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Understanding the Role of Hospice Care: Reflections from a Service-Learning Project

Introduction

Death is an inevitable part of life. “Unlike other conditions and life experiences, which only affect a certain percentage of the world’s population, the end-of-life is a stage in the process of living, which all people will eventually face” (Huffman, 2020, p.1). To be able to effectively care for those in the end stages of life, healthcare professionals must “be aware and recognize disease trajectory in those with terminal or life-limiting illnesses. In this way, they can prepare for the issues of concerns which these patients face” (Huffman, 2020, p.1). This requires a shift in thinking away from the curative aspects of medicine, to treating symptoms and improving quality of whatever life remains in a person.

Competent, compassionate, and effective end-of-life (EOL) care is a crucial competency especially for nurses. Nurses are witnesses to some of the most vulnerable and sensitive events in patients' and families' lives. End of life is one of those events.

End-of-Life Care

End-of-Life Care (EOL), or hospice care, is specified for people “with a terminal illness with less than 6 months to live, and curative treatments are no longer options” (Huffman, 2020,

p.2). Two or more providers must diagnose a patient's condition with the prognosis of 6 months or less to live in order to qualify for this care. By opting for hospice care, the patient will no longer seek treatment from a facility other than the facility they've chosen for hospice care. This puts an end to visits to an emergency room and other facilities that utilize the curative approach to treatment. After electing end-of-life care, the patient has around the clock access to a hospice facility with a treatment team who is equipped to handle his or her unique situation and diagnosis. The goal of EOL Care is to control the patient's symptoms in order to increase quality of life as they undergo the dying process. Common symptoms include "anxiety, pain, dyspnea, cough, fatigue, insomnia, nausea, and vomiting" (Zeng, 2018, p.2).

Hospice care includes palliative care, but these two disciplines are distinct. Palliative care is used to control symptoms for patients who may or may not be seeking curative treatment. Palliative care is "specialized medical care for people with serious illness. Serious illness is one with high risk of mortality that negatively affects quality of life or function or is burdensome in symptoms, treatments, or caregiver stress" (Tatum, 2020, p.1). And so, EOL Care joins with palliative care in order to control symptoms in a setting fit for a patient no longer seeking curative treatment. Schlick (2019) states that some of benefits of palliative care include, "improved quality of life, less end-of-life treatment, and decreased medical costs".

End-of-Life Nursing

In order to become a hospice care nurse, students must obtain their Associate's degree, Bachelor's degree, or Master's degree in nursing. They must then obtain their Registered Nurse (RN) license through examination. Then they must have 2-3 years of experience in a critical care setting. Often, hospice care nurses are palliative care certified, but palliative care nurses do not need to be hospice certified.

Service-Learning Project

This service-learning project focused on hospice care. The project was conducted at Circle of Life Hospice in Springdale, Arkansas where patients can receive hospice care at home or through the inpatient facility. The inpatient facility is used for patients who are trying to gain better control of symptoms so that they can be more stable and comfortable once at home. Some patients choose to live their final days at the hospice inpatient facility so they are close to medical personnel in case symptoms suddenly worsen. Patients receiving home hospice care have Circle of Life Hospice nurses visit to fulfill their treatment plans. Most of the time, these patients are more stable, and their symptoms are more controlled.

My Role

During my time at Circle of Life Hospice, I fulfilled the role of Inpatient Volunteer as well as Respite Volunteer. As an Inpatient Volunteer, I spent my time visiting with the patients and their loved ones. My job was to make sure their needs were being met and if things were not suitable, I knew who to notify. These patients are looking to be stabilized to either return home with hospice care or to stay at the facility in order to be closer to medical staff. Often, these patients were more medically unstable and so my experiences varied each day. Most visitors that I met at the inpatient unit were in the process of saying their final goodbyes to their loved ones. My time was spent knocking on doors and letting visitors and patients know that I was there if they needed anything at all, whether that be their nurse or a cup of coffee, but most often they needed a listening ear. I sat in silence with my patients while holding their hands and also listened for minutes on end without speaking at all. I formed relationships with these people, and

I was able to see the importance of compassionate care and the positive impact of active listening.

As a respite volunteer I would go to patient's homes and provide respite for their caregiver(s). This contributed to preventing caregiver burnout and offered patients the chance to make connections with new people beyond their caregiver(s). This respite and personal connections contributed greatly to better quality of life for many patients.

As a volunteer I was also able to be a part of the interdisciplinary care team at Circle of Life Hospice. My role on the team was that of patient advocate, which meant I was responsible for communicating patient needs and questions to the team of providers.

Reflections

I had many meaningful experiences while working as a volunteer at Circle of Life Hospice, the first of which was being part of an interdisciplinary team. The interdisciplinary team for each patient at Circle of Life Hospice consists of: doctors, nurses, chaplains, social workers, hospice aids, bereavement counselors, and trained volunteers. I had not previously realized how important it is to have a volunteer be a part of the interdisciplinary team when providing EOL Care. To have a person whose sole job is to advocate for the patient and their loved ones is incredible precious and allows for the delivery of care to be that much more effective and meaningful. Being a part of the interdisciplinary team also helped me better understand the importance of interdisciplinary care for hospice patients. Every patient enters EOL Care with different needs whether they be physical, emotional, or spiritual. The team works

together using a patient- and family-centered approach to address the unique needs of each patient.

During my time volunteering at Circle of Life Hospice, I gained valuable experience learning about the art of hospice care from the nurses I interacted with. Hospice nursing is unique in that the everyday tasks of medication administration, assessments, and charting are still required, but also these nurses have the additional responsibility of providing an immense amount of support to their patients and their families. I believe what sets hospice nurses apart is the support they must offer to their patients, considering the unique circumstances that surround caring for a dying patient. Hospice nurses must complete their patient care tasks while also providing emotional, physical, spiritual, and psychosocial support for their patients as well as their loved ones.

To have a front seat watching the nurses care for their patients while working in a setting that is engulfed with the ever presence of grief was incredible. My biggest takeaway was watching how they went through their day-to-day tasks with the knowledge that the grief of their patients, their loved ones, and even their own was present. Instead of denying the grief they faced it and had various strategies to work through the grief they experienced. As nurses in any field, we must understand that grief is a part of the dying process which means it is a part of life and a part of being human. I learned that we, as nurses, must empower our patients to go through their own unique grieving process, whether they have lost a limb or lost the independence they had prior to their hospitalization.

I also appreciated learning about the presence of Palliative Care and symptom management in the Hospice Care setting. Dying does not have to be painful, which goes against everything I had thought before beginning this project. It was interesting learning about the

various measures we, as nurses, can take to provide the best care possible for our patients. I also am thankful to have learned about the various cultural factors that must be considered when providing End of Life Care, and honestly any area of the medical field. Every single person is different which means every single death is different, and as nurses, we must accommodate for those differences in our provision of care.

This service-learning experience has greatly impacted my personal growth as a nurse. I did not realize how important a listening ear is when taking care of people. It does not take any convincing for people to communicate their needs when they know you will listen without any judgment, especially when they are as vulnerable as they are in a healthcare setting. In terms of professional growth, I learned many practical skills when volunteering at Circle of Life Hospice that can be applied in every medical setting. My biggest takeaway was the fact that death is a part of life and that it is my job to be sure that I have come to terms with my own mortality in order to help my patients and families become comfortable with the reality of dying also.

Volunteering at Circle of Life Hospice has taught me that death can be a positive and peaceful event in the lives of everyone it affects. One specific lesson I learned, was that sometimes you don't need to know exactly what to say or do in order to support a patient's and family's unique needs. I thought I would have to be strategic in my communication in order to figure out how to best provide for these families but in reality, all I had to do was be present and listen, and anything they needed from me they would communicate. This looked different for every individual. There was one day that I held one of the pediatric patients for an hour while she slept and then another day, I spent an hour talking with one of the patients and painting her nails. Every person had unique needs and trusted me to help meet those needs. I was blown away by the utter humanity I saw in each person I interacted with, without any action on my part. It was

an incredibly humbling experience to work with and learn from the patients and staff at Circle of Life Hospice.

This project has shined a light on ideas surrounding EOL Care that I am now able to apply to any and all areas of nursing. My negative beliefs surrounding hospice care before taking part in this project have been torched, I now recognize the great impact of EOL Care. I began this project feeling uncomfortable with the idea of death, and even more so with the concept of talking to those who are dying or whose loved ones are dying. Now, after diving headfirst into the volunteering at Circle of Life Hospice, I am no longer swollen with discomfort but rather filled with humility and awe that I have had the chance to be a part of these people's lives in such an intimate way.

After giving myself space to dwell on the this unfortunately taboo topic, I have a sense of peace with death which allows me to better serve my future patients. In conjunction with learning to face my own mortality, I was also able learn about and to better understand the unwavering presence of grief when working as a nurse in any healthcare setting. We cannot ignore it; we must make room for it in the care of our patients. And by accepting grief however it may manifest we, as nurses, can empower our patients to accept their grief as well.

Before starting this project, I associated EOL Care with depression and hopelessness, almost as if you had lost a fight. This experience has taught me that taking your last breath is as much a part of life as taking your first. This is not something we can avoid; every human will die. This concept is no longer troubling to me. If anything, I am truthfully more at peace as I reflect on my own life and the lives of patient's I have had the privilege to talk to. I have come to peace with the fact that everyone dies. Because of this project I believe that dying is as precious as life itself. And I want to be a part of helping others explore the beauty of dying as well. By

giving patients and their loved ones the space to grieve, we can encourage them to bravely accept their circumstances and be thankful for the legacy they are leaving behind with their loved ones.

Considerations for Healthcare Practitioners

In order to normalize EOL Care and consequently make it more accessible, we must educate our healthcare practitioners regarding the benefits of hospice care and better recognize patients that warrant EOL Care. Patients often struggle with advance care planning, but providers can be a resource in those discussions. As Brinkman-Stoppelenburg (2014) reports, “There is evidence that advance care planning positively impacts the quality of end-of-life care.” The sooner potential hospice patients are identified, the sooner we can intervene and increase quality of life for these people. A research study that was conducted to look into the end of life for advanced myeloma patients found that “patients who were transfusion-dependent, on dialysis, or survived for less than one year were more likely to enroll late in hospice and experience aggressive medical care at the end of life” (Odejide, 2018, p.1). Research has also found that “internationally, a range of home-based palliative care programs, implemented at the population level, demonstrated cost savings and reduced intensive care near the end of life” (Ankuda, 2018, p.1). Another research study was conducted to figure out the best way to teach physicians about end-of-life care so that they are more likely to include it as an option for patients who would qualify. The study found that the teaching must include reframing the term hospice. As healthcare professionals “we are challenged to become a part of the shift from hospice meaning "giving up" to hospice meaning "giving more, but differently" (Hudak, 2016, p.1). The purpose of the article was “to frame a communication approach that any oncologist can incorporate into his or her practice that will facilitate the timely referral of appropriate patients

for hospice care” (Hudak, 2016, p.1). These findings can be implemented in every healthcare setting where end-of-life care patients are seeking treatment.

As a future nurse I must be aware of the socioeconomic, cultural, and religious factors that impact the quality of my nursing care. I must advocate for “policy development to enable accessibility and utility of palliative and end-of-life care services” (Ramasamy Venkatasalu et al., 2018, p.1). It is also important to consider the much-needed adjustments that should be made in baccalaureate nursing curricula to ensure a workforce that is competent in EOL Care.

In addition, we must also educate the public. An article researching the gap between the community and hospice volunteers found that there is a lack of volunteer involvement for hospice care. People avoid volunteering in hospice centers for many different reasons but we cannot deny that the lack of community engagement is tied to the stigma surrounding the care for the death and dying. In order to lessen the stigma surrounding the concept of hospice care, we must educate the public. Their research found that there is “substantial scope for hospices to develop the strategic aspects of volunteering through greater community engagement and involvement and by increasing diversity and exploiting volunteers' 'boundary' position more systematically to educate, recruit and raise awareness” (Morris, 2015,p.1).

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