

Vignette #14: 1:01.45-1:04.25

I Said ‘Yes’ Because I Want to Live (3 min.)



Objective

By the end of this vignette, viewers will be able to discuss palliative care in relation to a long term illness or condition.

Summary

This vignette showcases a young boy who describes that his “proteins were escaping from his body,” requiring that he receive a heart transplant in order to live. He admits that he cries sometimes and his mother comforts him, and that he wants to become a nurse as a result of all he’s been through.

Patient Highlighted

Jose, 12-year-old who has undergone a heart transplant 3-4 months prior to filming his segment.

Discussion Point

Jose states that he said “yes” to the heart transplant because he still wants to be alive. While there is no indication in the film that Jose is dying, as health care professionals we are aware that the long term effects of organ transplant, anti-rejection medications, and other confounding factors can be debilitating and daunting, especially for a young boy.

Discussion Question 1

How can palliative care be helpful to a family in Jose’s situation?

Further Discussion/Points as Needed to Prompt Audience Interaction

Think about the definition of *palliative care*. Palliative care as defined by the *End-of-Life Nursing Education Consortium Core Curriculum (ELNEC) Guide* (revised, Jan. 2016):

“Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.” (CMS, 2008; NCP, 2013; NQF, 2006)

What are some of the needs Jose and his family may experience as a result of his heart transplant and the long-term care that he will require? (Examples include financial burdens, medication side effects [one can see he has the characteristic facial swelling common with steroid use], fear of organ rejection, need for re-hospitalization, possible death).

Discussion Question 2

Reflect on what you might say to Jose when you hear him say that sometimes he cries.

Further Discussion/Points as Needed to Prompt Audience Interaction

What kinds of questions would you ask him about his crying? Do you think Jose would benefit from a referral to another health care professional? Or to someone else such as a spiritual/religious figure in his life?

Suggested Applicability to Nursing Courses and/or to Care Settings

Courses: Palliative/Hospice Care; Pediatric Nursing; Introduction to Nursing; Mental Health Nursing; Medical/Surgical Nursing; and any course focused on communication, growth and development, and/or family systems.

Care Settings: Orientation and/or in-service programs for health care providers in primary, acute, long term, hospice/palliative care, and/or home care settings.

Suggested Congruence with ELNEC Modules

Palliative Nursing Care; Symptom Management; Ethical Issues in Palliative Care Nursing; Cultural/Spiritual Considerations in End-of-Life Care; Communication; Loss, Grief, Bereavement.

References for Palliative Care Definition

ELNEC-Core Curriculum © COH & AACN, 2007. Revised January 2016.

Centers for Medicare & Medicaid Services (CMS). (2008). Medicare and Medicaid programs: hospice conditions of participation; final rule. Federal Register. Vol 73. Washington, DC: Author. Last accessed December 11, 2015 from: <http://www.gpo.gov/fdsys/pkg/FR-2008-06-05/pdf/08-1305.pdf>

National Consensus Project (NCP) for Quality Palliative Care (2013). Clinical practice guidelines for quality palliative care, 3rd edition. Last accessed December 11, 2015 from: http://www.nationalconsensusproject.org/Guidelines_Download2.aspx

National Quality Forum (NQF). (2006). A national framework and preferred practices for palliative and hospice care quality. Washington DC: Author. Last accessed December 11, 2015 from: http://www.qualityforum.org/publications/2006/12/A_National_Framework_and_PREFERRED_Practices_for_Palliative_and_Hospice_Care_Quality.aspx