

Research Methods in Palliative Care
Course Director: Robert Arnold, M.D.

This special methods course will provide the critical bridge between the more general research skills, which are the focus of the CRTP, and the particular challenges of doing patient-oriented research in palliative care. This 1-credit course, along with “Principles and Practice of Palliative Care,” is the cornerstone of the CRTP Concentration in Palliative Care. It consists of the following components:

- Discussion of the use of specific research methods and their strengths and limitations in palliative care;
- Review of landmark research articles in palliative care and a critical appraisal of the methodologies;

The course is taught in a graduate seminar fashion with an emphasis on discussion and critical analysis. Sessions are often be co-moderated by a palliative care physician and a researcher with the particular methodological expertise under discussion.

The learning objectives for the 16-hour, 8-session course include:

- Describe the various research methods that are commonly used in palliative care;
- Describe the unique methodological issues raised by research in palliative care.
- Describe the unique ethical issues raised by research in palliative care;
- Describe some of the major research papers in palliative care.

Evaluation:

Students will be evaluated on the basis of their active engagement with assigned readings and their ability to apply the course material to a palliative care research project of their own. **As written exercises, students will (1) write weekly critical reviews of published articles in terms of methods and results; and (2) at the mid-point in the course will write the Specific Aims for a research project in palliative care.**

Session 1: Introduction/ Ethical and logistic issues raised by research in palliative care
Instructor: David Barnard, Ph.D.

Learning Objectives:

1. To describe three unique ethical problems in using palliative care subjects for research
2. To describe three unique ethical issues associated with informed consent in palliative care research
3. To describe ways to deal with the unique ethical issues associated with palliative care research
4. To describe logistical issues associated with the enrollment of patients into palliative care studies
5. To describe the ethical issues associated with doing a placebo controlled study of AHBR cream for N/V in home hospice patients

Required Reading:

1. Casarett D FB, Kirchling J, Levetown M, Merriman MP, Ramey M, Silverman P. NHCOP Task force statement on the ethics of hospice participation in research. *J of Pall Med.* 2001;4(4):441-450.
 2. Cassarett D, Knebel A, Helmers K, eds. Ethical Challenges of Palliative Care Research: *J Pain Symptom Management*; 2003; No. 25.
-

Session 2: Symptom focused research in palliative care

Instructor: Robert Arnold, M.D.

- Epidemiological reviews of symptom focused research
- Interventional studies of symptom focused research

Learning Objectives:

1. To describe two different validated instruments for assessing symptoms in palliative care symptoms
2. To describe the methodological issues associated with clinical trials designed to decrease symptoms in individual patients
3. To critical review the studies of antidepressants for neuropathic pain
4. To design a new study of an antidepressant for metastatic cancer related neuropathic pain

Required Reading:

1. <http://www.symptomresearch.nih.gov>; Chapter 1-3
2. Max MB. How to move pain and symptom research from the margin to the mainstream. *J Pain*. 2003; 4:355-360.
3. Von Gunten, CF. Interventions to manage symptoms at the end of life. *J Pall Med* 8: (s1):

Suggested Reading:

1. <http://www.chcr.brown.edu/pcoc/BIBLIOGRAPHIES.HTM>
2. <http://www.symptomresearch.nih.gov>; Chapter 6 and 19
3. Dy, S. M., S. M. Asch, et al. (2008). Evidence-Based Standards for Cancer Pain Management. *J Clin Oncol* 26(23): 3879-3885.
4. Dy, S. M., K. A. Lorenz, et al. (2008). Evidence-Based Recommendations for Cancer Fatigue, Anorexia, Depression, and Dyspnea. *J Clin Oncol* 26(23): 3886-3895.
5. *J Pall Med*. V8: (suppl)
6. End of life care and outcomes.
<http://www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=hstat1a.chapter.77852>

Session 3: Quality of life/dying/patient preferences in palliative care research

Instructor: Judith Erlen, R.N., Ph.D.

Learning Objectives:

1. To describe the positive and negatives of the various instruments used to measure quality of life in end-of-life care
2. To describe the analytical issues which complicate measuring patient assessed quality of life in palliative care
3. To describe the methodological issues involved in using surrogate's assessment in palliative care research
4. To design a study examining the effect of discussions of advance care planning on the quality of life of patients with metastatic cancer and their families.

Required Reading:

1. Addington-hall J, McPherson C. After-Death Interviews with Surrogates/Bereaved Family Members: Some Issues of Validity. *Journal of Pain and Symptom Management*. 2001; 22(3):784-790.
2. Kristjanson L. Validity and reliability testing of the famcare scale: measuring family satisfaction with advanced cancer care. *Soc Sci Med*. 1993; 36(5):693-701.
3. Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: observations of patients, families, and providers. *Ann Intern Med*. 2000;132(10):825-832.

Suggested Reading:

1. Sulmasy D, McIlvane J. Patients' rating of quality and satisfaction with care at the end of life. *Arch Int Med.* 2002; 162(18):2098-2104.
 2. Singer PA, Martin D, Kelner M. Quality end-of-life care: Patient perspectives. *JAMA.* 1999; 281(2):163-168.
 3. <http://www.chcr.brown.edu/pcoc/Quality.htm>
-

Session 4: Communication research in palliative care**Instructor: Robert Arnold, M.D.**

- Focus group research focused on communication skills
- Observational research on doctor-patient communication skills
- Patient preference studies regarding communication

Learning Objectives:

1. To describe the various research methods that have been used to assess communication in palliative care
2. To critically assess the positive and negatives of the various research methods designed to study communication in palliative care
3. To design a study using either focus groups, patient survey or observation to assess communication regarding prognosis and end-of-life topics with patients with congestive heart failure

Required Reading:

1. Koropchak, C, Pollack, KI, Arnold RM et al. Studying communication in oncologist-patient encounters. *Palliat Med* 2006; 20; 813
2. Roter, D., Observations on methodological and measurement challenges in the assessment of communication during medical exchanges. *Patient Educ Couns*, 2003. 50(1): p. 17-21.
3. Curtis, J.R., et al., Studying communication about end-of-life care during the ICU family conference: development of a framework. *J Crit Care*, 2002. 17(3): p. 147-60.
4. Butow PN KJ, Beeney LJ, Griffin A, Dunn SM, Tattersall MHN. When the diagnosis is cancer: patient communication experiences and preferences. *Cancer.* 1996; 77:2630-2637.
5. Tulsky, JA Interventions to enhance communication among patients, providers and families. *J Pall Med.* 2005; 8(suppl 1)

Suggested Reading:

1. Sandvik, M., et al., Analyzing medical dialogues: strength and weakness of Roter's interaction analysis system (RIAS). *Patient Education and Counseling*, 2002. 46(4): p. 235-241.
 2. Roter, D. and S. Larson, The Roter interaction analysis system (RIAS): utility and flexibility for analysis of medical interactions. *Patient Education and Counseling*, 2002. 46(4): p. 243-251.
 3. Detmar SB MM, Wever LD, Schornagel JH, Aaronson NK. Patient-physician communication during outpatient palliative treatment visits. *JAMA*. 2001;285(10):1351-1357.
 4. Ford S, Hall A, Ratcliffe D, Fallowfield L. The medical interaction process system (MIPS): an instrument for analyzing interview of oncologists and patients with cancer. *Social Science Medicine*. 2000; 50:553-566.
-

Session 5: Caregiver research**Instructors: Richard Schulz, PhD**

- Health effects of care giving
- Bereavement in the context of care giving
- Preparedness for death
- Qualitative and quantitative methods used to study care giving

Learning Objectives:

1. To describe the various tools for measuring the effects of bereavement, strategies for conducting bereavement research
2. To describe the health effects of care giving and how bereavement impacts caregivers
3. To describe three major methodological issues associated with conducted bereavement research
4. To develop a study examining how pre-death interventions might affect the bereavement process

Required Reading:

1. Schulz, R., Boerner, K., & Hebert, R.S. (2008). Caregiving and bereavement. In M.S. Stroebe, R.O. Hansson, H. Schut, & W. Stroebe. *Handbook of Bereavement Research and Practice: 21st Century Perspectives*. Washington, DC: American Psychological Association Press.

2. Schulz, R., & Beach, S. (1999). Caregiving as a risk factor for mortality. The caregiver health effects study. *Journal of the American Medical Association*, 282, 2215-2219.
3. Schulz, R., Mendelsohn, A.B., Haley, W.E., Mahoney, D., Allen, R.S., Zhang, S., Thompson, L., & Belle, S.H. (2003). End of life care and the effects of bereavement on family caregivers of persons with dementia. *New England Journal of Medicine*, 349(20), 1936-1942.

Suggested Reading:

1. Prigerson HG, Maciejewski PK, Reynolds C, et al. Inventory of Complicated Grief: A Scale to Measure Maladaptive Symptoms of Loss. *Psychiatry Research*. 1995;59:65-79
 2. <http://www.chcr.brown.edu/pcoc/Griefa.htm>
-

Session 6: Quality improvement/system change research in palliative care

Instructor: Mark Roberts, M.D.

- Measuring the impact of palliative care services

Learning Objectives:

1. To describe the process of rapid sequence quality improvement
2. To describe the methodological issues associated with quality improvement research
3. To design a study to determine if the quality of dying has been improved by a palliative care service OR to determine if the quality improvement process in a nursing home has improved pain management in nursing home patients

Required Reading:

1. Fortner B, Oken T, Ashley J, et al. The zero acceptance of pain quality improvement project. *J Pain Symp Management*. 2003; 25(4):334-342.
 2. Lynn J, et al. Reforming care for persons near the end of life: the promise of quality improvement. *Ann Inter Med*. 2002; 137(2): E-117- E-122.
 3. Weissman DE, Griffe J, Gordon DB, Dahl JL. A Role Model Program to Promote Institutional Changes for Management of Acute and Cancer Pain. *Journal of Pain and Symptom Management*. 1997; 14(5):274-279.
-

Session 7: Education Research

Instructors: David Barnard, Ph.D. and Robert Arnold, M.D.

Learning Objectives:

1. To describe the variables that one would want to measure when assessing palliative care education

2. To describe the advantages and disadvantages of using survey, focus group and observational methodologies to assess students' education in palliative care
3. To design a study examining the influence of the "informal curriculum" on students' palliative care education.

Required Reading:

1. Sullivan A, Lakoma M, Block S. The status of medical education in end-of-life care: A national report. *JGIM*. 2003; 18(9):685-696.
2. Ury WA, Rahn M, Tolentino V, al e. Can a Pain Management and Palliative Care Curriculum Improve the Opioid Prescribing Practices of Medical Residents? *JGIM*. 2002; 17(8):625-631.
3. Ury WA, Reznich CB, Weber CM. A needs assessment for a palliative care curriculum. *J Pain Symptom Manage*. 2000; 20(6):408-416.
4. Fallowfield L JV, Farewell V, Saul J, Duffy A, Eves R. Efficacy of a cancer research UK communication skills training model for oncologists: a randomized controlled trial. *Lancet*. 2002; 359(9307):650-656.
5. Saunderson EM. General practitioners' beliefs and attitudes about how to respond to death and bereavement: qualitative study. *Br Med J*. 1999; 319:293-296.
6. Schneiderman LJ, Kaplan RM, Pearlman RA, al. e. Do physicians' own preferences for life-sustaining treatment influence their perceptions of patients' preferences? *J Clin Ethics*. 1993; 4:28-33.
7. Furstenberg CT, Ahles TA, Whedon MB, et al. Knowledge and Attitudes of Health-Care Providers Toward Cancer Pain Management: A Comparison of Physicians, Nurses, and Pharmacists in the State of New Hampshire. *Journal of Pain and Symptom Management*. 1998; 15(6):335-349.

Suggested Reading:

1. Lasch K GA, Wilkes G, Carr D, Lee M, Blanchard R. Why study pain? A qualitative analysis of medical and nursing faculty and student's knowledge of and attitudes to cancer pain management. *J Pall Med*. 2002; 5(1):57-73.
2. <http://symptomresearch.nih.gov/index.htm> Chapter 7
3. Sulmasy D. A Randomized Trial of Ethics Education for Medical House Officers. *Journal of Medical Ethics*. 1993; 19:157-163.
4. Prystowsky JB, Bordage G. An outcomes research perspective on medical education: the predominance of trainee assessment and satisfaction. [see

comment]. [Review] [5 refs] [Journal Article. Review] *Medical Education*. 35(4):331-6, 2001 Apr.

Session 8: Health service research in palliative care

Instructor: Amber Barnato, M.D., M.P.H.

- Variations in health care utilization using large databases
- Organizational variables in palliative care
- Economic analysis in palliative care

Learning Objectives:

1. To describe the various national databases for examining palliative care variables
2. To describe some of the methods that can be used to assess the impact of organizational variables in end of life care
3. To describe the methodological issues associated with economic analysis in palliative care

Required Reading:

1. Peruse the Dartmouth Atlas of Health Care, <http://www.dartmouthatlas.org/>. Use the “Data Table” function to compare end-of-life health services utilization in the Pittsburgh HRR to another HRR of interest to you, and to compare hospitals within Pittsburgh’s HRR.
2. Bach PB, Schrag D, Begg CB. Resurrecting treatment histories of dead patients: a study design that should be laid to rest. *JAMA*. 2004; 292(22):2765-70.
3. Lin C, Farrell MH, Lave JR, Angus DC, Barnato AE. Organizational determinants of hospital end-of-life treatment intensity. *Med Care*. In press.
4. Bryce CL, Loewenstein G, Arnold RM, Schooler J, Wax RS, Angus DC. Quality of death: assessing the importance placed on end-of-life treatment in the intensive-care unit. *Med Care*. 2004; 42(5):423-31.

Suggested Reading:

1. http://symptomresearch.nih.gov/chapter_10/index.htm
2. http://symptomresearch.nih.gov/chapter_12/index.htm
3. http://symptomresearch.nih.gov/chapter_18/index.htm
4. <http://www.dartmouthatlas.org>

General Resources:

In addition to the specific readings assigned for particular classes, we expect that trainees will be familiar with the following resources which they will use throughout their time in the program.

1. NIH State-of-the-Science Conference on Improving End-of-Life Care
<http://consensus.nih.gov/PREVIOUSSTATEMENTS.htm#EndOfLifeCare>
<http://symptomresearch.nih.gov/index.htm> (To view the webcasts as well as download both the AHCPR reports and the speaker summaries)
<http://symptomresearch.nih.gov/index.htm>
2. Rubenfeld GD, Curtis JR. End-of-Life care in the intensive care unit: A research agenda. *Crit Care Med.* 2001;29(10):2001-2006.
3. Phillips, RS, Hamel, MB, Covinsky, KE, Lynn, J. Findings from SUPPORT and HELP. *JAGS.* 2000: 48(5S) 1-233.
4. Portenoy R, Bruera E, eds. *Issues in palliative care research.* New York: Oxford University Press; 2003
5. <http://www.chcr.brown.edu/pcoc/toolkit.htm>