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A Hospice Social Worker's Journey: Ethics, Values, and
Overcoming Personal Biases

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As I sat next to Julia's bed and watched it become increasingly more difficult for her to breathe, I found myself growing more and more angry. I was angry with Jane, Julia's daughter, who couldn't come to terms with her mother's death and repeatedly kept telling me "she's just not ready to go, she has more life left in her." I was angry with the doctor who not only refused to have an honest conversation with Jane and tell her that her mother was dying, but who also refused to order medications that could alleviate Julia's labored breathing and make her more comfortable. And I was angry with the medical profession as a whole; a profession that I believed was clearly not doing its part to educate people about the process of dying and, as a result, was inadvertently and unnecessarily allowing people to die painful and at times agonizing deaths.

Julia, a 92-year-old woman admitted to the nursing home with a primary diagnosis of advanced Alzheimer's disease. When she entered into the nursing home she was already in the end-stages of this disease process as evidenced by a poor appetite, inability to walk, bowel and bladder incontinence, minimal communication skills, orientation only to self, and behavioral disturbances (Taber's Cyclopedic Medical Dictionary, 2013). Despite Julia's terminal diagnosis and her debilitated condition, her daughter signed her medical code status as a full code. This included all life-sustaining treatments such as CPR, dialysis, tube-feeding, hospitalization, and any other procedure deemed necessary to prolong her life. Although the interdisciplinary team of which I was a part believed that palliative care or hospice would have been a more appropriate and beneficial choice for both Julia and Jane, Jane had tremendous difficulty accepting her mother's condition and refused to make any changes to the code status. Of course

the physician's reluctance to speak candidly with Jane about her mother's prognosis had a

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significant impact on her ability to accept her mother's condition. Consequently, this hindered any attempts at discussing alternative treatment options. The end result was that Julia died without the benefit of medications that could have alleviated her suffering, and Jane was left in shock as she believed that her mother would miraculously improve.

Unfortunately this was not the first case, nor has it been the last, in which I believe the physician has done a grave disservice to both the patient and the family. Take, for instance, Mr. Smith and his family. Mr. Smith is a 76-year-old man with a diagnosis of Stage IV pancreatic cancer that has metastasized to almost every organ in his body, including his bones. Since starting my internship this past September, Mr. Smith has been in and out of the hospital at least a dozen times. In reviewing his medical record, I discovered that this has been a pattern for the past year-and-a-half. Although his admitting diagnoses vary, they all stem from his primary diagnosis of cancer. Each time Mr. Smith is admitted into the hospital, it is quite apparent that his physical, emotional, and mental well-being are quickly deteriorating. His cognitive status has drastically declined throughout the six months that I have known him. He is barely eating or drinking and he has rapidly lost weight, particularly in the past month. He is also displaying signs and symptoms of a condition known as *terminal restlessness*. This condition is typically seen in patients who have less than two months to live and is marked by restlessness, increased anxiety, and periods of yelling out. The person simply has difficulty getting comfortable due to the natural process of the body "shutting down" (Karnes, 2013). Despite the many indications that Mr. Smith is nearing the end of life, his physician has not spoken with the family about palliative care or hospice services and Mr. Smith's code status has remained a full code.

Recently, Mr. Smith went into cardiac arrest and CPR was administered. He is now in ICU,

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unresponsive, and on a ventilator.

These cases, and many others like them, have very often evoked strong emotions and feelings within me. They have caused me to examine my personal values and beliefs about end-of-life care, the ethical responsibility of health care professionals to both the patient and the family, and how, as a social worker, I can be an effective and compassionate advocate for those who are nearing the end of life.

My personal values and beliefs regarding end-of-life care have primarily been shaped by the experiences I have had both working and interning in a medical setting. I think it is of the utmost importance that we allow people to die with comfort and dignity. When I say this I'm certainly not implying that we shouldn't treat those with cancer or that when a person reaches a certain age we no longer provide any aggressive medical treatment. What I mean is that when the physician has determined that an individual is in the end-stages of his/her disease process and that it is both futile and harmful to continue performing medical procedures, we have an ethical obligation to speak with the patient and the family about alternative options such as palliative care or hospice.

I believe that as health care professionals we are responsible for educating people about the risks and benefits of medical treatments and procedures so that they can make informed and knowledgeable decisions. For instance, the majority of people given CPR do not survive. In a study of 26,095 patients who received CPR, only 3,968 (or 15.2%) survived and were released from the hospital (Dunn, 2007). Those with the greatest chance of survival were people who experienced a specific kind of abnormal heart rhythm (ventricular tachycardia or fibrillation) and

those who were generally healthy and the cardiac arrest was their only medical problem (Dunn, A HOSPICE SOCIAL WORKER'S JOURNEY 4

2007). Patients with the least chance of survival (less than 2%) were those who had two or more medical conditions, those who were dependent upon others for their care or who lived in a long-term care facility, and those who had a terminal disease (Dunn, 2007).

Whether or not to place a feeding tube into a patient who is in the end stages of life is another medical intervention that should be thoroughly explained to the patient and his/her family.

The decision on whether or not to use a feeding tube for a person who is barely eating or drinking because he/she is in the end stages of life is, of course, a very difficult one for a family.

As a social worker in a medical setting, being knowledgeable about the metabolic changes that occur within the body as a person nears the end of life is essential in helping patients and families to make the decision that is best for them.

During the natural process of dying there is a significant decrease in appetite and thirst as the body's metabolism begins to shut down. As this is occurring the body is no longer able to build tissues and organs; this process is referred to as an anabolic state of metabolism (Retrieved from www.hospicepatients.org, 2016). Eventually, whether or not nutrition is taken in, the body's tissues and organs begin to break down in what is known as a catabolic state of metabolism.

When the body is in a catabolic state food is no longer absorbed, tissues no longer heal well, infection is difficult to cure, and the irreversible process of dying is taking its natural course (Retrieved from www.hospicepatients.org, 2016). "Whether a patient eats food, is fed a liquid diet through a feeding tube, or receives intravenous nutrition (total parenteral nutrition or "TPN"), the nutrients taken in will not stop this catabolic process" (Retrieved from www.hospicepatient.org, 2016). Forcing nutrition and hydration into a dying person will not

prolong life. In fact, many indications suggest that it can actually lead to a painful and

uncomfortable death because the body's organs cannot process the nutrients and fluids that are being taken in (Dr. Bruce Johnson DO, personal communication, Dec. 2015). Terminally ill patients do not die because they stop eating; they stop eating because they are dying.

And what is the best option for the terminally ill patient [in the end stages of life] or for the patient who is actively dying? Although my personal belief is that comfort care or hospice is the best option, both for the patient and the family, this is not always embraced by either for various reasons. Some people, of course, have told me they "want to fight until the very end." Some have said that they knew someone who went into hospice and died a week later. There are those who have said that they'd "just feel too guilty" signing their loved one up with hospice services or discontinuing aggressive medical treatments. Still others, and this is a common misconception about hospice, believe that morphine will be given in excess and the patient will die prematurely. In actuality, the opposite of this has been shown to be true. Terminally ill patients who are given morphine to relieve both pain and respiratory discomfort actually live longer than those who are not given morphine (Fohr, 1998). "Rather than hastening death, the correct use of morphine is more likely to prolong a patient's life because he/she is now comfortable, rested, and pain-free" (Fohr, 1998). Because pain is such a "powerful antagonist to respiratory depression," even when morphine is administered in large doses respiratory depression is "rarely seen" (Fohr, 1998).

Regardless of the reason a patient or family declines hospice, as a social worker I am bound by the NASW's Code of Ethics to honor a person's right to self-determination. This ethical responsibility states that "social workers respect and promote the right of clients to self-

determination and assist clients in their efforts to identify and clarify their goals” (NASW, 2008).

Although I have honored the wishes of the patient and/or family, and I will certainly continue to do so, at times this has been challenging and something with which I have struggled. Admittedly there have been times when I have felt angry with family members because I have judged them as being selfish; selfish because instead of choosing comfort care or hospice for their loved one they continued to pursue medical treatment. In all honesty, I have actually felt infuriated at times because the family could not come to terms with the fact that the patient was dying and wouldn’t allow medications to be given for comfort.

For many reasons I realized that I needed to conquer these biases and judgments in order to be an effective advocate not only for the patient but also for the family. Although my anger was coming from a place of compassion for the patient, I recognized that I also needed to be more compassionate and understanding towards the family. Who was I to be casting such harsh judgment on someone who is grieving the impending death of their parent, or spouse, or sibling? How could I possibly fathom the pain and heartache one must feel knowing that their loved one is dying when I have never been in such a situation? Moreover, *they* are the ones faced with having to make such difficult decisions as to whether or not they should have a feeding tube inserted in their loved one or an IV started for hydration, *not me*.

Recognizing and admitting to myself that these were judgmental and negative feelings I was experiencing was the first step for me in reconciling them. I did, in fact, begin to imagine that each situation in which I was involved was happening to me and my loved one. I routinely began asking myself how would I react and what difficult choices and decisions would I make? I listened carefully to what the family members were telling me. One woman, whose mother was

long you have your mother when she dies, it’s never long enough.” Another woman, who was a hospice nurse, told me “all your education and knowledge goes out the window when it’s your loved one, you act on emotion not logic.” This comment was said in response to her having made the decision to place a feeding tube into her mother when she stopped eating and drinking, despite knowing the futility of this intervention.

While assessing my emotional reactions and judgments to specific cases, I also began asking myself what could I do to become the effective and compassionate advocate that I wanted to be for the patient *and* the family? Adhering to the social work core value of competency and the ethical principle which accompanies it was a key factor in being able to do this. This principle states “social workers practice within their areas of competence and develop and enhance their professional expertise. Social workers continually strive to increase their professional knowledge and skills and to apply them in practice” (NASW, 2008).

Learning the facts about various interventions and procedures such as CPR, tube feeding, and the effective and safe administration of pain medication has allowed me to better serve my clients. In addition, becoming knowledgeable about alternative options to the more aggressive medical procedures, such as palliative care or hospice, has been an essential element in helping me to educate patients and families thereby empowering them to make the best choice for them.

For example, there continues to be the belief amongst many in our society that hospice is only an appropriate choice for those in the last few weeks or month of life. Given the facts, however, many people come to understand that this is not the true philosophy of hospice. In actuality, hospice care is for those with a “life-limiting progressive illness with six months or less to live if

the disease runs its natural course” (Dunn, 2007). The belief is that early admission into a

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hospice program affords the hospice team more time to fully understand the needs of both the patient and the family so that an individualized plan of care can be developed (Dunn, 2007). When a relationship of trust and understanding is formed between patient, family, and the hospice team, the full benefits of this service are attained by both patient and family.

Although the full benefits of hospice certainly include keeping the patient comfortable and free from pain, they also include addressing the emotional, psychological, and spiritual needs of the patient and the family. I personally believe that these very important needs are generally ignored by our physicians and by the medical profession as a whole. The primary focus and goals of our physicians and hospitals in the United States is to cure patients (Dunn, 2007).

Again, I don’t disagree with this philosophy if it’s appropriate and if the treatment plan and interventions are not harmful to the patient. Also, I would always advocate for a patient’s right to self-determination and to receive all the medical intervention he/she desires if this is his/her choice. However, when the decision has been made by the patient, family, or both that hospice *is* the best option, the benefits for both are wonderful.

Of particular benefit and value is the quality time that patients and families are able to spend with one another when the decision has been made to sign on with hospice. When both have come to the decision that there will no longer be trips back and forth to the hospital, there will no longer be invasive procedures, there will no longer be medical tests or scans, there will be no more of the interventions that have been ongoing, the patient and family experience a sense of peace and acceptance. Patients and their loved ones are able to share memories, laugh and cry together, tell stories, give gratitude to one another, ask for and give forgiveness and, of course,

say good-bye to one another on their terms. Patients are also afforded the opportunity to speak

with their spiritual advisor and to make amends with their God. In fact, it never ceases to amaze me the number of people who, after speaking with their religious counselor, pass away shortly thereafter. What a gift it is for the dying person to be able to complete “unfinished business” and to have closure in his/her life.

As I continue to work in the field of social work I no longer pass judgment on those who are struggling with the impending death of a loved one; instead I show compassion and empathy. I also continue to educate my clients, both patient and family, of the benefits and value of hospice services. I will continue teaching others about the true philosophy of hospice and to help them understand that choosing hospice is not about “giving up,” but is instead about making a caring and loving choice. It's a rare chance for patients and their loved ones to heal wounds and spend quality time with one another. Ultimately, my goal is to continue working with patients and their families who are dealing with grief, loss, and end-of-life issues. I have found the journey to be extremely rewarding and I have come to realize that it is truly an honor and privilege to be a part of people's lives in such an intimate and personal way.

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