COURSE HCE-756: END OF LIFE ETHICS

[This course is part of the Catholic program in Healthcare Ethics]

Spring 2019 (December 2018)
College: McAnulty College and Graduate School of Liberal Arts
Syllabus: HCE-756, END OF LIFE ETHICS, Spring 2019
Course: Tuesday 3:05-5:45 pm, Fisher Hall tbd
Office hours: Appointment, Fisher Hall 300;
Tel. (412) 396-4504
Email: tenhavelh@duq.edu
Course instructor: Henk ten Have, M.D., Ph.D.
Professor of Healthcare Ethics, Center for Healthcare Ethics
Duquesne University, 600 Forbes Avenue, Pittsburgh

OUTLINE
The course will focus on 3 research competencies in relation to end-of-life ethics:

1. Historical and cultural analysis
   - Death and dying in history
   - Changes in attitudes towards death over time
   - Changes in attitudes towards death in religion and culture
2. Systematic examination of relevant fundamental philosophical and ethical issues
   - goals of medicine and healthcare
   - compassion
3. Critical clarification of ethical debates and concerns
   - Compassionate care; the right to try
   - Futility
   - Persistent vegetative state
   - Withholding and withdrawing treatment
   - Medical cannabis
   - Hospice and palliative care
   - Euthanasia
   - Assisted suicide
   - Dementia care

COURSE DESCRIPTION
The course will make students familiar with ethical issues related to the end of life, especially in relation to Catholic moral teaching. It will focus on will focus on the historical, philosophical and ethical analysis of these issues. The course will consist of four research projects. The first will examine the historical, religious and cultural attitudes towards death and dying. It will ask the question why death and dying have become a moral challenge today. The second research project will be a collaboration with some other students and will focus on a particular topic in end-of-life ethics. In class, a video will be shown. Students will then clarify the debate, and articulate the various ethical considerations that are relevant. They will pay critical attention to the philosophical debate on the goals of health care. Compassion is an important virtue for health professionals what does it imply when faced with suffering, death and dying?
Physicians should save human life but at what price? Is assisting in suicide or providing euthanasia compatible with the goals of medicine? The third research project focuses on specific ethical problems that arise in healthcare practice: palliative care, euthanasia, and assisted suicide. These problems all include the basis question how human beings should deal with pain, suffering and desperation. The fourth research project is longitudinal. Students have to write a substantial course essay. They have to choose a research thesis concerning an ethical problem in end-of-life care and develop a robust argument. This course essay should address all research competencies of the course.

COURSE OBJECTIVES
Upon completion of the course students should master the following competencies, as should be demonstrated both in specific research projects and in the course essay:

a. A historical and cultural analysis of present-day debates on end-of-life issues, explaining on the one hand the moral traditions that are involved in these debates, and on the other hand the evolution of moral views and attitudes towards death and dying over time;

b. Systematic examination of fundamental philosophical and ethical issues, understanding and explaining how the contemporary debates are informed and framed by fundamental interpretations of basic notions such as goals of medicine and healthcare, and compassion;

c. Critical clarification of ethical debates and concerns regarding practical issues in healthcare ethics, viz. euthanasia, assisted suicide, palliative and hospice care.

LEARNING OUTCOMES
The course will contribute to the accomplishment of the general HCE Program Learning Outcomes. All of following Learning Outcomes pertain to HCE-656.

a. Fundamental Knowledge.
   Students can understand and analyze HCE theory and methods as well as major applied topics in end-of-life ethics.

b. Multi-disciplinary Study.
   Students can critically relate HCE with multi-disciplinary fields in health care, specifically in connection to the historical background and the philosophical interpretation of fundamental notions and evolving social and cultural attitudes.

c. Scholarship
   Students can research and write scholarly essays, teach and communicate effectively, and present academic papers that:
   • present cogent arguments(s),
   • engage scholarly literature, and
   • demonstrate critical thinking and analysis.

COURSE METHODOLOGY
The course will have weekly classes. The general aim of the course, as one of the courses in the HCE graduate program, is to prepare students for the writing of the Dissertation Proposal. In particular, it will focus on the development of research competencies in
connection to the area of global bioethics. This aim implies that the emphasis in the course will be on student learning rather than instructor teaching. Students will especially be trained in doing research, critically analyzing scholarly literature, presenting research results and discussing them in a peer setting, and writing critical and analytical papers on relevant topics.

Student will have to focus on four Research Projects:

**RESEARCH PROJECT 1**
Research competency of historical and cultural analysis
8 Page Project
Thesis: *Why is death and dying an ethical concern today?*
Format: 8 pages (font 12; double-spacing) plus approximately 30 references/end notes
Required Readings:
1. Philippe Aries, *Western attitudes towards death: From the Middle Ages to the present*;
3. Lydia Dugdale (ed.): *Dying in the twenty-first century. Toward a new ethical framework for the art of dying well*.
Submit paper before January 25 (tenhaveh@duq.edu)
In class 3 (29 January 2019) each student will be invited to briefly present his or her paper.

**RESEARCH PROJECT 2**
Each class will address a specific topic in end of life ethics. To introduce this topic a video will be shown. Then the various ethical dimensions of the topic will be elaborated and discussed (emphasizing the ethical problems but also argument pro and con specific policies and actions). Each class will be prepared by a team of 2 or 3 students. Students will clarify the debate and articulate the various ethical considerations that are relevant. They will pay critical attention to the philosophical debate on the goals of health care and will relate the subject to the following book: Eric Cassell, *The nature of suffering and the goals of medicine*.
Requirements:
- Each team of students prepares and analyses the video before class
- Study the relevant literature about the topic
- Identify the relevant ethical positions and arguments regarding the topic
- Relate the issue to questions of suffering and compassion, as well as goals of medicine (referring to the book of Cassell)
- Assign duties to each student
- Make sure that you obtain the relevant literature
- Make a one-page hand-out of relevant issues to be discussed
- During class, following the video, present the main ethical issues for minimally 30 and maximally 45 minutes
- Conduct a serious discussion with the other students by preparing a list of pertinent questions to be discussed for at least 45 minutes
- Close the discussion with a summary of the main conclusions
RESEARCH PROJECT 3
Research competency of critical clarification of ethical debates and concerns.
This research project has two parts:
1. **Research Paper of 8 pages**
   - **Assignment:** Provide a critical assessment of the Catholic point of view regarding palliative sedation.
   - **Format:** 8 pages (font 12; double-spacing) plus approximately 30 references/end notes
   - **Required Readings:**
     2. Identify at least 2 documents issues by the Vatican regarding end-of-life ethics that are relevant for the ethical debate on palliative sedation
   - **Submit the paper before April 5, 2019 ([tenhaveh@duq.edu](mailto:tenhaveh@duq.edu))**

2. **Oral presentation in class 12 (9 April 2019)**
   Prepare a presentation about the Catholic point of view regarding palliative care and palliative sedation. Briefly discuss:
   - a. how are these terms used or defined?
   - b. what are the moral arguments used?
   - c. how is palliative sedation justified?
   - **Conditions for the presentation:**
     - you may use power point but it is not required
     - duration is maximum 6 minutes
   - **Homework:** preparing the presentation will require homework to identify the relevant literature.
   - Presentations will take place during class 12 (9 April 2019).

RESEARCH PROJECT 4
This is the writing of a substantial research essay. The course research essay will require students to substantively apply the Course Research Competencies to a particular issue (theoretical or practical). Requirements:
2. **Start to reflect on the thesis of your research essay from the beginning of the course.**
3. **Thesis and 1-page outline with basic bibliography to be submitted by the end of week 4 (Feb.8) (email to [tenhaveh@duq.edu](mailto:tenhaveh@duq.edu)).**
4. **You will receive feedback before the next class.**
5. **Depending on your thesis, you can use the assigned literature but you will also need to do homework to integrate the relevant literature.**
6. **Progress will be reported in the classes.**
7. **Each student will briefly present the research essay (max. 6 minutes) during the final class and submit a copy of the essay by date assigned.**
8. **The essay length should be 20 pages, font 12, double-spacing (not including the notes and bibliography).**
9. Students must adopt the format of the *Chicago Manual of Style*, as required by the College for dissertation submissions.

10. Select an Essay Title that identifies a research thesis. For example:
   i. “The usefulness of the notion of futility in the debate on withholding life-sustaining treatment” (combining historical, philosophical and ethical analysis).
   ii. Another example: “Is terminal sedation ethically justified in the context of palliative care?”

11. Present a brief Introduction and Conclusion.

12. Notes to the references made in the essay.
   i. Use end notes (as opposed to foot notes at the bottom of the page).
   ii. Do not use notes for narrative explanations – they belong in the main text.
   iii. There should be approximately 100 end notes in the essay.

13. Bibliography. List all the references in alphabetical order. Only list items actually referred to in the essay.

14. Divisions and subdivisions. Use major divisions and subdivisions, evenly distributed throughout the essay, to lay out the sequence of concepts.

15. Use of online references. Online references must be accurately identified with complete web address etc, including the date of access.

**COURSE READINGS**

**Required reading: Books**


**Research competency #1: Historical and cultural analysis**


**Research competency #2: Systematic examination of fundamental philosophical and ethical issues**


**Compassionate use; right to try**

Video: The ethics of compassionate care (16 minutes)  
[https://www.youtube.com/watch?v=D5JrTyYhLgs](https://www.youtube.com/watch?v=D5JrTyYhLgs)

a. Rebecca Dresser: “Right to try” laws: The gap between experts and advocates.”  


**Futility**

Video: Medical futility: who decides to stop treatment (17 minutes)  
[https://www.youtube.com/watch?v=p_y3f4vPqa0](https://www.youtube.com/watch?v=p_y3f4vPqa0)


b. Paul R. Helft, Mark Siegler, and Joh Lantos: “The rise and fall of the futility movement.”  

c. Lawrence Schneiderman: “Defining medical futility and improving medical care.”  


e. G.T. Brown: “Medical futility in concept, culture, and practice.”  
Persistent vegetative state
Video 1: Karen Ann Quinlan (8 minutes)
https://www.youtube.com/watch?v=Q9P-NA7ITNC

Video 2: Vegetative state (13 minutes)
https://www.youtube.com/watch?v=89Y6V340Xpk


Withholding and withdrawing treatment
Video 1: Ethical Challenges Related to Withholding or Withdrawing Medical interventions (11 minutes)
https://vimeo.com/251818400

Video 2: Intending to hasten death (6 minutes)
https://bioethicsarchive.georgetown.edu/phlx101-02/video/aSTbaylnBE4.html


Medical cannabis
Video 1: A doctor’s case for medical marijuana (15 minutes)
https://www.ted.com/talks/david_casarett_a_doctor_s_case_for_medical_marijuana/discussion?utm_campaign=BeepBeepBites%20
Video 2: Medical marihuana (16 minutes)
http://time.com/3931863/medical-marijuana-benefits/


Hospice and palliative care
Video 1: Palliative care vs hospice: How are they different (7 minutes)
https://www.youtube.com/watch?v=BmTmS7ygRPs

Video 2: A good death: The inside story of a hospice. A special report (11.50 minutes)
https://www.youtube.com/watch?v=nyPZEtCa88k


Euthanasia
Video: Allow me to die; euthanasia in Belgium (52 minutes)
https://www.youtube.com/watch?v=hCRpuTRA7-g


**Assisted suicide**

**Video 1:** Assisted suicide; Harriet Scott’s story (15 minutes)  
[https://www.youtube.com/watch?v=s_lR5uSemSE](https://www.youtube.com/watch?v=s_lR5uSemSE)

**Video 2:** Euthanasia, physician-assisted suicide and advance care directive (4 minutes)  
[https://www.youtube.com/watch?v=1LNVzfJuQh0](https://www.youtube.com/watch?v=1LNVzfJuQh0)


**Dementia care**

**Video 1:** How to approach persons with dementia (4 minutes)  

**Video 2:** CNN’s world’s untold stories: Dementia village (23 minutes)  
[https://www.youtube.com/watch?v=LwiOBlyWpko](https://www.youtube.com/watch?v=LwiOBlyWpko)


**Research competency #3: Critical clarification of ethical debates and concerns**


**Palliative sedation**

**COURSE SCHEDULE**

<table>
<thead>
<tr>
<th>Date</th>
<th>Topic</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jan. 15</td>
<td>Course introduction. Overview of end-of-life ethics, Syllabus, Class Presentations, Research papers and Course Essay.</td>
<td>Video: Atul Gawande on end-of-life care (7 minutes) <a href="https://www.youtube.com/watch?v=jISIN7FF56Y">https://www.youtube.com/watch?v=jISIN7FF56Y</a></td>
</tr>
<tr>
<td>Jan. 22</td>
<td>Compassionate use; right to try</td>
<td>Video: ‘Right to try’ gives terminal patients access to new drugs (9 minutes) <a href="https://www.youtube.com/watch?v=-1Lvw28Pa5A">https://www.youtube.com/watch?v=-1Lvw28Pa5A</a></td>
</tr>
<tr>
<td>Jan. 29</td>
<td>Research paper 1: Dealing with death</td>
<td>Presentations and discussion of research paper: Why is death and dying an ethical concern today?</td>
</tr>
</tbody>
</table>
Feb. 5  
**Topic:** Futility  
Video and student analysis #1

Feb. 12  
Kelly lecture  
Submit Essay Thesis, 1-page outline, basic bibliography, by Fri.Feb.8

Feb. 19  
**Topic:** Persistent Vegetative State  
Video and student analysis #2

Feb. 26  
No class: preparing student presentations

March 5  
Spring break

March 12  
**Topic:** Withholding and withdrawing treatment  
Video and student analysis #3

March 19  
**Topic:** Medical cannabis  
Video and student analysis #4

March 26  
**Topic:** Hospice and palliative care  
Video and student analysis #5

April 2  
**Topic:** Euthanasia  
Video and student analysis #6

April 9  
**Topic:** Research paper 2: Palliative sedation  
Presentations and discussion of research papers

April 16  
**Topic:** Assisted suicide  
Video and student analysis #7

April 23  
**Topic:** Dementia care  
Video and student analysis #8

April 30  
**Topic:** Course review and course essay

**Deadline for course essay: 1 May 2019:** Submit 20-page research essay (double spacing). Student written evaluation of course.

**HCE HANDBOOK.** The Center for Healthcare ethics has developed a Handbook of Policies, Procedures, and Guidelines to guide students in all curriculum related matters. The Handbook is available on the website of the Center.
**COURSE GRADE.** There will be no examinations. The course grade will be assigned based on the quality of the course Research Essay and the two Research Projects. The grade will be a combination of 15% for the first Research Project, 15% for the second Research Project, and 70% for the final course essay. No midterm grades will be assigned. End of term grades will be assigned adopting grading policy in the McAnulty College and Graduate School of Liberal Arts, as follows:

- A  4.0 distinguished scholarly work
- A-  3.7
- B+  3.3
- B  3.0 normal progress towards degree
- A-  2.7
- C+  2.3
- C  2.0 warning; student subject to departmental action
- F  0.0

**ACADEMIC INTEGRITY.** This syllabus incorporates the “Expectations of Academic Integrity.” Cheating and plagiarism cannot be tolerated. All relevant policies of the McAnulty College and Graduate School of Liberal Arts apply.

**REASONABLE ACCOMMODATIONS.** Students with documented disabilities are entitled to reasonable accommodations if needed. If you need accommodations, please contact the Office of Freshman Development and Special Student Services in 309 Duquesne Union (412-396-6657) as soon as possible. Accommodations cannot always be granted retrospectively.

**PRIVACY.** To provide distance access to HCE courses, all classes are videotaped and available for later use. The videos are stored on MediaSite in the secure cloud. Duquesne University has a non-disclosure agreement with the MediaSite vendor that protects the privacy and security of the data and students. That means that the videos stored in the MediaSite cloud are not available to anyone without defined access. The HCE Faculty (i.e., the course Instructor) is the only one who may authorize access to the videos, typically only to students registered for the class.