

**Instructors:**

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**Class Schedule:** Wednesdays, 2-4 pm - October 7 – October 28, 2009 (4 weeks)

**Learning Objectives:**

- Introduce and explore the practice of palliative care
- Explore psychosocial and spiritual aspects of palliative care
- Identify basic concepts of pain and symptom management
- Discuss the experience of loss and accommodation of grief
- Explore the integration of palliative care with disease-directed therapy

**Session I: October 7, 2009**

**2:00 pm – 4:00 pm**

Introduction to Palliative Care

In this session we will explore the concept of suffering and discuss key domains of palliative care.

Readings in preparation for class:

- Morrison S, Meier D. Palliative Care. N Engl J Med (2004) 350: 2582-2590 (*pdf attached*)
- National Consensus Project. Clinical Practice Guidelines for Quality Palliative Care: Executive Summary. (2004) <http://www.nationalconsensusproject.org> (*pdf attached*)
- Cassell E. Diagnosing Suffering: A Perspective. Ann Internal Med (1999) 131: 531-534 (*pdf attached*)

**Session II: October 14, 2009**

**2:00 pm – 4:00 pm**

Preparing for Death: Grieving a Loss

In this session we will explore spiritual aspects of care and identify issues related to grief and loss.

Readings in preparation for class:

- Munoz, Daniel. "The Death of Mr. G." Hopkins Medical News, Fall 2002  
<http://www.hopkinsmedicine.org/hmn/F02/top.html>
- Sulmasy, D. Spiritual Issues in the Care of Dying Patients. JAMA 2006; (11) 1385-1392. <http://jama.ama-assn.org/cgi/reprint/296/11/1385>
- Warm, E. Fast Facts and Concepts #32: Grief and Bereavement (Part 1), January 2001. End-of-Life Physician Education Resource Center, [www.eperc.mcw.edu](http://www.eperc.mcw.edu) (*pdf file attached*)
- Martin, Steve. "The Death of My Father" The New Yorker, June 17, 2002 (*pdf file attached*)

**Session III: October 21, 2009**

**2:00 pm – 4:00 pm**

The Right to Self-Determination "It's About How You Live" not "Death Panels"

In this session we will explore the legal and ethical aspects of palliative care and consider the care of the imminently dying patient.

Readings in preparation for class:

- Hoffman, J. The last word on the last breath. The New York Times, October 10, 2006.  
<http://www.nytimes.com/2006/10/10/health/10dnr.html?ex=1187841600&en=9d1413fb43be0e18&ei=5070>

- Advance Directives: A Guide to Maryland Law on Health Care Decisions (*pdf file attached*) Please try to complete this for yourself.
- Five Wishes (*to be distributed in class on 10/14/09*) Please try to complete this for yourself.

**Session IV: October 28, 2009**

**2:00 pm – 4:00 pm**

Palliative Care is Good Patient Care

In this session we will explore the integration of the domains of palliative care, identify strategies for good communication and discuss shared decision-making.

Readings in preparation for class:

- Mack J, Wolfe J. Early integration of pediatric palliative care: for some children, palliative care starts at diagnosis. Curr Opin Pediatr (2006)18:10-14. (*pdf file attached*)
- Stein, Rob. At the end of life, a racial divide. The Washington Post, March 12, 2007. [http://www.washingtonpost.com/wp-dyn/content/article/2007/03/11/AR2007031101565\\_pf.html](http://www.washingtonpost.com/wp-dyn/content/article/2007/03/11/AR2007031101565_pf.html)
- Talking about treatment options and palliative care: a guide for clinicians (*pdf file attached*)

**Criteria for student evaluation:**

Each student is expected to

- engage in course discussions and
- participate in course exercises

Each student is expected to write a 1-2 page reflection following each class based on the readings and course discussion. Possible questions for the journal reflection:

- What inspired you this week?
- What surprised you?
- What concerned you?

These journal reflections are due on the Monday following each class and should be submitted by e-mail ([nhutton@jhmi.edu](mailto:nhutton@jhmi.edu)).

**PALLIATIVE CARE SELECTIVE  
PATIENT, PHYSICIAN AND SOCIETY  
JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE**

**Role Play on Interdisciplinary Palliative Care**

**Nancy Hutton, M.D.**

**Developed 2006**

**Last update 2009**

**Learning Objectives:**

- To experience one role of the medical student on a clinical rotation
- To experience viewing a clinical situation from another person's perspective
- To introduce the multiple professional disciplines involved in the care of hospitalized patients
- To explore a strategy that promotes effective communication and care-planning

**Activities:**

**1. Video clip** introduces Mr. and Mrs. Davis and the story of their granddaughter, Sherquonda: "Speaking the Same Language" Initiative for Pediatric Palliative Care

**2. Written description of clinical context for role play sequence:**

Sherquonda Davis is a 9 year old girl who was diagnosed with a brain tumor six months ago. She underwent surgery to try to resect the tumor, but part of it was invading her brainstem and could not be removed. She had radiation therapy for six weeks to try to shrink the remaining tumor, but it is growing again according to her last MRI. Her grandparents were told at the time of diagnosis that her cancer could not be cured.

Sherquonda has been in the hospital for the past 4 weeks because she choked on some food and aspirated it into her lungs, causing a severe pneumonia. Although the antibiotics seem to have helped her breathing, she is getting worse from a neurologic perspective. She is progressively losing control of her motor skills and has periods of time when she doesn't seem aware of her surroundings.

**3. Role Play - Afternoon Rounds** (small groups of 3 students)

MR. DAVIS: You have just arrived in your granddaughter's hospital room after a long day at work. Your wife has been with her all day, and tells you that she has been sleeping a lot and not eating. You feel like Sherquonda is slipping away from you. You want her to be comfortable and at peace. Although this is a very sad time, you have faith that she will be with God after she dies, and this helps you to cope. You wonder how soon she will die and what her dying will be like.

MRS. DAVIS: You have been staying with Sherquonda around the clock for the past 3 days. She is clearly getting worse and you are afraid something bad could happen the moment you turn your back. It breaks your heart to see her like this. You think there must be something else the

doctors can do to slow down the tumor and help her feel better enough to go home again. You know the other children miss her and they miss you too.

**MEDICAL STUDENT ON PEDIATRIC TEAM:** You are making your rounds late in the afternoon, checking on your patients before it is time to signout for the evening. You head for Sherquonda's room, thinking about how sad it is that she should have an incurable brain tumor, but being glad that you are part of a team that provides good palliative care for patients regardless of their prognosis. You know that the whole interdisciplinary team is getting together tomorrow to discuss how she is doing and to update her care plan. You think it would be a good idea for her grandparents to meet with key team members beforehand to share their hopes and concerns at this stage in Sherquonda's illness.

#### **4. Role Play - Family Meeting** (group of 6 students do role play, rest of class observes)

**MR. DAVIS:** You feel like Sherquonda is slipping away from you. You want her to be comfortable and at peace. Although this is a very sad time, you have faith that she will be with God after she dies, and this helps you to cope. You wonder how soon she will die and what her dying will be like.

**MRS. DAVIS:** You have been staying with Sherquonda around the clock for the past 4 days. She is clearly getting worse and you are afraid something bad could happen the moment you turn your back. It breaks your heart to see her like this. You think there must be something else the doctors can do to slow down the tumor and help her feel better enough to go home again. You know the other children miss her and they miss you too.

**SOCIAL WORKER:** You have been working with the Davis family since Sherquonda's diagnosis. While Mrs. Davis was initially reluctant to talk with you, you have now developed an excellent rapport. You often serve as advocate during family meetings to ensure that Mr. and Mrs. Davis.

At today's family meeting, your goal is to assess their understanding of the current medical situation and elicit any questions that they may have regarding Sherquonda's current status.

**CHAPLAIN:** You are the chaplain for pediatrics. You have worked with the Davis family for months and are aware that their Baptist faith plays an important role in their coping.

At today's family meeting, your goal is to reassess how their faith is affecting their ability to cope, learn about how much their own religious community is supporting them and inquire about any religious rituals that might be important to Sherquonda or to them at this point in her illness.

**CHILD LIFE SPECIALIST:** You studied early childhood development in college and did a field placement in Child Life here at the Children's Center. You love your work with children and families, helping kids to understand what is going on and to find ways to cope with scary or painful situations.

You have worked with Sherquonda's siblings and cousins to prepare them for her death.

At today's family meeting, your goal is to assess how the siblings are coping and assess for the needs of Sherquonda and her siblings at this time (i.e., legacy or memory-making activities or hospital visitation).

ONCOLOGIST: You have been working with the Davis family since shortly after Sherquonda's diagnosis. You know that this is a bad tumor. You were honest with the Davises when you first met them that this form of cancer could not be cured. Her aspiration pneumonia confirms that the advancing tumor is already interfering with her ability to eat and swallow safely and other staff members are already asking what else can be done to help her.

As her attending physician, you want to understand the grandparents' current views and preferences for her medical care and treatment. You might say:

I am very concerned about Sherquonda. I believe her pneumonia is a sign that she has entered the final phase of her life. When a child's condition becomes this serious, most families want to think again about what type of care is most important for their child. Some families want the opportunity to have their child at home again, some families want supportive care in the hospital, and some families want to pursue experimental treatments even when there is no proof that they might help their child. Have you thought about these issues? How are you feeling about them today?

**5. Role Play – Interdisciplinary Team Meeting** (group of up to 18 students do role play, rest of class observes)

SOCIAL WORKER: You have been working with the Davis family since Sherquonda's diagnosis. While Mrs. Davis was initially reluctant to talk with you, you have now developed an excellent rapport. You often serve as advocate during family meetings to ensure that Mr. and Mrs. Davis have understood the medical information provided.

Your concern today is that the plan be communicated to all members of the team so that the family hears a consistent message.

CHILD LIFE SPECIALIST: You studied early childhood development in college and did a field placement in Child Life here at the Children's Center. You love your work with children and families, helping kids to understand what is going on and to find ways to cope with scary or painful situations.

You have worked with Sherquonda's siblings and cousins to prepare them for her death. You are concerned about the hospital policy limiting visits of children under the age of 12: this means Shaquonda will not be able to see her siblings and cousins.

NURSE MANAGER: Sherquonda has been on your hospital unit several times in the past. Unfortunately right now there are visiting restrictions for children due to RSV (a contagious respiratory virus.) You must decide whether or not make an exception for her siblings and cousins. If you do make an exception to allow the visit, other families on the floor may be upset about why the rule was not enforced for one family.

PRIMARY NURSE: You are Sherquonda's primary nurse. You are seeing a steady decline in her ability to interact with you and her family. You notice that she grimaces when you change her position.

CHAPLAIN: You are the chaplain for pediatrics. You have worked with the Davis family for months and are aware that their Baptist faith plays an important role in their coping. The family believes that if God wills it, God will cure her; if God wills it, God will call her home. They find comfort when the family gathers for prayer.

NEUROSURGEON: You performed the original surgery and know from firsthand experience that this child's brain tumor is incurable. It will continue to grow, putting pressure on her brainstem, eventually causing her to lose her ability to swallow or protect her airway from aspiration. You think that placing a feeding tube into her stomach would provide nutrition in a safe manner, allowing her to live as long as possible without the risk of aspiration.

ONCOLOGIST: You have been working with the Davis family since shortly after Sherquonda's diagnosis. You know that this is a bad tumor. You have been working tirelessly in the laboratory for years to refine a new anti-tumor protein that is finally being tested for safety in children with incurable brain tumors. You want to offer this treatment to Sherquonda. Even though you know that the research protocol says that there is no chance for direct benefit from this experimental treatment, you will feel terrible if it turns out to be effective and you let Sherquonda die without the opportunity to try it.

SENIOR PEDIATRIC RESIDENT: You are halfway through your last year of pediatric specialty training. You are efficient and organized and an effective team leader.

You have been working on this unit for the past two weeks. You have seen the decline in Sherquonda's condition. You know that her gag reflex is failing and that a sudden aspiration could cause her to obstruct her airway and stop breathing, causing a cardiorespiratory arrest. You need to clarify her "code status" so that you know how to respond if this occurs.

PEDIATRIC INTERN: You just graduated from medical school six months ago, but it seems like years. This is your first rotation through the pediatric oncology unit.

You have been on the service for two weeks. You feel a bit overwhelmed by the number of very sick patients you have to care for right now. You feel that you should spend more time with this patient and her family, but you are not sure what you can really do to help. Can she go home from the hospital?

MEDICAL STUDENT ON PEDIATRIC TEAM: You have been on the team for two weeks and have spent time with Sherquonda and her grandparents every day. You feel good that you have helped them get answers to their questions. And Sherquonda seems to recognize you when you come into the room. You are not sure what to expect over the coming weeks, but you want to be sure that Sherquonda and her family get the best support available at what is a very difficult time for them. Her grandparents told you last night that this is in God's hands, and that they are hoping for a miracle.

COMMUNITY PEDIATRICIAN: You haven't seen Sherquonda since her diagnosis until today's visit. You realize that she is dying and want to support the family as best you can. You continue to see the other children in the family for checkups and minor illnesses. You are willing to be available on call if the family should choose to take Sherquonda home on hospice care.

GASTROENTEROLOGIST: You have not met this patient or family, but you are here at the meeting because she may require a feeding tube placed under anesthesia. You know that you could accomplish this with minimal risk to the patient.

NEUROLOGIST: You were just consulted two days ago to reassess this patient's neurological status. You see evidence of brainstem compression, with loss of gag reflex, difficulty swallowing, and irregular breathing. You believe her death is imminent, in the next few days.

RADIATION ONCOLOGIST: You provided the radiation treatment for Sherquonda several months ago. You just reviewed her last MRI and you are willing to try a second course of palliative radiation to see if it can shrink the tumor enough to help her be more alert.

PAIN SERVICE NURSE PRACTITIONER: You have been seeing Sherquonda on a daily basis during this admission. Your team provided pain medicine for her chest pain and shortness of breath due to the pneumonia, which is now resolving. You worry that she is experiencing headache from tumor growth, but she is no longer able to speak for herself. You wonder what observations others have made of her regarding the presence of pain.

HOSPICE NURSE: You have not met the patient or family. You were invited to the meeting by the case manager, so that you could hear about her in case she gets referred to hospice. You have lots of experience working with sick children at home. You want to know what her personal care needs are, such as her need for bathing, toileting, turning, eating, or taking medication. And you want a sense of the household and family setting.

CASE MANAGER: You are responsible for discharge planning for this pediatric unit. You have worked with the Davis family since Sherquonda's first admission to the hospital six months ago. They are a lovely family who care deeply about the children and take wonderful care of Sherquonda. Based on your past experience, you think they would all be happier being together at home during Sherquonda's final days, so you invited the hospice nurse to attend today's meeting to initiate that process.

PHYSICAL THERAPIST: You have been seeing this patient for passive "range of motion" exercises every day during this admission. Her muscle tone continues to increase, making it more and more difficult to work with her arms and legs. She grimaces, becomes agitated, and sometimes cries when you move her joints. You know it is important to maintain some flexibility in her joints so that it is easier to take care of her. But you hate doing something that seems to cause her distress.