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Principles of Shared Decision Making and Health Literacy in the Clinical Setting

Spring 2012

Mondays 9-12 am, January 23 – April 30

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Overview:

This course will provide a comprehensive introduction to principles of shared decision making and health literacy and their implications for clinical communication. Topics will include basic and applied research on shared decision making, principles of designing and evaluating patient decision aids, principles of health literacy, research on relationship between health literacy, numeracy, and health outcomes, best practices for communication with individuals who have limited numeracy or health literacy, best practices (and controversies) in communicating probabilities and their associated uncertainty about screening and treatment outcomes, and best practices for designing and evaluating written information for clinical populations (such as intake forms, brochures, and informed consent documents).

Course activities will include interactive lectures, class discussions, class member presentations, guest presentations, and class activities.

Each *class activity* will be prepared by the instructors or by guest speakers.

Evaluation: Grades will be based on two class presentations (40%), class participation (10%), and a final paper due on the last day of classes (50%).

Class member presentations: Class members will give two presentations during the course:

(1) Class members will sign up to present a project of their choice (relevant to one of the course topics) to receive feedback from the class and instructors. The presentation can include a “work in progress” or a more finished product. These presentations can be related to the final paper, although this is not a requirement. Class members should plan to present for 15 minutes, followed by class discussion.

(2) At the end of the class, class members will present their final paper. Class members should plan to present for 20 minutes.

Final paper. The final paper will be broken down into three sections (due at different points in the semester):

- a. topic (1 paragraph), background and significance section (20%) due March 12
- b. full paper due at the start of the last class (April 30), incorporating feedback from the first submission (30%).

The final paper should be no longer than 10-15 pages double spaced using Arial font size 11 with 1” margins. The final paper can build on the first class presentation if desired. The paper topic can relate to any topic discussed during the class. There are two options for the paper:

1. An evaluation or critique of an existing strategy used in a clinic, with a solution for how to improve it based on principles of health literacy or shared decision making (or both). Possible paper structure can include a description of the problem (background/significance), a description of possible solutions, and then a selection of one solution and an explanation of how it could work to improve practice.
2. Develop a research proposal for empirically testing an intervention to improve clinical practice based on either a health literacy or shared decision making issue. The structure should include a description of the problem (background/significance), a possible solution or intervention to address the problem, and research methods that will be used to measure and evaluate the intervention.

Course note: This course can serve as a precursor to M17-531 (Decision analysis for clinical investigation and economic analysis).

BLACKBOARD

We will use Blackboard to manage our class, access assignment instructions, and post course-related questions. Blackboard can be accessed at <https://bb.wustl.edu/>. Log in with your WUSTL Key, and the course should appear on the homepage. We will use the Discussion threads for general questions related to lecture and assignments. Students should post all general questions that may be relevant to others in class to the Discussion thread. Student-specific questions should be emailed directly to the instructor(s).

Attendance

Class attendance is required. As a courtesy to other students, you are expected to arrive on time. More than two absences from class may result in a lowered grade. Do not enroll if you have more than two absences already planned. The value of the class stems from the quality of the dialog and conversations with peers and course instructors.

Health Literacy Sessions (Kaphingst)

Jan 23: What is Health Literacy?

Overview of course; definitions and components of health literacy; epidemiology of health literacy in the U.S.

Class activity: American Medical Association training and discussion

Readings:

Baker DW. The meaning and the measure of health literacy. *J. Gen. Intern. Med.* 2006;21:878-883.

Paasche-Orlow M. Caring for patients with limited health literacy. *JAMA.* 2011; 306:1122-1129.

Paasche-Orlow MK, Parker RM, Gazmararian JA, Nielsen-Bohlman LT, Rudd R. The prevalence of limited health literacy. *J. Gen. Intern. Med.* 2005;20:175-184.

Jan 30: Health Literacy Pathways (guest presenter: Melody Goodman, MS, PhD)

Associations between health literacy, health outcomes, and health services use; possible mechanisms; health disparities and health literacy

Class activities: Discussion of pathways by which health literacy impacts health outcomes; discussion with Dr. Goodman of variables affecting health literacy

Readings:

Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Viera A, Crotty K, Holland A, Brasure M, Lohr HN, Harden E, Tant E, Wallace I, Viswanathan M. Health Literacy Interventions and Outcomes: An Updated Systematic Review. Evidence Report/Technology Assessment No. 199. AHRQ Publication Number 11-E006. Rockville, MD: Agency for Healthcare Research and Quality, 2011. <http://www.ahrq.gov/clinic/tp/lituptp.htm#Report> Pages 25-45.

Paasche-Orlow MK, Wolf M. The causal pathways linking health literacy to health outcomes. *American Journal of Health Behavior.* 2007;31(Suppl 1):S19-S26.

Sentell TL, Halpin HA. Importance of adult literacy in understanding health disparities. *J. Gen. Intern. Med.* 2006;21:862-866.

Feb 6: Assessing Health Literacy of Patients (guest presenter: Richard Griffey, MD, MPH)

Objective health literacy measures, subjective health literacy measures, limitations of existing measures

Class activity: Assessment of health literacy skills using common measures; case example from health literacy assessment in ED by Dr. Griffey

Readings:

Mancuso JM. Assessment and measurement of health literacy: An integrative review of the literature. *Nursing and Health Sciences*. 2009;11:77-89.

Baker DW, Williams MV, Parker RM, Gazmararian JA, Nurss JR. Development of a brief test to measure functional health literacy. *Patient Educ. Couns.* 1999;38:33-42.

Chew LD, Griffin JM, Partin MR, et al. Validation of screening questions for limited health literacy in a large VA outpatient population. *J. Gen. Intern. Med.* 2008;23(5):561-566.

Feb 13: Assessing Health Literacy Demands of Health Care System

Assessment of written materials; Health literacy issues in health care system access and navigation

Class activity: Assessment of BJC environment

Readings:

Doak CC, Doak LG, Root JH. *Teaching Patients with Low Literacy Skills*. 2nd ed. Philadelphia: J.B. Lippincott Company; 1996.

<http://www.hsph.harvard.edu/healthliteracy/resources/doak-book/index.html>

Chapter 4

Rudd R. Navigating hospitals: Literacy barriers. Literacy Harvest, 2005. <http://www.hsph.harvard.edu/healthliteracy/practice/environmental-barriers/index.html>

Feb 20: Health Literacy Interventions (guest presenter: Vetta Sanders Thompson, PhD)

Health literacy interventions; State of the evidence; Directions for future research

Class activity: Discussion of educational intervention approaches with Dr. Sanders Thompson

Readings:

Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Viera A, Crotty K, Holland A, Brasure M, Lohr HN, Harden E, Tant E, Wallace I, Viswanathan M. Health Literacy Interventions and Outcomes: An Updated Systematic Review. Evidence Report/Technology Assessment No. 199. AHRQ Publication Number 11-E006. Rockville, MD: Agency for Healthcare Research and Quality, 2011. <http://www.ahrq.gov/clinic/tp/lituptp.htm#Report> Pages 143-159.

Letters responding to Low Health Literacy. *Ann. Intern. Med.* 2011; 155:793-795.

Clement S, Ibrahim S, Crichton N, Wolf M, Rowlands G. Complex interventions to improve the health of people with limited literacy: A systematic review. *Patient Educ. Couns.* 2009;75:340-351.

Shrank WH, Gleason PP, Canning C, et al. Can improved prescription medication labeling influence adherence to chronic medications? An evaluation of the Target pharmacy label. *J. Gen. Intern. Med.* 2009;24(5):570-578.

Feb 27: Health Literacy and Provider-Patient Communication (guest presenter: Amy McQueen, PhD)

Oral health literacy; health literacy and provider-patient communication; best practices in provider-patient communication

Class activity: Strategies for clear communication with patients

Readings:

Williams MV, Davis T, Parker RM, Weiss BD. The role of health literacy in patient-physician communication. *Fam. Med.* 2002;34(5):383-389.

Schillinger D, Bindman A, Wang F, Stewart A, Piette J. Functional health literacy and the quality of physician-patient communication among diabetes patients. *Patient Educ. Couns.* 2004;52:315-323.

Gallagher JM, Post DM, Weiss BD, et al. Patients' question-asking behavior during primary care visits: A report from the AAFP National Research Network. *Annals of Family Medicine.* 2010;8:151-159.

March 5: Health Literacy and SDM

Effect of health literacy on decision making preferences; Health literacy and shared decision making framework; Directions for future research

Class activity: Evaluation of a risk communication tool

Readings:

McCaffery KJ, Smith SK, Wolf M. The challenge of shared decision making among patients with lower literacy: A framework for research and development. *Med. Decis. Making.* 2010;30:35-44.

Kim SP, Knight SJ, Tomori C, Colella KM, Schoor RA, Shih L, Kuzel TM, Nadler RB, Bennett CL. Health literacy and shared decision making for prostate cancer patients with low socioeconomic status. *Cancer Investigation.* 19(7): 684-691.

Lillie SE, Brewer NT, O'Neill SC, et al. Retention and use of breast cancer recurrence risk information from genomic tests: the role of health literacy. *Cancer Epidemiol. Biomarkers Prev.* 2007;16(2):249-255.

Shared Decision Making Sessions (Politi)

March 12: What is Shared Decision Making (SDM)?

Origins of SDM/practice variation research, Core elements of SDM, SDM and health policy (AHRQ, health care reform, state policies), SDM and health outcomes, SDM and cost

Class activity: attend at least one session at the CER symposium focused on SDM (Mar 13/14)

Readings:

Wennberg, J. (2011). Time to tackle unwarranted variations in practice. *BMJ*, 342: d1513.

Fowler, F. J., Levin, C.A. et al. (2011). Informing and involving patients to improve the quality of medical decisions. *Health Affairs* 30(4): 699-706.

Makoul, G. and M. L. Clayman (2006). An integrative model of shared decision making in medical encounters. *Patient Education and Counseling*, 60(3): 301-312.

Optional: Spring, B. (2008). Health decision making: Lynchpin of evidence-based practice. *Medical Decision Making*, 28(6): 866-874.

March 19: Decision Psychology

Psychological processes affecting accuracy in medical diagnosis, heuristics, biases affecting medical decisions.

Class activity: Numerous interactive activities are incorporated into the lecture

Readings:

Ubel, P. (2010). Beyond Costs and Benefits: Understanding How Patients Make Health Care Decisions. *The Oncologist*, 15(suppl 1):5–10.

Slovic, P. & Peters, E. (2006). Risk perception and affect. *Current Directions in Psychological Science*, 15, 322-325.

Chapman, G.B., Li, M., Colby, H., & Yoon, H. (2010). Opting in versus opting out of influenza vaccination. *JAMA*, 304(1), 43-44.

Optional: Gigerenzer, G. & Gaissmaier, W. (2011). Heuristic decision making. *Annual Review of Psychology*, 62, 451-482.

Optional: Tversky, A. & Kahneman, D. (1974). Judgment under uncertainty: Heuristics and biases. *Science*, 185, 1124-1131.

March 26: Numeracy and Risk Communication—Patients

Definition of numeracy, how can it influence decision-making, numeracy and health outcomes, strategies to communicate risks to facilitate understanding

Class activity: case examples of risk communication strategies and implications of them (see Decisions of the Month)

Readings:

Fagerlin, A., Zikmund-Fisher, B.J. & Ubel, P.A. (2011). Helping Patients Decide: Ten Steps to Better Risk Communication. *Journal of the National Cancer Institute*, 103, 1436–1443

Epstein, R. M., D. N. Korones, et al. (2010). Withholding information from patients--when less is more. *New England Journal of Medicine* 362(5): 380-381.

Nelson, W., Reyna, V.F., Fagerlin, A., Lipkus, I. & Peters, E. (2008). Clinical implications of numeracy: Theory and practice. *Annals of Behavioral Medicine*, (35): 261-274.

Optional: Lipkus, I. M. (2007). Numeric, verbal, and visual formats of conveying health risks: Suggested best practices and future recommendations. *Medical Decision Making*, 27: 696-713

Optional: Woloshin, S. & Schwartz, L.M. (2011). Communicating Data About the Benefits and Harms of Treatment: A Randomized Trial. *Annals of Internal Medicine*, 155, 87-96.

April 2: Patient Decision Aids

History of PtDAs, IDPAS, how DAs are incorporated in practice (including implementation in the UK, Canada, Germany, and the US), sample DAs, evaluating PtDAs (IPDASi), who should be responsible for decision communication or administering DAs?

Class activities: evaluating a decision aid, evaluating a consultation using the OPTION scale

Readings:

O'Connor, A.M., Wennberg, J., Legare, F., Llwellyn-Thomas, H. et al. (2007). Toward the 'tipping point': decision aids and informed patient choice. *Health Affairs*, 26(3), 716-25.

Street, R. (2007). Aiding Medical Decision Making: A Communication Perspective. *Medical Decision Making*, 27, 550-553.

Elwyn G, Frosch D, Volandes AE, et al. (2010). Investing in Deliberation: A definition and classification of decision support interventions for people facing difficult health decisions. *Medical Decision Making*, 30(6), 701-11.

Nelson, W.L., Han, P.K.J., Fagerlin, A., Stefanek, M., & Ubel, P.A. (2007). Rethinking the Objectives of Decision Aids: A Call for Conceptual Clarity. *Medical Decision Making*, 27(5), 609-618.

Optional: Elwyn, G., O'Connor, A.M., Newcombe, R., Politi, M. et al. (2009). Assessing the quality of decision support technologies using the International Patient Decision Aid Standards instrument (IPDASi). *PLOS One* 4(3): e4705.

Optional: Elwyn, G., O'Connor, A.M., Stacey, D., Volk, R. et al. (2006). Developing a quality criteria framework for patient decision aids: Online international Delphi consensus process. *British Medical Journal*, 333: 417.

April 9: Risk Communication and Risk Perception—Public (guest presenter: Erika Waters, PhD, MPH)

Drug Facts Box, Data in Direct-to-Consumer Ads, Framing Effects, *Your Disease Risk*, Risk communication and the media.

Class activity: Risk Communication in the Media (Dr. Waters)

Readings:

Gigerenzer, G., Gaissmaier, W. et al. (2008). Helping doctors and patients make sense of health statistics. *Psychological Science in the Public Interest* 8(2): 53-96.

Schwartz, L.M., Woloshin, S. & Welch, H.G. (2009). Using a Drug Facts Box to Communicate Drug Benefits and Harms: Two Randomized Trials. *Annals of Internal Medicine*, 150, 516-527.

April 16: Values Clarification/Preference Elicitation Exercises (guest presenter: Liana Fraenkel, MD, MPH, Yale University School of Medicine)

utility assessments, narratives, balance sheets, diabetes cards, values during the consultation

Class activity: evaluating different types of values clarification exercises

Readings:

Epstein, R. M. and Peters, E. (2009). Beyond information: Exploring patients' preferences. *JAMA*, 302: 195-197.

Stiggelbout, A.M. & deHaas, J.C.J.M. (2001). Patient preference for cancer therapy: An overview of measurement approaches. *Journal of Clinical Oncology*, 19(1), 220-230.

Shah, N.D., Mullan, R.J., Breslin, M.A., Yawn, B.P., Ting, H.H. & Montori, V.M. (2010). Translating Comparative Effectiveness Into Practice: The Case of Diabetes Medications. *Medical Care*, 48(12), 1-6.

April 23: Informed Consent and SDM (guest presenter: Holly Taylor, PhD, Johns Hopkins University School of Public Health)

health literacy interventions for informed consent, SDM interventions for informed consent

Class Activity: Evaluating existing informed consent documents

Readings:

Entwistle V. (2008) Supporting participation in clinical research: Decision aids for trial recruitment? *Health Expectations*; 11: 205-207.

Flory J & Emanuel E. (2004) Interventions to improve research participants' understanding in informed consent for research: A systematic review. *JAMA*, 292: 1593-601.

Krumholz HM. Informed Consent to Promote Patient-Centered Care. *JAMA*. 2010; 303: 1190-1191.

Desch K, Li J, Kim S, Lavalentha N, Metzger K, Siemieniak D, Ginsburg D. (2011). Analysis of informed consent document utilization in a minimal-risk genetic study. *Annals of Internal Medicine*; 155: 316-22.

Optional: Sessums, L.L., Zembrzuska, H, & Jackson, J.L. (2011). Does This Patient Have Medical Decision-Making Capacity? *JAMA*, 306(4):420-427.

April 30: Student Paper/Project Presentations