ADVANCED DIRECTIVES: AN OVERVIEW

Melinda Hertlein

*Eastern New Mexico University, **USA***

ABSTRACT

Advanced directives are important for individuals to have documented their wishes when end of life decisions need to be made. Quality of life has a unique definition to each individual. Every individual has the right to their own belief and perspective of how they want to direct their health care. During medical emergencies, life sustaining measures are taken to preserve and maintain life. Many of times the outcomes do not result in the quality of life that the individual would want resulting in end of life discussions. This is why the importance of advanced directives should be a priority within our county to reduce the amount of unnecessary healthcare cost and burdens on family and friends.

Keywords: *Advanced directives, Living will, Health care surrogate, Palliative care, End of life*

Advanced Directives

Quality of life is unique and different for each individual. When an individual is facing a life-threatening injury or illness many want to be comfortable and be able to focus on their quality of life. There are other individuals that want to be kept alive as long as possible regardless of measures that would have to be made. Each individual should make their own decisions regarding their care during these difficult times. This is why it is crucial for advanced directives to be completed and discussed with family and friends. Advanced directives include completing a living will and appointing a health-care proxy. Advanced directives only become effective when the individual is no longer able to communicate their health care decisions.

Living Will

A living will allows the individual to document what treatments and care they would want to receive in a life threatening situation. The living will instructions will be referred to if there is a terminal or end-stage condition and there is little to no chance of recovery. This may also include conditions of permanent and irreversible unconsciousness such as a coma or vegetative state. In the event of an irreversible and severe mental or physical illness that prevents the individual from communicating with others, recognizing family and friends, and caring for themselves would refer to the living will (Duke, 2007).

When completing a living will the individual has to evaluate possible outcomes if their health declines that may affect their quality of life (Stevens, 2016). The individual would document if they would want to be dependent on machines, such as dialysis or a ventilator. Being able to think clearly and make their own decisions is also a factor to be considered. The individual would also need to consider if they would happen to become incontinent and unable to perform basic activities of daily living that would not improve over time. Having severe pain without a chance of improvement is also another variable. The development of severe symptoms such as, difficulty breathing, nausea, vomiting, almost all of the time that is not improved with treatment. These are all factors that an individual needs to take into consideration when completing their advanced directives.

Designated Health Care Surrogate

The designation of a health care surrogate allows the individual to appoint someone to communicate heath care decisions on their behalf (Duke, 2007). The health care surrogate should be an individual that knows and understands the individual’s wishes. The health care surrogate can talk with the health care providers and access medical information. This individual will be able to provide consent for any treatments and participate in discharge planning. The health care surrogate is the individual that will follow the wishes of the patient. The health care surrogate is the individuals advocate whether it is time to make end of life decisions or continuing care when they are unable to voice their decisions.

Advanced Directive Barriers

The Patient Self-Determination Act was passed in 1991 in an effort to facilitate autonomous, independent decision making before the end of life. This allows the individual the opportunity to make health care decisions before they are unable to (Duke, 2007). Approximately 37% of individuals in the United States have Advanced Directives (Crist, 2017). Some of the major barriers of individuals not completing advanced directives is that there is a lack of knowledge, inability to understand the medical terminology of the forms, and not understanding the process of completing them. The hospital and primary care settings are a common time for patients to be introduced to the advanced directive process. It is common that patients report that they do not need to complete an advanced directive because their decision will be made by the physician, family, or God (Duke, 2007). The discussion of advanced directives should be initiated by primary care physician because they are most familiar with the patients’ medical, social, and financial status.

End of Life Decisions

End of life decisions for family members when the individual does not have an advance directive can be difficult and stressful. Family stress that is associated with withdraw of life support has been shown to be high for up to six months (Duke, 2007). This is an extreme burden on the family when making end of life decisions. These family members are not only grieving the loss of their loved one but hoping that they made the right decision of withdrawing care.

Working in the hospital setting for many years there have been so many cases that have personally affected my thoughts regarding advanced directives. A few years back there was an elderly patient in her 90s that we had to initiate CPR. Unfortunately, she was not a DNR and after about 45 minutes of attempted resuscitation the code was stopped by the attending physician. This was a horrible feeling as the chest compressions were being performed on this frail elderly woman. The entire time thinking how wrong this was feeling she was being beat up as she was trying to pass.

This was upsetting to all of the health care providers as this elderly woman did not need to go through something so traumatic just prior to her death.

Palliative Care

Palliative care is a much needed resource in all healthcare settings and in the community. The use of palliative care teams can reduces length of stay in hospital settings and improves symptom management. They are also able to address advanced directives with patients and family members (Kupensky, Hileman, Emerick, & Chance, 2015). The palliative care team is a useful resource as long as the healthcare staff continues with the plan of care that has been made with these individuals. This is why it is crucial for the nursing staff that is caring for these patients to have the education and knowledge of palliative care, appropriate pain management, and understanding of symptom management.

There have been studies that have revealed a lack of palliative care knowledge and adequate pain control by health care providers. This is related to inadequate education, lack of curriculum regarding pain management, and the attitudes and beliefs pertaining to adequate pain control for palliative care patients (Prem et al, 2012). There definitely is a need for further education regarding palliative care and pain control for the terminally ill. Hospital systems would benefit from incorporating more appropriate policies for palliative care within healthcare settings. There needs to be adequate pain management pharmaceuticals available with the appropriate education. Palliative care education and information needs to be provided to the leadership team, healthcare providers, and the public to ensure the proper palliative care is being provided to these individuals. There should be an implementation of palliative care programs within acute care and outpatient setting to better manage terminally ill patients.

Care Coordination

Care Coordination within the hospital setting is a team that has a multidisciplinary approach that assists with discharge planning and assists in complex cases (Maulik & Horak, 2010). The care coordination team within the hospital setting consist for a RN case manager and social worker. The RN case manager reviews clinical information and follow the patient through the hospitalization ensuring they are receiving the care indicated for their diagnosis. The social worker is able to work with the patient focusing on sociodemographic, social systems, and managing care (Bronstein, Berkowitz, James, & Marks, 2015). The care coordination team assesses each patient and provides advance directive information. The care coordination team collaborates with the palliative care team when having end of life discussions with patients and family members.

There have been numerous family meetings that I have been involved in when discussing end of life care with family members. There have been such a wide variety of perspectives, emotions, and beliefs when having these discussions. Some are receptive to the information being provided while others become angry and are in denial of the inevitable realization of death of their loved one.

Withdrawing versus withholding of medical care

There are many different perspectives with the subject of withdrawing and withholding life sustaining therapies. According to Glick (2005), Western philosophers and lawyers have reported the terms of withdrawing and withholding are interchangeable. As a medical professional these terms convey very different meanings. As a healthcare professional in the critical care unit within the hospital setting, the withdrawal of life sustaining measures occurs when it has been determined that the patient's quality of life would not be desirable and it is time for the end of life process to begin. Withholding life sustaining therapies allows the end of life process to begin and not being interrupted by life prolonging treatments.

Among the Jewish traditions regarding end of life defines a clear definition in regards to withholding and withdrawing medical care. In 2005, the Israeli End of Life Act was passed that allows the withholding of life sustaining therapies under certain circumstances but forbids direct withdraw of care (Glick, 2015). Every patient situation is unique and there are always different perspectives from the patient, family, and healthcare providers. The majority of times life sustaining measures are performed in trauma and critical situations. The emotions during these times are high and the normal human response would be to do everything to sustain life.

CONCLUSION

The discussion of advanced directives is most commonly done by physicians, lawyers, and healthcare professionals (Duke, 2007). Unfortunately, many of times these discussions are being done during critical times. The initiation of advanced directives should be done when the individual is mentally clear and able to convey their wishes. Palliative care, whether in the inpatient or outpatient setting should be introduced especially when a patient has been given a diagnosis of a chronic condition. Palliative care is not just end of life care but rather symptom management and the discussion of the disease process. It seems all too common that newly diagnosed patients of chronic conditions are not being provided all the information and prognosis of their disease process. As death is inevitable for all of us, it is something that should be discussed with physicians, family, and friends so the transition can be made peacefully with dignity and respect.

REFERENCES

1) Bronstein, L., Gould, P., Berkowitz, S., James, G., & Marks, K. (2015). Impact of a social work care coordination intervention on hospital readmission: A randomized controlled trial. *National Association of Social Workers, 60*(3), 248-255.
2) Crist, C. (2017). Over one third of U.S. adults have a medical advanced directive. *Health Affairs, 36*(7).
3) Duke, G., Thompson, S., & Hastie, M. (2007). Factors influencing completion of advanced directives in hospitalized patients. *International Journal of Palliative Nursing, 13*(1), 39-43.
4) Gathwaite, J. (2005). Sometimes they teach us. *Journal of Nursing, 32*(7).
5) Glick, S. (2015). Withdrawing or withholding life-sustaining therapy. *Bioethics, 29*(9), 680. Retrieved from: https:doi.org/10.1111/bioe.12172
6) Kupensky, D., Hileman, B. M., Emerick, E. S., & Chance, E. A. (2015). Palliative medicine consultation reduces length of stay, improves symptom management, and clarifies advance directives in the geriatric trauma

population. *Journal of Trauma Nursing: the Official Journal of the Society of Trauma Nurses, 22* (5) 261-265.

7) Maulik, S. & Horak, B. (2010). Care coordination. *Trustee*, 34-35.
8) Prem, V., Karvannan, H., Kumar, S., Karthikbabu, S., Syed, N., Sisodia, V., & Jaykumar, S. (2012). Study of nurses' knowledge about palliative care: A Quantitative cross-sectional survey. *Indiana Journal of Palliative Care, 18*(2). 122-127. doi:10.4103/0973-1075.100832
9) Stevens, C. (2016). Geriatric trauma: A clinical and ethical review. *Journal of Trauma Nursing, 23*(1), 36-41. doi.org/10.1097/JTN.0000000000000179