members with whom I worked with during my palliative care elective to preserve their privacy.

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