

HBEH 727, Patient Advocacy: Healing the Healthcare System

Department of Health Behavior
UNC Gillings School of Global Public Health

Fall 2012

Meeting Time: Thursdays, 2:00 pm – 4:50 pm
Location: Rosenau Room 332

Course Instructors:

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Course Purpose:

This interdisciplinary course is designed as an introduction to patient advocacy for graduate and advanced undergraduate students in the health professions at UNC. We will cover a range of topics including ethics, health policy and access, advocacy for special populations, and patient-centric approaches to health system change across all junctures of the U.S. health system. Students will have the opportunity to explore multiple perspectives through guest lectures, discussion, a brief advocacy volunteer experience, interviews with patients, providers or caregivers, analyzing the advocacy agendas of different types of organizations, developing a well-crafted op-ed, and by developing a “pitch” for legislative change to a state legislator on the topic of your choice. By emphasizing the possibility for creative micro- and macro-level solutions to patient care issues, and by providing concrete examples of successful strategies as practiced by the local and national advocates who will be our guest speakers, we hope that students will come away with a deeper understanding of issues related to advocacy and the ability to apply what they have learned in practical ways.

Course Description:

Patient advocacy has been emerging in recent years in response to widespread structural problems in the health care system. In particular, concerns about health care access, quality and equity have prompted the creation of health advocacy organizations as well as a vigorous interest in advocacy among individuals working within health care institutions. The overarching goal of the course will be to expose students to as many different aspects of advocacy and advocacy strategies, as possible, at multiple levels of the socio-ecological framework.

A patient advocate is someone whose primary goal is to act in the best interests of patients, who, weakened by illness, are often unable to advocate for themselves. Advocates may serve one specific individual or an entire category of people such as breast cancer patients, elderly nursing home residents, or terminally ill children. They may seek change at the individual, community, institutional, or policy levels. And they may target their efforts at various junctures of the health system, from increasing access to primary healthcare, to improving patient experience once individuals and populations have accessed care, to improving conditions for those residing in institutions such as long-term care or mental health facilities. Grassroots organizations, government agencies, national and local non-profits, internet support groups, online resources, medical schools, local family practices, parents and patients themselves all play a vital role in advocacy efforts. This course will prompt students to examine the “how’s” and “why’s” that lead many individuals to transfer their involvement from self-advocacy or advocacy on behalf of loved-ones to advocacy on a larger scale.

The course will begin by exploring concepts central to patient advocacy and some of the historical and theoretical foundations of the field. Students will examine some of the ethical issues that permeate all dimensions of patient advocacy, including access to care, patient safety, and health inequality. We will look at social and cultural issues, racial and socioeconomic disparities, and the impact that these factors have on health and the experience of health care. Illness narratives, guest speakers, interviews, and class discussions will facilitate a multi-dimensional understanding of illness from the perspective of the patient, caregiver, and provider. The course will examine potential solutions as well as problems, focusing on creative innovations that are currently making a difference in patient care. Students will also learn about the central role that communication plays in advocacy.

Because patient advocacy is inherently pragmatic, students will have the opportunity to identify and follow through with a brief volunteer placement (in pairs or groups of 3) that will allow them to put what they are learning about patient advocacy into practice. Students will also have the opportunity to analyze the advocacy campaigns of the patient advocacy organization of their choice, as well as develop talking points for the issue of their choice, to be used in “pitching” a change in legislation to a state legislator. Ideally, talking points will be connected to the course’s final written assignment, an Op-Ed. Both assignments are designed to help students synthesize course material, apply their learning to an issue of interest, and practice two powerful forms of advocacy.

Course Learning Objectives:

As participants in this course, students will . . .

1. Be able to define patient advocacy in several different ways.
2. Identify and apply ethical principles to the practice of patient advocacy, and distinguish these from ethical frameworks used in medicine and public health. Specifically we will examine ethics as they relate to health care access, health disparities, patient safety, vulnerable populations, and clinical research.
3. Explore factors that contribute to medical errors and, more broadly, communication breakdown among patients and providers and across health systems. Specify ways in which the movement to improve health care quality is influencing current ideas for system change.
4. Explore human illness from the perspective of patient, physician, caregiver, and self. Discover ways in which the health care system can be improved by incorporating aspects of the patient voice.
5. Define “patient-centered care”/“family-centered care”/ and “patient directed care” and describe how this philosophy differs from a more traditional biomedical approach.

6. Identify tools and approaches employed by patient advocates, including clinical advocacy, media advocacy, motivational interviewing, institutional change, community organizing, and policy-making.
7. Identify methods for practicing patient advocacy in a culturally competent manner, focusing on the needs of vulnerable, minority, and underserved populations.
8. Develop patient advocacy skills (as described above) in a conscious way through a brief volunteer experience conducted in a structured setting.
9. Develop media advocacy skills by writing a persuasive op-ed on a topic of interest to you. This piece will help the student synthesize knowledge from course readings, lectures, discussions, interviews, volunteer experience, and other outside sources.
10. Develop legislative advocacy skills by researching, and making a “pitch” for change to a state legislator on the (public) health/patient advocacy topic of your choice.

Required Textbooks and Additional Materials:

The primary textbook for this course will be *Patient Advocacy for Health Care Quality: Strategies for Achieving Patient-Centered Care*, edited by Earp, J.L., French, E.A. & Gilkey, M.B., published by Jones and Bartlett (2007). This book can either be purchased at the Health Affairs bookstore or online. Students will also be asked to obtain a copy of the play *Wit* by Margaret Edson. All other course readings are available via Sakai. Readings are posted under *Course Documents* according to due date.

Grading:

Assignment	Points	Due Dates
Class Participation Attendance & Contributions to regular class discussion Discussion Questions x 3	15 12 3	Ongoing
Interview Interview Presentation Interview Paper	30 10 20	9/27 and 10/04 10/11
Final Paper (Op Ed)	20	November 15
Volunteer Experience (10 hr) and Brief Report Volunteer Experience Brief Report	15 10 5	November 29
“Pitch” to state legislator	20	December 6
TOTAL	100	

Honor Code:

All students are expected to abide by the Honor Code for the University of North Carolina at Chapel Hill (<http://honor.unc.edu/honor/index.html>). Specific instructions regarding academic dishonesty may be found in the *Instrument of Student Judicial Governance*, Section II. B. (<http://instrument.unc.edu/>). Please speak with one of the instructors if you have any questions about these policies and procedures.

Note: most problems with plagiarism in any or all its forms (including patchwork plagiarism) come as a result of (a) not giving yourself enough time to complete a written assignment; and (b) not giving yourself enough time to be in thorough command of the concepts and material you are working with. Writing is a challenge at any level: start early. Be aware that instructors may submit your work to www.turnitin.com, an online academic plagiarism detector, if we suspect a case of plagiarism.

Class Participation:

1. **Attendance:** Students are expected to attend class each week. Please notify our TA, Nakeva Wilkins, in advance of any planned absences. Unexplained absences, and absences without prior notification to the instructor(s), will be reflected in the student's final class participation grade.
2. **Class Participation:** Participation in class discussion may encompass several different components including active listening, asking questions, sharing ideas, being respectful of different perspectives, encouraging others to speak, helping to facilitate small group discussion, etc. For those of you who are shy, you should push yourselves to speak up. For those of you who speak freely, consider using this comfort level with public discourse to encourage others to speak up.
3. **Discussion Questions.** (See below).

Assignments:

1. **Assigned Readings:** Please complete all readings assigned for a specific date prior to coming to class.
2. **Discussion Forum Questions:** To facilitate active engagement with course readings, students will submit one or more discussion questions in time for at least 3 of our 13 class sessions. This task will require planning ahead, because they will be **due to the TA at 9:00 am on the Wednesday before class via Sakai, under "class discussions."** Please write discussion questions that are specific, will likely prompt discussion, and that draw from course content or readings. Your question need not be long. The goal is to help us frame our discussion during class by raising issues that can be discussed in depth with your peers.
3. **Interview, Presentation and Analytical Reflection Paper (30 points) (Paper Due Thursday, Oct. 11):**
Students will conduct one interview with a patient, a professional advocate, or family caregiver. They will select an individual who falls into one of these three categories, conduct the interview, present their interview experience to the class, and write a brief analytical paper on that interview (there will be a handout on this). Students should design their own interview guides. The questions listed below are provided as suggestions.

A. Interview:

Interview a patient:

How has your life changed because of your illness? How have your relationships with other people changed? What has been the most difficult aspect of being or having been ill? What has surprised you? Have you experienced any unexpected benefits as a result of your illness? What have your providers done really well? What could be improved about the medical care you have received? Have you tried to communicate with your doctors (or hospitals) about how they might provide better care? How did they respond? What was the end result? What do you wish that others (i.e. your caregivers, healthcare providers, family members, society as whole) could understand about what it's like for you to be a patient? What do patients need or want that they do not currently receive? How could healthcare be improved for other patients like you? What kinds of issues "keep you up at night" with worry or frustration?

Interview a professional advocate:

What makes a good patient advocate? What character qualities should an advocate have? Give some examples of how these qualities have played out in an unfolding situation. How might these same qualities "backfire"? What special skills might a patient advocate need to develop? [And what special skills did you need to develop when you became an advocate?] What are some of the greatest challenges (provide examples)? What ethical issues have you had to confront as an advocate, and how have you resolved them? What kinds of patient advocacy issues/situations "keep you up at night" with worry or frustration?

Interview a family caregiver:

How do family members/friends function as patient advocates? What are some of the unique challenges and benefits associated with this type of arrangement? What has it been like for you to interact with physicians, nurses, other healthcare providers? What strengths do you feel are most important to develop as a patient advocate? What do you wish that others (i.e. your caregiver, healthcare providers, and/or society as a whole) could understand about your role as a caregiver? How might you educate them about your experience? What have you learned from your experience? What kinds of issues “keep you up at night” from worry or frustration?

B. In-Class Presentation:

If your interviewee had been invited as a guest speaker for our course, what would he or she want to share? What do your classmates need to know in order to better address the needs of someone like your interviewee? Prepare a ten minute in-class presentation about your interview experience. Spend no more than five minutes describing the interviewee and allot the remainder of the time to sharing your reactions, reflections, lessons learned, and ideas for change from the interview. You do not need to prepare slides for the presentation, but it should be well organized, succinct, and make several well-thought through points.

C. Paper:

Write a 3-page analytical reflection paper based on your interview experience.

- Write no more than one page describing your interviewee. Whom did you interview? What is his or her story?
- Spend the last 2 pages analyzing your interview experience and the insights you gained. Questions you might explore include the following:
 1. In what ways did the information shared by your interviewee fit with preconceived notions you had of patients? Of caregivers? Of advocates?
 2. Did you have any insights about what kind of advocacy (if any) the individual participated in? Its effectiveness?
 3. Did you share your interviewee’s “reading” of events, or did your interpretations differ somewhat, and why?
 4. What might you want to change (personal practice, organizational culture, provider education and training, etc.) as a result of your interview? How might you facilitate that change? In what ways does this individual’s interpretation of his/her experience accord with your background knowledge? In what ways does it diverge?
- The paper is due **Thursday, October 11**. It should be 3 pages, typed, double-spaced, using a 12 point font, with one inch margins. Include references as applicable. We will give you some pointers on writing short essays as the semester progresses.

4. Volunteer Experience (15 points): The volunteer experience should be completed, with the report submitted, by Thursday, November 29. Patient advocacy is pragmatic in that it is responsive to immediate and long-term problems; it requires long-term strategy and short term tactics. To help deepen students’ grasp of (and skill with) patient advocacy concepts and practices, all students will carry out a brief patient advocacy volunteer experience. The goal of this assignment is to help students relate what they are learning about in readings, lectures, class discussion, and guest speaker presentations with what it is like to practice patient advocacy on the ground in an area that is of interest to them. Students have room for creativity with this assignment; however, in the interest of efficiency, we recommend working in pairs or groups of three. This will streamline the process of identifying practicum opportunities and will help students tackle a substantive advocacy assignment.

- If students are already volunteering/engaging in advocacy for a particular organization, they may continue working with that organization for this assignment. **However, this assignment should represent an effort that is distinct from previous or ongoing work with the organization.**
- The volunteer experience will encompass a minimum of 10 hours. Brief proposals for volunteer placements, and what will be accomplished during the placement, should be submitted at the beginning of class on **09/6/12**.

- Upon completion of the volunteer placement, each student or student team will submit a brief report detailing the nature of the work completed and his/her reflections about the experience. If the experience resulted in a product (an op-ed; an interview guide; a tip sheet, etc.), please submit that product with the report. All volunteer reports will include the dates and hours worked, a brief description of the work, the name and address of the organization, and the signature of the mentor or supervisor. This report is due at the beginning of class on 11/29/12.

Note: some students may wish to take advantage of the fact that course instructors have already lined up 5 different volunteer opportunities. Each of those opportunities can accommodate 2-4 students. Course instructors cannot promise students a placement in these pre-arranged volunteer opportunities, but will try to accommodate student interests, as feasible.

5. **Final Paper (20 points):** The op-ed assignment is designed to help students synthesize course content and apply it practically to their own fields of study and/or special interest areas. It will be due on 11/15/12. It should be 3 pages, typed, double spaced, 12 point font, with one inch margins, and should be followed by a bibliography. Please use a standard citation format (MLA, APA). This paper will be due at the beginning of the class period. **Late papers will not be accepted.** If circumstances result in the need for a late paper, prior arrangements for this possibility **must** be made with the course directors.

Assignment Specifics:

Identify one specific change that you believe would improve health care for patients, providers, and/or the system as a whole. Then write an op-ed piece for the *Raleigh News and Observer* (3 double-spaced pages maximum). To prepare for this assignment, read other op-ed pieces that have already been published, identifying what you like and don't like about each opinion piece.

- Consider the following questions as you structure your argument: How can you frame your message in order to get your readers' attention? How do you want them to respond? Create a simple, persuasive, and well-developed argument to advocate for the change you have identified.
- Append a bibliography of secondary sources used for your Op-Ed.
- Make sure your topic is sufficiently focused and clear by crafting an effective thesis statement.

Bad thesis statement: All doctors should provide patient-centered care.

Better thesis statement: Medical school curricula should require all students to pass at least one course in patient-centered communication skills before they graduate.

Additional (better) sample thesis statements:

- Even small co-pays may prevent eligible families from enrolling their kids into the State Children's Health Insurance Program (SCHIP) and should be eliminated.
- State law should be changed so that occupational therapists can be reimbursed for providing orthotics to patients.

6. **Final Exam** (Thursday, December 8th at 2:00 PM or TBD): There will be no final exam in this course. However, we will meet for 3 hours during the final exam time. During this class, you will be asked to **team up with one or two other class members** to role play a legislative "pitch" focused on a patient advocacy issue of your choice. In other words, you will prepare talking

points for a meeting with a state legislator. You will have **12 minutes** with that legislator (including pleasantries and answering questions the legislator may have). Your overall goal is to raise the legislator's awareness of, and gain buy-in for, legislation on (or funding for) a particular issue that you have researched. The "pitch" should be timely in that what you're asking for is a real need at this time. Dimensions to consider when preparing for your meeting include:

- What specific outcome do you want to achieve (Legislation? Funding?)
- What is the quickest, clearest, highest-impact way of orienting the legislator to the problem?
- What is your solution?
- How will your solution help solve the problem?
- What questions might a legislator ask following your initial pitch?
- What are some reasons the legislator might not want to support your pitch?
- Who are some of your natural allies (coalitions) in this enterprise? How would they feel about your proposal?
- How can you frame your pitch in an environment where you can guarantee that there will be no new taxes?

For this assignment, we will invite two state legislators to our class. We will share profiles of them (i.e., their background and political interests/agendas) with you so that you will be able to tailor your pitch to the individual you'll be facing.

Students' pitches will be evaluated based on a rubric, which we will share with you when we discuss the assignment.

We recommend that you practice your talking points with friends as a way of preparing for this assignment. We also recommend that you streamline your work on this (and other) assignment(s) by having your volunteer experience, Op-Ed, and the legislative pitch focus on the same topic, if this is feasible.

Attendance is required. Food will be provided.

Note: Ideally, students can dovetail assignments. In other words, if a student is interested in issues of aging, s/he may wish to interview her grandmother (or her grandmother's caretaker), do the advocacy volunteer placement with an organization that focuses on aging, and then write the op-ed and do the legislative pitch on a timely issue related to this larger topic. This dovetailing of assignments is not required, but such an approach would be strategic in that you would develop expertise in an interest area even as you practice your advocacy skills focused on an issue that is important to you. The one possible roadblock to this approach is the fact that you **must** team up with another class-mate for your legislative pitches, and we **recommend** that you team up with another classmate (or two) for your volunteer experience.