



FACILITATION GUIDE FOR PROGRAM 1

CONDITION: CRITICAL HEALTH CARE IN THE UNITED STATES

A Series of Education Programs on Health Care Ethics

Ethics Program 1: Persisten Vegetative State, “To Live... or Let Die”

The Persistent Vegetative State and end-of-life care featuring the case of Terri Schiavo

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SECTION I

Narrative Video with Expert Commentary

NARRATIVE VIDEO

The 30-minute video portrays Terri Schiavo as a patient requiring end-of-life care and purportedly in a persistent vegetative state. Her artificial feeding was permitted to be withdrawn by the courts in an effort to respect her previously indicated wishes. The story presents the discord in Terri's family: between her parents (Bob and Mary Schindler) who wanted to have guardianship of Terri so they could keep her alive, and her husband (Michael Schiavo) who wanted to respect Terri's wishes by letting her die. The ethical debate on Terri's story is presented in four sections in the video.

1. Diagnosis of Terri Schiavo
2. Patient Rights of Terri Schiavo
3. Terri Schiavo as a PVS Patient: Killing or Letting Die?
4. Family Discord, Court Resolution, and National Politics

EXPERT COMMENTARY

The video has expert commentary by internationally recognized figures in the debate on patients in a persistent vegetative state, including: Dan Callahan, PhD; Eric Cassell, MD; Karen Lebacqz, PhD; Rebecca Dresser, JD.

LEARNING OBJECTIVES

The 30-minute video enables participants to foster discussion at the end of each section as well as at the end of the program. Participants will be able to:

- identify problems connected with diagnosing a persistent vegetative state
- indicate the rights of a patient in end-of-life care
- understand the distinction between killing and letting die in end-of-life care
- identify court resolutions and political debates on end-of-life care

STRUCTURE OF THE EDUCATION SESSION

The facilitator should explain the learning objectives, show the video, and then engage the participants in discussion and/or assign follow-up projects.



SECTION II

Discussion Questions for the Program

I DIAGNOSIS OF TERRI SCHIAVO

- What was the family dispute about the diagnosis of Terri Schiavo?
- What is an acceptable description of the persistent vegetative state?

Answers

II PATIENT RIGHTS OF TERRI SCHIAVO

- What constitutional rights did Terri Schiavo have as an end-of-life care patient?
- What is the role of competency in protecting patient rights in health care?

Answers

III TERRI SCHIAVO AS A PVS PATIENT: KILLING OR LETTING DIE?

- What was the definition of being a PVS patient in Florida where Terri Schiavo lived?
- Is the withdrawal of artificial feeding from a PVS patient a form of killing?

Answers

IV FAMILY DISCORD, COURT RESOLUTION AND NATIONAL POLITICS

- What resolution did the courts reach for Terri Schiavo's end-of-life care?
- In what way was the Terri Schiavo case connected with the political debate over a right-to-life and right-to-die?

Answers



SECTION III

Project or Assignments for the Program

These projects or assignments could be distributed among participants for them to expand on the answers in the discussion section by further review of the video.

I DIAGNOSIS OF TERRI SCHIAVO

- Explain the family dispute about the diagnosis of Terri Schiavo.
- Provide an acceptable description of the persistent vegetative state.

II PATIENT RIGHTS OF TERRI SCHIAVO

- Explain what constitutional rights Terri Schiavo had as an end-of-life care patient.
- Explain the role of competency in protecting patient rights in health care.

III TERRI SCHIAVO AS A PVS PATIENT: KILLING OR LETTING DIE?

- Provide the definition of being a PVS patient in Florida where Terri Schiavo lived.
- Explain whether 974 the withdrawal of artificial feeding from a PVS patient is a form of killing.

IV FAMILY DISCORD, COURT RESOLUTION AND NATIONAL POLITICS

- Explain the resolution the courts reached for Terri Schiavo's end-of-life care.
- Explain any connection between the Terri Schiavo case and the political debate over a right-to-life and right-to-die.



SECTION IV

Individual Learning Model

The Individual Learning Model complements the Group Learning Model by providing individual students with interactive independent study. This self-learning multimedia tool contains quizzes, on-screen readings, and videos for the entire DIA Learning Ethics Series.

INDIVIDUAL LEARNING MODEL

The Individual Learning Model is a chaptered, Web-based program available as Full Course or Selected Topics. It offers the following items:

- 60-minute narrative video with expert commentary
- Up to 12 chaptered curriculum topics, each including:
 - 5-minute narrative video components
 - On-screen reading components
 - On-screen quiz components
- Pre-test and post-quiz learning outcome measurement
- Real-Time Score-tracking
- Automated Certification by recognized accrediting bodies

COURSEWORK

The Catholic Version of the Individual Learning Model for Ethics Program 1 includes the following coursework:

- Chapter 1. Patient Decision-Making Capacity
- Chapter 2. The Description of Persistent Vegetative State
- Chapter 3. The Purpose of Advance Directives
- Chapter 4. Institutional Ethics Committees
- Chapter 5. Ethics Committees and Ethics Consultation in End-of-Life Care
- Chapter 6. Medical Futility and Inappropriate Care in End-of-Life Care
- Chapter 7. Withholding/Withdrawing Medical Treatment: Artificial Nutrition and Hydration
- Chapter 8. Professional Responsibilities in Caring for PVS Patients
- Chapter 9. JCAHO Accreditation Standards and Organizational Ethics
- Chapter 10. JCAHO Accreditation Standards on Patient Rights and Treatment
- Chapter 11. Resolution of Previous Legal Cases in End-of-Life Care: cluster #1
- Chapter 12. Resolution of Previous Legal Cases in End-of-Life Care: cluster #2



QUESTIONS & ANSWERS

Discussion Questions for the Program

The suggested “answers” simply indicate some items from the video that relate to the question. The facilitator should encourage a broad range of responses from the video and beyond.

I DIAGNOSIS OF TERRI SCHIAVO

- **What was the family dispute about the diagnosis of Terri Schiavo?**

Since 1990, Terri Schiavo was in what some doctors diagnosed as a “persistent vegetative state” or PVS. They say she was unaware of her surroundings and unable to communicate or respond in a meaningful or purposeful way. Terri’s parents, the Schindler family, sought guardianship to look after her, arguing that although she was brain damaged she was not in a persistent vegetative state. Her husband Michael Schiavo believed that Terri was in a persistent vegetative state. He also claimed she had indicated that she did not want to live in such a way. Hence, to honor her wishes, he pursued court action to withdraw the feeding tube that would lead to Terri’s death in approximately a two-week period.

- **What is an acceptable description of the persistent vegetative state?**

A persistent vegetative state occurs when the higher brain is effectively destroyed. There is still lower brain activity, but the higher cortex, which is the basis of cognitive functioning, is lost. But the patient still has some brain activity and is not totally dead.

II PATIENT RIGHTS OF TERRI SCHIAVO

- **What constitutional rights did Terri Schiavo have as an end-of-life care patient?**

The U.S. Supreme Court had previously ruled that everyone has a constitutional right to reject unwanted medical treatment. After a multi-year court battle, the courts agreed with Michael Schiavo that Terri was in a persistent vegetative state and that she would not have wanted to live in that condition. In a legal sense, her husband sought to enforce her constitutional right to refuse unwanted medical treatment. That is, the case enforced what the courts had determined to be, by clear and convincing evidence, Terri’s wishes.

- **What is the role of competency in protecting patient rights in health care?**

There appears to be a consensus in society that it is permissible in some circumstances to forgo nutrition and hydration if a patient asks for that to be done. There is a clearly defined right for such a decision to be taken by a competent patient. If the patient is competent the court will support the patient’s decision. However, when the patient is not competent, the family is faced with deciding what should be done, and often that causes dispute.



QUESTIONS & ANSWERS

Discussion Questions for the Program

III TERRI SCHIAVO AS A PVS PATIENT: KILLING OR LETTING DIE?

- **What was the definition of being a PVS patient in Florida where Terri Schiavo lived?**

A persistent vegetative state is a condition of people with severe brain injuries who have lost all upper brain functions. In Florida law the persistent vegetative state means a permanent and irreversible condition of unconsciousness in which there is: (a) the absence of voluntary action or cognitive behavior of any kind; (b) an inability to communicate or interact purposefully with the environment. In the case of Terri Schiavo, each side focused on different words to support their respective cases. The attorney for the Schindler family argued that in Florida law there has to be an absence of any kind of behavior in order to diagnose an individual as a PVS patient. Hence, insofar as Terri exhibited a few voluntary or cognitive behaviors, she could not be described as being a PVS patient. In contrast, the lawyer for Michael Schiavo argued that Terri did not act purposefully, and therefore she could be described as being a PVS patient according to Florida law. He clarified that in a medical context ‘purposeful’ is described as a cognitive response. He explained that PVS patients could moan, cry, or make bodily movements as reflexes, but without purpose or cognition.

- **Is the withdrawal of artificial feeding from a PVS patient a form of killing?**

In the case of Terri Schiavo, some argue that withdrawing artificial feeding to let her die was a form of euthanasia. Others claim that withdrawing artificial feeding based on Terri’s wishes simply let her underlying pathology take its natural course to death. Most consider that justifiably withholding or withdrawing medical treatment is not a form of killing, for example if the patient indicated a wish not to be in that state. Euthanasia can be described as a deliberate effort to end the life of a patient, intending the patient’s death, for merciful reasons. But when a treatment is stopped because it is useless, then the goal is to stop a useless treatment, not to kill the patient.

IV FAMILY DISCORD, COURT RESOLUTION AND NATIONAL POLITICS

- **What resolution did the courts reach for Terri Schiavo’s end-of-life care?**

Legally, the case of Terri Schiavo was a question of whether she should be allowed to die, that is, letting her die by stopping artificial feeding as a medical treatment. Florida’s Supreme Court upheld the lower court rulings to honor Terri’s wishes. The lower courts had found clear and convincing evidence that Terri would not have wanted to live in the circumstances she faced.

- **In what way was the Terri Schiavo case connected with the political debate over a right-to-life and right-to-die?**

Some considered the case of Terri Schiavo to be not just a medical question but also a political question to pursue debate around the right-to-life movement or to permit euthanasia based on the right-to-die movement.