defining hope

Study Guide

Carolyn Jones Film • Produced by Lisa Frank

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Educational material created by Diana Mager, DNP, RN-BC, Associate Professor of Nursing, Fairfield University, for the American Nurses Foundation
Objective
By the end of this video segment, viewers will be able to reflect upon how the wishes and beliefs of adult family members may influence their children's or sibling's care wishes.

Summary
After having a second surgery for a recurrent brain tumor, a young woman is struggling with memory loss. She meets with a health care professional to develop ways to improve her quality of life. She has refused radiation after the surgery, as her sister states that they are considering what is the most important: the quality of life remaining, versus the quantity, or number, of years of life remaining.

Patients Highlighted
Alena Sydnor, young woman first diagnosed with a brain tumor in 8th grade. She has had several surgeries and, as a result, suffers from memory loss.

Discussion Point
Alena's mother has ongoing concerns about her daughter's future ability to care for herself. Together, Alena and her family decide that Alena will forego radiation because of the possibility of further memory loss. Alena's sister openly states that she'd rather have the years left with Alena to be of better quality, than to have her for longer without being able to function.

Discussion Question 1
Alena cries when her sister speaks about quality versus quantity of life. What do you think is going through Alena’s mind?
Further Discussion/Points as Needed to Prompt Audience Interaction
Does it appear that Alena feels the same way about quality versus quantity? Do you think she may feel guilty, or feel like a burden to her family? If you were present during this conversation, what might you have said to Alena when witnessing her tears as her sister spoke? (Examples may include, “Alena, I see you are crying. Can you share what you are feeling right now?”)

Discussion Question 2
Discuss some of the difficulties that could arise surrounding care decisions when your patient is a child or a minor.

Further Discussion/Points as Needed to Prompt Audience Interaction
There are many factors to consider. (Examples include legal and ethical ramifications, child/minor’s maturity level and level of understanding of the situation, difficulty for a parent to make a decision to stop lifesaving interventions.) What are some others? What could the nurse do to assist Alena and her family in making such difficult decisions and then to live with the results of those decisions?

Suggested Applicability to Nursing Courses and/or to Care Settings
Courses: Palliative/Hospice Care; Introduction to Nursing; Home Health/Community Nursing; Mental Health Nursing; Pediatric Nursing; Medical/Surgical Nursing; and any course focused on communication, long term care, quality of life, 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.

Related Video Segments
#10: It’s Not Always About Death, It’s About Living Life to the Fullest; #11: Is It Worth It? I Don’t Know ...
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.

Objectives
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.givetонursing.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 of 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