

defining hope

Study Guide



CAROLYN JONES FILM • PRODUCED BY LISA FRANK

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Video Segment #12

I Said ‘Yes’ Because I Want to Live (3:08 min.)

www.hope.film/study-guide-videos

For CNE credits: <https://waldenuniversitycne.rievent.com/a/LGMNCW>



Objective

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

Summary

This segment 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, Feb. 2018):

“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.” (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 February, 2018.

National Consensus Project (NCP) for Quality Palliative Care. (2013). *Clinical practice guidelines for quality palliative care*, 3rd edition. Accessed November 16, 2017 from: <https://www.nationalcoalitionhpc.org/ncp-guidelines-2013>

National Quality Forum (NQF). (2006). *A national framework and preferred practices for palliative and hospice care quality*. Washington DC: Author. Accessed November 16, 2017 from: http://www.qualityforum.org/publications/2006/12/A_National_Framework_and_PREFERRED_Practices_for_Palliative_and_Hospice_Care_Quality.aspx

USING THIS GUIDE

Defining Hope is a one-hour, eighteen-minute film. This guide was developed to stimulate audience reflection, conversation, and interaction. This guide highlights 14 brief video segments so that viewers may watch single segments of the film focused on particular topics.

The individual video segments can be viewed for free at www.hope.film/study-guide-videos

Nurses can receive free contact hours for watching each video segment and completing the evaluation thanks to the generous support of Walden University. Walden University is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation. For more information visit www.hope.film/study-guide-videos

Each of the 14 segments is based on the following template:

Segment #1-14, Title, Length: Each segment is numbered, titled, and followed by the approximate length of run time in minutes for that segment.

Objective/s

A minimum of one learning objective is included for each video segment.

Summary

There is a brief overview of the segment followed by a description of the patient or nurse highlighted therein.

Discussion Points

Each summary is followed by a suggested "discussion point" that the speaker/educator may use to initiate conversation or to present more insight into that segment.

Discussion Question/s

Discussion points are followed by a minimum of two discussion questions designed to encourage reflection and discussion among audience members. Questions were developed to stimulate interaction; there are no "right" or "wrong" answers.

Further Discussion/Points as Needed to Prompt Audience Interaction

Discussion questions are followed by further discussion points in the event that the audience

requires more prompting or encouragement to share ideas.

Suggested Applicability to Nursing Courses and/or to Care Settings

This section provides suggested courses (nursing or other), as well as other care settings where educators may find value by embedding particular video segments into curriculum to highlight a point.

Suggested Congruence with ELNEC[®] Modules

This section provides suggested End-of-Life Nursing Education Consortium (ELNEC)[®] modules where ELNEC[®] educators may find value by embedding particular segments into their curriculum. ELNEC[®] is a national education initiative to improve nursing education on end-of-life care. The project is administered by the American Association of Colleges of Nursing and City of Hope.

Related Segments

Some segments are related to others presented elsewhere in the film. This section provides the titles of any related video segments.

References

If materials or other sources were used within a section, a reference list is provided.

OBJECTIVES

By the end of this film, viewers will be able to:

1. Discuss key factors that affect patient and family decision making about end-of-life care.
2. Differentiate between hospice and palliative care.
3. Compare and contrast the terms sympathy and empathy.
4. Discuss internal conflicts that people may encounter when making decisions about whether to pursue aggressive treatment for life threatening illnesses.
5. Describe the role of the nurse in palliative care/hospice settings.
6. Discuss how family members play a significant role in decision making surrounding care choices.

ABOUT THIS GUIDE

Guide created by Diana Mager, DNP, RN-BC, Associate Professor and Director of Continuing Education, Kanarek Center for Palliative Care for Nursing Education, Marion Peckham Egan School of Nursing and Health Studies.

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The American Nurses Foundation

The American Nurses Foundation is dedicated to transforming the nation's health through the power of nursing. It helps nurses help people by supporting, recognizing and investing in the 4 million nurses across the United States. Learn more about the American Nurses Foundation and recognize nursing excellence at www.givetonursing.org

The Rita & Alex Hillman Foundation

The Rita & Alex Hillman Foundation cultivates nurse leaders, supports nursing research and innovations, and disseminates new models of care—all critical to transforming our health-care system into one that is more patient-centered, accessible, equitable, and affordable; one that delivers the high-quality care patients need and deserve. Learn more about the Rita & Alex Hillman Foundation and our approach to nursing-driven innovation at www.rahf.org

OTHER RESOURCES BY CAROLYN JONES

From the creators of *Defining Hope*, further film and narrative resources about nurses and nurses' care for the seriously ill can be found at:

www.DyingInAmerica.org, an interview project that examines the dying experience through the eyes of nurses.

www.AmericanNurseProject.com, a multimedia initiative to elevate the voice of nurses in this country by capturing their personal stories through photography and film. A portion of all proceeds benefit a scholarship fund for nurse education through the **American Nurses Foundation**.

THE FILM

The full film is available at www.hope.film. A portion of the proceeds from this documentary support programs that advance expertise in palliative nursing practice at the American Nurses Foundation and Jonas Nursing and Veterans Healthcare.

For more information visit www.hope.film