

*“For being human holds a special grief
Of privacy within the universe
That yearns and waits to be retouched
By someone who can take away
The memory of death”*

-Epic of Gilgamesh, interpretation by Herbert Mason

Introduction:

My project focusing on end of life care has three facets: shadowing, research, and service. The goal of my project is to actively experience how hospice and palliative care providers use interdisciplinary care to meet the many needs of patients and families at one of the most important times of their lives. I will also administer an informal survey which focuses on the different ways nurses, physicians, chaplains, and social workers communicate with the patient. The data from the survey will be used to compile some simple pointers and guidelines that medical students could use in end-of-life care of future patients or eventually in counseling of patients about a serious diagnosis. Finally, I will compile a list of different services (wound care, EMR, incontinence services, 24-hour triage, etc.) offered by hospice centers in the Wichita area.

Background:

I have always had a knack for story-listening—not story telling. I am a lousy story teller, but there are few things in life that I enjoy more than sitting down with a friend, relative, or even a complete stranger and hearing her talk about her life, her experiences, her day. The wealth of experiences lived by each person and the kaleidoscope of views through which different people see those experiences have always enchanted me. For this reason, when I volunteered to serve lunch and assist the residents of the Catholic Care Center retirement community during the summer after my senior year in high school, I was in heaven! Some days, I received a comprehensive history lesson on World War II. Other days I was enthralled with detailed family genealogies traced as far back as the landing of the Mayflower. Hundreds of cherished family stories were entrusted to me and thousands of photos of grandchildren were placed lovingly in my hands. There is an undeniable wisdom, no matter how simply expressed, which prevails among those of a ripe, elderly age.

I found this same brand of wisdom again three years later when I worked at Camp Sanguinity, a summer camp for children on active treatment for cancer. Children always have stories to tell, but the stories told by these children were different. These stories sounded old and wise like those I had been privileged to listen to at the Catholic Care Center. I remember Shelby’s (pseudonym) stories most. Shelby, like many of the kids at Camp Sanguinity, did not have hair, but she had such amazing blue-green eyes that they did not at all seem to be lacking a frame of eyelashes and eyebrows. They smiled along with her whole face when she laughed. There was also a depth in her eyes that showed evidence of pain and suffering beyond her years; however, I was surprised to find no fear in her eyes despite her dire diagnosis. The reason Shelby had no fear became clear to me as I listened to her stories.

She spoke of her cancer as a blessing. It had brought her family closer together. Before her diagnosis her parents had been arguing all the time and struggling to stay together, but the

fight for her health had once again united them in a single purpose. It brought out the best in her friends and classmates. Teasing and ridicule that she used to receive had been replaced by kind gestures and support that made her feel supremely loved and cherished. Finally, she said, it gave her the opportunity to come to camp each summer and experience things that she might not otherwise have been able to do: horseback riding, rockwall climbing, ziplining, and archery among her favorites. I was challenged by her outlook. Somehow, this thirteen year old girl was making me feel childish and foolish in comparison. Shelby passed away just a few months after telling me her stories and I have always felt incredibly blessed to have heard them.

There seems to be an invaluable wealth of wisdom in those nearing the dusk of their life. Those passing from this life seem to come to terms with death in ways as diverse as the lives they lead. I have had only limited exposure to people at the end of life and no exposure to the palliative care or hospice care environment. I am, however, drawn to the idea that each day of a person's life is valuable and should be enjoyed and cherished, not as a stepping stone to the next day or week or year, but simply for itself, in all of its wonderful 24 hours. I feel this is the focus and the goal of palliative care and hospice care medicine: to truly celebrate and honor a life when it becomes evident that it will end soon. I would love the opportunity to be able to learn and then share with my colleagues how best to aid these amazing patients in enjoying their time to tell the last of their stories.

Description:

I will be performing a primarily experiential learning project in palliative care and hospice medicine in Kansas City and Newton. Care for patients who are dying is a challenge faced by nearly all doctors. It is so universal that the *American Association of Medical Colleges* specifies that medical colleges need to produce compassionate and empathetic doctors who "care for people who are dying, even when disease-specific therapy is no longer available or desirable" (AAMC Report 2008). Research has shown that demonstration of empathy and compassion in end of life care leads to increased patient satisfaction, a reduction in negative symptoms, greater patient compliance, and reduced patient anxiety. Unfortunately, the evidence also "continues to show that in many institutions, [education for end of life care] remains at best ill-timed and often substandard or nonexistent" (Janssen 2010). I hope to help alleviate this gap in training by personally observing end-of-life care in a variety of environments, administering a survey to help elucidate elements of patient communication that are important for successful end-of-life care, and bringing my experiences and knowledge back to my peers and colleagues.

I have organized shadowing in three different palliative care or hospice care environments in Kansas City and the Wichita area. I will be working with Dr. Donna Ewy in the palliative care unit at the Via Christi Newton Clinic. Dr. Ewy is the medical director for Hospice Care of Kansas and family practice and palliative care doctor at the Via Christi Newton Clinic. I will be shadowing Dr. Ewy, the advanced registered nurse practitioner, and the chaplain in Newton as they care for palliative care patients. I will also be shadowing Dr. Ewy as she makes her rounds to 12 area nursing homes for palliative care work. I will also be shadowing Dr. Lindy Landzaat, an associate professor of internal medicine and palliative care doctor at KU hospital, while she is on palliative care service. Finally, I will be shadowing Dr. Ann Allegre and her staff at the Kansas City Hospice House. Dr. Allegre is the director of medical programs for Kansas City Hospice House, an unique care center which focuses on creating a home-like environment for patients and their families when care for the very ill or terminally ill becomes overwhelming.

As part of my shadowing experience, I would like to administer an informal survey (attached) to care providers willing to participate. It is designed to provide guidance for medical students on how to communicate with patients at the end of life. It will draw upon the knowledge and experience of many different types of care providers, including chaplains, physicians, nurses, and social workers. I have discussed this survey with Dr. Landzaat, Dr. Ewy, and Dr. Allegre.

I have also been in contact with Dr. Jerry Old, chief medical officer for Hospice Care of Kansas. He suggested that I might integrate a service aspect into my project by working to compile a reference sheet that contains all of the services offered by Wichita area hospice care centers to be used in area emergency rooms. A student on a hospice care internship a few years ago made a similar list for the Kansas City area, which is now widely used. Dr. Old thought it might be helpful for the Wichita area to have a reference sheet as well. Throughout the summer, I will be collecting information on which services are offered by Wichita area hospice care centers via phone surveys. I will then compile this information into a concise reference sheet that can be administered to area emergency rooms for quick referral reference.

Timeline		
Dates	Project	Purpose
May 21-25, June 2-3	Shadowing with Dr. Landzaat at KU Hospital on palliative care service	-- Experience palliative care in a hospital environment --Administer/collect provider survey
May 26-June 17	Shadowing with Dr. Ewy and staff at the Newton Via Christi Clinic on palliative care service	--Experience palliative care in a small-town clinic\ --Administer/collect provider survey --Compile hospice care reference sheet via phone surveys of Wichita area hospice centers
June 18-22	Shadowing with Dr. Landzaat and KU Hospital on palliative care service	--Experience palliative care in a hospital environment --Administer/collect provider survey
June 23-July 15	Shadowing with Dr. Ewy and staff at the Newton Via Christi Clinic on palliative care service	--Experience palliative care in a small-town clinic' --Administer/collect provider survey --Finish collecting information for hospice care reference sheet
July 16-July 27	Shadow Dr. Ann Allegre and staff at Kansas City Hospice House	--Experience palliative care in a family-supportive hospice house environment --Administer/collect provider survey

Methods:

I contacted Dr. Lindy Landzaat, an internal medicine and palliative care doctor at KU Hospital, to shadow for those time periods which she will be on palliative care service (May 21-25, June 2-3, 18-22). After filling out the appropriate paperwork, I will be able to shadow her at KU, and administer the optional survey to healthcare providers such as nurses, chaplains, social workers, and physicians during my time on service with her.

I have also contacted Dr. Donna Ewy, a family medicine and palliative care doctor at the Via Christi Clinic in Newton, Kansas. Although she spends quite a portion of her time in family practice, I will shadow her during the time that she will be on service for palliative care. The rest of the time I will spend shadowing the ARNP and chaplain on the palliative care unit at Via Christi clinic. The advantage of shadowing different healthcare providers is being able to observe

the different methods of communication used by different providers as well as the unique role which each person on the interdisciplinary team plays in the care of each patient. I will again administer the survey to the healthcare providers at this site. During whatever free time I may have or on the weekends, I will be working to compile a list of services offered by hospice care centers in the Wichita and surrounding areas using phone surveys.

Finally, I have scheduled a shadowing experience with Dr. Ann Allegre and her staff at the Kansas City Hospice House. In this unique environment resembling a home with the medical security that a hospital provides, Dr. Allegre suggested that I spend some time again shadowing with different care providers in an effort to really observe the communication that takes place between various caregivers and the end of life patient. I will again administer the survey to those caregivers willing to participate at KC Hospice House.

I have attached the pertinent email communications with Dr. Lindy Landzaat and Dr. Donna Ewy approving my shadowing experience with each of them. I have also attached the email communications with Kansas City Hospice House, although the final approval confirming me to work from July 16-27 was given during a phone conversation with Dr. Ann Allegre on Thursday, February 9th. I will be receiving the necessary paperwork within the next couple of weeks via email.

Dr. Jerry Old, a family practitioner and hospice and palliative care doctor in Lenexa, will be my contact for guidance on how to most efficiently and completely compile the list of services offered by hospice care centers in Wichita.

During my time in Kansas City, I will stay in my apartment at Rainbow Ridge. While I shadow in Newton, I will stay with my parents in Wichita.

I will be contacting the KU Human Subjects Committee to determine if I will need to apply for IRB exempt status in order to administer the survey.

Budget:

Budget	
Apartment Rent (June and July)	\$1250
Utilities	\$300
Food/Living Expenses	\$400
Gas and Transportation (Wichita, Newton, Hutchinson)	\$300
Total	\$2250

“Gaston exhausted every word he knew in Japanese to comfort Tsukada. He came to Tsukada’s room every day after that and held the dying man’s hands between his own palms, talked to him and encouraged him. Kiguchi could not tell whether such comfort eased Tsukada’s pain. But the figure of Gaston kneeling beside his bed looked like a bent nail, and the bent nail struggled to become one with the contortions of Tsukada’s mind, and to suffer along with Tsukada.

Two days, later, Tsukada died. His face was more at peace than anyone had imagined it could be, but a look of peace always comes at last to the dying...Kiguchi could not help but feel that this peaceful death-mask had been made possible because Gaston had soaked up all the anguish in Tsukada’s heart.”

--from “The Case of Kiguchi” in *Deep River* by Shisaku Endo

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