

UNIVERSITY OF PENNSYLVANIA
SCHOOL OF SOCIAL POLICY & PRACTICE
SWRK739
Illness and Family Caregiving, Fall 2021

Instructor: Allison Werner-Lin
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Office hours: Thursdays 12-2pm

COURSE DESCRIPTION

This course provides hands-on learning opportunities for students to gain expertise in focuses on social work practice in medicine. Opportunities for learning revolve around students acquiring a robust understanding of the relationships between physical health, social environments, and psychosocial functioning. Student learning will be grounded in the biopsychosocial-spiritual model, and will address a number of domains, including the impact of illness on families over the life course, the impact of a diagnosis on family functioning, medical decision making, coping, health beliefs and spirituality, culture and social class. Classroom content will include conceptualization of illness challenges from the presentation/prevention of symptoms to the end of life, in addition to writing case material, building self-awareness and identifying clinical interface issues, and the compilation of a “clinician’s toolbox” for direct practice on the front lines.

SOCIAL WORK LEARNING OBJECTIVES

- Understand the impact of illness and family caregiving as they intersect with life course tasks and human development.
- Develop proficiency in evaluating psychosocial aspects of disease development, particularly with respect to developments in genomics and pre-symptomatic disease testing.
- Develop proficiency in basic medical terminology.
- Apply theoretical perspectives and knowledge base of social work practice in health care settings.
- Access resources and services for a variety of disorders and population groups, including identifying trustworthy and legitimate web-based resources.
- Integrate knowledge of health beliefs and the meaning of illness, disability, and loss for patients and families.
- Navigate end-of-life conversations with clients and their families.
- Understand holistic health care needs as they relates to diverse cultures and at risk populations.

INTERPROFESSIONAL LEARNING OBJECTIVES:

- Collaboration with an interprofessional team in efforts to address patient concerns and needs.
- Effectively communicate with interprofessional team to overcome professional bias and optimize the options available to patients and their families.
- Collaborate with and learn from other professionals to practice in a client-centered, culturally competent matter.

EXPECTATIONS & GRADING

Required Texts.

- McDaniel, S. H., Doherty, W. J., & Hepworth, J. (2014). *Medical family therapy and integrated care*. American Psychological Association. (Available online through library)
- Gehlert, S., & Browne, T. A. (2019). *Handbook of health social work*. Hoboken, NJ: Wiley.

Recommended texts and literature.

- Ginsberg, Nackerud, & Larris (2003). *Human biology for social workers*. Allyn & Bacon.
- Fadiman, A. (1998). *The spirit catches you and you fall down*. New York: Farrar, Straus and Giroux.
- Kleinman (1988). *The illness narratives: Suffering, healing & the human condition*. Basic Books.
- Skloot, R. (2010). *The immortal life of Henrietta Lacks*. New York, NY: Broadway Books.
- Sontag, S. (2001). *AIDS and its metaphors*. New York: Picador.

Academic Integrity. Students are expected to conduct themselves consistent with the University of Pennsylvania's Code of Academic Integrity, which presents standards regarding plagiarism, multiple submissions of academic work, and other infractions. Students are expected to be familiar with the Code, which can be found at <http://www.vpul.upenn.edu/osl/acadint.html>. Student assignments may be assessed using "Turn-it in" or other plagiarism tools. If a student is suspected of plagiarism or any other violation of academic integrity, the student will be referred to the University Office of Academic Integrity.

GRADING: ASSIGNMENT	DUE DATE	Total of 100 points
Class participation	ongoing	20 points
Ethnographic/The Biopsychosocial-Spiritual Interview	Oct 22	30 points
Healthtalk.org Pecha Kucha	Nov 11, 18, 23	30 points
Simulation Reflection	Nov 30	20 points
TOTAL		100 points

ASSIGNMENT 1: Participation in Class and Simulation (20% of grade)

- 1. Attendance is mandatory. Missing more than two classes could result in failing the course.**
Classroom learning is a fundamental component of your professional education. Students are expected to attend each class session in full. If you are unable to attend class for any reason, you must notify your instructor in advance and propose how you will make up the content you missed. If students miss 2 or more classes, including *partial* absences, the instructor will submit a course problem notice.
- 2. Come to class prepared.** Complete the assigned readings prior to each class. Demonstrate engagement with course readings and concepts through the quality and quantity of oral participation. Participate actively and relevantly in experiential exercises. Demonstrate an integration of course material with field in class and in the field.

3. **Simulation Guidelines.** Simulation provides immersive, interdisciplinary instruction to learners across levels under the guidance of expert practitioners and educators. Students are all expected to participate. Students will suspend disbelief during simulation; behave ethically, professionally, and collegially; practice skills in partnership with other learners; and receive and respond to feedback in interaction with actors and instructors.

EVALUATING WRITTEN ASSIGNMENTS. All papers are to be of second-year graduate level quality, well documented, using APA format, and submitted on time. Papers will be evaluated on the following criteria:

- Extent to which the paper follows specified requirements of the assignment
- Organization & conceptual clarity
- Incorporation and demonstrated understanding of course concepts
- Use of scholarly literature as well as evidence of critical thinking and engagement with the literature (no name dropping)
- Quality of writing (includes spelling, grammar, punctuation)
- Integration of assignment with field experiences
- Reflection on one's use of self
- Evidence of cultural awareness

ASSIGNMENT #2: Ethnographic/The Biopsychosocial-Spiritual Interview

Due October 21st to CANVAS by 11:59pm. Worth 30% of final grade

The objective of this assignment is to enhance your clinical practice skills by gaining an increased appreciation what it means to "live with" a chronic and/or life-threatening health condition.

1. **Students will work in pairs.** Select an interviewee who is **not** a client. The person should be currently living with or have survived a chronic and/or life-threatening health condition. This can be either the affected individual or a caregiver.
2. **Develop an interview guide to refer to during your interview.** Use the BioPsychoSocial Spiritual Interview chapter discussed in class as your guide. You are also encouraged to create your own questions. *Please include your interview guide as an appendix to your paper.* **Interviews should be approximately 60-75 minutes long** and conducted in person, by phone or skype/zoom.

SEPARATELY, write an 8-10 page paper. Be sure to *accurately cite relevant, recent biomedical information*. It may be helpful to search PubMed, PsychINFO, Social Services Abstracts, and other allied health databases for peer-reviewed journal articles about the participant's condition.

- a. Present your joint assessment of the participant's story. Address functioning in each of the domains (general, biomedical, psychological, social/ environmental, and spiritual).
 - b. Discuss the psychosocial features of the illness for the individual, family and social life. Address the patient's strengths and challenges in treating or managing their illness.
 - c. Consider how your participant's experience of illness has changed over time. You may use direct quotes from the informant.
 - d. Discuss the interview process, including engagement and building rapport.
 - e. Address interface issues raised during the interview, including thoughts about content and process of interview and analysis (no more than 1-2 pages).
3. Include *either* a genogram or ecomap.

ASSIGNMENT #3 Healthtalk.org Pecha Kucha Presentation

SCHEDULED IN CLASS November 11th; 18th; 23rd and materials uploaded to CANVAS by 11:59pm on presentation day. Worth 30% of final grade.

Healthtalk.org is a UK-based data archive that chronicles experiences with varied illnesses and disabilities across the life course. The website is organized by diagnostic label. Researchers conducted extensive in-person interviews with individuals impacted by each diagnosis, including an introduction to the medical terminology, procedures, and treatments. Many include video recordings of the speaker so you can hear their voice and watch their nonverbal behaviors as they talk about life-altering experiences.

****Students will discuss their identified area of practice with instructor by week 8, as there may be other recommendations for readings.**

1. **Select a topic of interest from Healthtalk.org**, review the content thoroughly.
2. **Create a “pecha kucha” presentation** on your chosen topic. A pecha kucha presentation is 6.30-minute presentation that serves as a fun teaching and learning tool for both educators and students. Write and submit a script for your pecha kucha presentation that cites at least **ten** resources including 4 or more scholarly peer-reviewed journal articles in your chosen area. Articles must be published in the last 15 years (older sources may be referenced if pertinent). In addition, relevant class readings, “popular” or fictional accounts or films, and other journal or internet sources may be selected to thoroughly review the specialized practice area.

ASSIGNMENT #4: Simulation Reflection

Due TUESDAY NOVEMBER 30 to CANVAS by 11:59pm. Worth 20% of final grade

Using APA style, and citing at least 5 references from this course syllabus or your own research, write a paper reflecting on your experiences in one of the two interprofessional simulation experiences with the School of Nursing. Consult with the IPE learning objectives for the activity.

1. **Reflection:** Reflect on your experience as a social worker, interprofessional collaborator, and as a peer. Choose 2 salient learning moments that stood out for you during the day. This learning could come from your experience of use of self, while you were acting in the sim, or in the group process/supervision with the social work and nursing students or faculty. This section should be approximately 2-3 pages.
2. **Integration:** Identify and describe 2 interventions. The first intervention should be one that you performed and the second should be one that a peer performed. Write an in-depth review of this intervention, approximately 2 pages about each. Integrate literature and course materials into each of your descriptions.
 - How was this intervention informed by literature/theory? Demonstrate an understanding of the intervention, its basis in theory/literature its use, its appropriateness with certain client populations.
 - Why do you think it was chosen given the presenting issues of the client?
 - Assess: What worked? What didn't? How could the intervention be delivered differently?
 - How did debriefing/supervision inform your thinking about this intervention, if at all?

SCHEDULE OF TOPICS with REQUIRED READINGS AND ACTIVITIES

SEPTEMBER 2 -- HISTORY OF HEALTH SOCIAL WORK

Watch before class: Netflix Original Series, *Lenox Hill*, Episode 8 "Pandemic"

Required Reading

- Gehlert, S. (2019). Conceptual Underpinnings of Social Work in Health Care. In S. Gehlert & T. A. Browne, T. A., Eds. (3-20). *Handbook of health social work. Third Edition*. Hoboken, NJ: Wiley.
- Browne, T. A. (2012). Social Work Roles and Health-Care Settings. In S. Gehlert & T. A. Browne, T. A., Eds. (21-38). *Handbook of health social work. Third Edition*. Hoboken, NJ: Wiley.
- Craig, S. L., & Muskat, B. (2013). Bouncers, brokers, and glue: The self-described roles of social workers in urban hospitals. *Health & social work, 38*(1), 7-16.
- Johnson, B. H. (2000). Family-centered care: Four decades of progress. *Families, Systems, & Health, 18*(2), 137-156.

Recommended Activity: My Family History Project <https://familyhistory.hhs.gov/FHH/html/index.html>

SEPTEMBER 9 -- BIOPSYCHOSOCIAL SPIRITUAL ASSESSMENT IN HEALTH CARE SETTINGS

Required Reading:

- McDaniel, S. H., Doherty, W. J., & Hepworth, J. (2014). *Medical family therapy and integrated care*. American Psychological Association. (Chapter 1, pp. 5-25; Chapter 3, 53-82; Chapter 7, 129-149)
- Hodgson, J., Lamson, A., Reese, L. (2007). The biopsychosocial-spiritual interview method. In Linville, D. & Hertlein, K. M. (2007). *The therapist's notebook for family health care*, pp. 3-12. Binghamton, NY: Haworth Press. (*Vital for Assignment #1*)
- Guidry-Grimes, L., Savin, K., Stramondo, J. A., Reynolds, J. M., Tsaplina, M., Burke, T. B., ... & Garland-Thomson, R. (2020). Disability Rights as a Necessary Framework for Crisis Standards of Care and the Future of Health Care. *Hastings Center Report, 50*(3), 28-32.

SEPTEMBER 16 -- THE DIAGNOSTIC ODYSSEY: THE ILLNESS LIFE CYCLE

Activity: Movie clips from *Wit*

Required Reading:

- McDaniel, S. H., Doherty, W. J., & Hepworth, J. (2014). *Medical family therapy and integrated care*. American Psychological Association. (Chapter 2, 27-52; Chapter 4, 83-93)
- Carmichael, N., Tsipis, J., Windmueller, G., Mandel, L., & Estrella, E. (2015). "Is it Going to hurt?": The impact of the diagnostic odyssey on children and their families. *Journal of genetic counseling, 24*(2), 325-335.
- American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine. (2002). A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics, 110*(Supplement 3), 1304-1306.

Recommended:

- Fadiman, A. (1998). *The spirit catches you and you fall down*. New York: Farrar, Straus and Giroux.

SEPTEMBER 23 -- HEALTH BELIEFS, SPIRITUALITY, AND ILLNESS NARRATIVES

Required Reading:

- Pentaris, P. (2019). Religion, Belief, and Spirituality in Health Care. In S. Gehlert & T. A. Browne, T. A., Eds. (279-302). *Handbook of health social work. Third Edition*. Hoboken, NJ: Wiley.
- Block, P. (2019). Developing a Shared Understanding: When Medical Patients Use Complementary and Alternative Approaches and Seek Integrative. In S. Gehlert & T. A. Browne, T. A., Eds. (303-330). *Handbook of health social work. Third Edition*. Hoboken, NJ: Wiley.
- Werner-Lin, A. & Gardner, D.S. (2009). Family illness narratives of inherited cancer risk: Continuity and transformation. *Families, Systems and Health*, 27(3), 201-212.
- Levin, J.; Chatters, L.M. & Taylor, R.J. (2005). Religion, health, and medicine in African Americans: Implications for physicians. *Journal of the National Medical Association*, 97, 237-249.

Recommended:

- Kleinman (1988). *The illness narratives: Suffering, healing & the human condition*. Basic Books.
- Sontag, S. (2001). *AIDS and its metaphors*. New York: Picador.

SEPTEMBER 30 & OCTOBER 7 -- ILLNESS AND THE FAMILY LIFE CYCLE

Activity: Movie clips from *Wit*; *Five Wishes*; Constructing an illness genogram
Simulation Preparation

- Doyle, M. (2015). Peer support and mentorship in a US rare disease community: findings from the Cystinosis in emerging adulthood study. *The Patient-Patient-Centered Outcomes Research*, 8(1), 65-73
- Hughes, M., Macica, C., Meriano, C., & Doyle, M. (2020). Giving credence to the experience of X-linked hypophosphatemia in adulthood: an interprofessional mixed-methods study. *Journal of Patient-Centered Research and Reviews*, 7(2), 176.

Required Reading October 8th:

- Carter, E. A., & McGoldrick, M. (1999). Overview: The expanded family life cycle: Individual, family, and social perspectives. In E. A. Carter & M. McGoldrick (Eds.), *The expanded family life cycle: Individual, family, and social perspectives* (3rd ed., pp. 1-26). Boston, MA: Allyn & Bacon.
- Rolland, J.S. (2019). Families and Illness. In Gehlert, S. & Arthur, T. (Eds.) *Handbook of Health Social Work*, 3rd Ed. (pp. 331-360). Wiley & Sons. San Francisco, CA.

Required Reading October 15th:

- Yvette Colón, Y. & Wladkowski, S. P. (2019) End of life care. In Gehlert, S. & Arthur, T. (Eds.) *Handbook of Health Social Work*, 2nd Ed. (pp. 569-). Wiley & Sons. San Francisco, CA.
- Steinglass, P., Ostroff, J. S., & Steinglass, A. S. (2011). Multiple family groups for adult cancer survivors & their families: A 1-day workshop model. *Family process*, 50(3), 393-409.

DUE WEDNESDAY OCTOBER 13TH -- ETHNOGRAPHIC/THE BIOPSYCHOSOCIAL-SPIRITUAL INTERVIEW

Submit to CANVAS by 11:59pm

OCTOBER 14 FALL BREAK, NO CLASS

TUESDAY OCTOBER 19 -- PALLIATIVE CARE SIMULATION

ATTENDANCE REQUIRED 7am-11am OR 12pm-4pm

Required Pre-Reading:

- Kovacs, P. J., Bellin, M. H., & Fauri, D. (2006). Family-centered care: A resource for social work in end-of-life and palliative care. *Journal of Social Work in End-of-Life & Palliative Care*, 2(1), 13-27.
- Reese, D. J., & Sontag, M. A. (2001). Successful interprofessional collaboration on the hospice team. *Health & Social Work*, 26(3), 167-175.
- Orchard, C. A., Curran, V., & Kabene, S. (2005). Creating a culture for interdisciplinary collaborative professional practice. *Medical Education Online*, 10(1), 4387.

THURSDAY OCTOBER 21 -- FAMILY PLANNING, PREGNANCY, INFERTILITY, AND ASSISTED REPRODUCTIVE TECHNOLOGY

Required Reading:

- McDaniel, S. H., Doherty, W. J., & Hepworth, J. (2014). *Medical family therapy and integrated care*. American Psychological Association. (Chapter 9, pp. 169-193)
- Brashler, R. (2019). Social Work Practice and Disability Issues. In S. Gehlert & T. A. Browne, (Eds.) *Handbook of Health Social Work*, 3rd Ed. (pp. 209-228). Hoboken, NJ: John Wiley & Sons.
- McCoy, J.L.M. (2008). "I'm not a saint": Burden assessment as an unrecognized factor in prenatal decision making. *Qualitative Health Research*, 18 (11), 1489-1500.

TUESDAY OCTOBER 26 -- INTIMATE PARTNER VIOLENCE AND PREGNANCY LOSS SIMULATION

ATTENDANCE REQUIRED 7am-11am OR 12pm-4pm

Required pre-reading

- Alvarez, C., & Fedock, G. (2018). Addressing intimate partner violence with Latina women: A call for research. *Trauma, Violence, & Abuse*, 19(4), 488-493.
- McMahon, S., & Armstrong, D. E. Y. (2012). Intimate partner violence during pregnancy: best practices for social workers. *Health & social work*, 37(1), 9-17.

OCTOBER 28 -- COUPLES AND ILLNESS: PATIENTS, PARENTS, PARTNERS

Required Reading:

- McDaniel, S. H., Doherty, W. J., & Hepworth, J. (2014). *Medical family therapy and integrated care*. American Psychological Association. (Chapter 8, 151-168)
- Robards, J., Evandrou, M., Falkingham, J., & Vlachantoni, A. (2012). Marital status, health and mortality. *Maturitas*, 73(4), 295-299.
- Williams, J. K., Skirton, H., Paulsen, J. S., Tripp-Reimer, T., Jarmon, L., McGonigal Kenney, M., ... & Honeyford, J. (2009). The emotional experiences of family carers in Huntington disease. *Journal of Advanced Nursing*, 65(4), 789-798.
- Turner, G. W. (2020). The Circles of Sexuality: Promoting a Strengths-based Model Within Social Work that Provides a Holistic Framework for Client Sexual Well-being. University of Kansas Libraries.
- Leung, M. W., Goldfarb, S., & Dizon, D. S. (2016). Communication about sexuality in advanced illness aligns with a palliative care approach to patient-centered care. *Current oncology reports*, 18(2), 11. (available through library)

TUESDAY NOVEMBER 2 -- SEXUAL HEALTH/LGBTQ SIMULATION

ATTENDANCE REQUIRED 7am-11am OR 12pm-4pm

Required Watching: **TRAINING VIDEO WITH JEFFREY JIN BEFORE SIMULATION**

Required pre-reading

- Bonvicini, KA & Perlin, MJ. (2003). The same but different: Clinician-patient communication with gay and lesbian patients. *Patient Education & Counseling*, 51; 115-122.
- Coker, T. R., Austin, S. B., & Schuster, M. A. (2010). The health and health care of lesbian, gay, and bisexual adolescents. *Annual review of public health*, 31, 457-477.
- Shukla, V., Asp, A., Dwyer, M., Georgescu, C., & Duggan, J. (2014). Barriers to healthcare in the transgender community: A case report. *LGBT health*, 1(3), 229-232.
- Fuzzell, L., Fedesco, H. N., Alexander, S. C., Fortenberry, J. D., & Shields, C. G. (2016). "I just think that doctors need to ask more questions": Sexual minority and majority adolescents' experiences talking about sexuality with healthcare providers. *Patient Education and Counseling*, 99(9), 1467-1472.

NOVEMBER 4 -- DEVELOPMENTAL CONCERNS FOR SICK CHILDREN, TEENS, AND WELL SIBS

Required Reading:

- McDaniel, S. H., Doherty, W. J., & Hepworth, J. (2014). *Medical family therapy and integrated care*. American Psychological Association. (Chapter 10, 195-212)
- Jones, B. L., Walsh, C., & Phillips, F. (2019). Social work with children and adolescents with medical conditions. In S. Gehlert & T. A. Browne, (Eds.) *Handbook of Health Social Work*, 3rd Ed. (pp. 361-380). Hoboken, NJ: John Wiley & Sons.
- Salsman, J. M., Bingen, K., Barr, R. D., & Freyer, D. R. (2019). Understanding, measuring, and addressing the financial impact of cancer on adolescents and young adults. *Pediatric blood & cancer*, e27660.
- Wiener, L., Kazak, A. E., Noll, R. B., Patenaude, A. F., & Kupst, M. J. (2015). Standards for the psychosocial care of children with cancer and their families: an introduction to the special issue. *Pediatric blood & cancer*, 62(S5), S419-S424.
- Alderfer, M. A., Long, K. A., Lown, E. A., Marsland, A. L., Ostrowski, N. L., Hock, J. M., & Ewing, L. J. (2010). Psychosocial adjustment of siblings of children with cancer: A systematic review. *Psycho-oncology*, 19(8), 789-805.

Recommended: <https://www.facebook.com/SuperSibs1/>

NOVEMBER 11 -- AGING AND THE END OF LIFE

DUE TODAY: *Pecha Kucha Presentations*

Required Reading:

- McDaniel, S. H., Doherty, W. J., & Hepworth, J. (2014). *Medical family therapy and integrated care*. American Psychological Association. (Chapter 13, 255-273)
- Balaswamy, S. Lee., S. E. Diwan, S., (2019). Social work with older adults in healthcare settings. In S. Gehlert & T. A. Browne, (Eds.) *Handbook of Health Social Work*, 3rd Ed. (pp. 381-410). Hoboken, NJ: John Wiley & Sons.
- Gardner, D. S., Doherty, M., Bates, G., Koplrow, A., & Johnson, S. (2018). Racial and ethnic disparities in palliative care: A systematic scoping review. *Families in Society*, 99(4), 301-316.

NOVEMBER 18 -- FAMILY LIFE AND THE GENETIC REVOLUTION

Watch before class: The Gene: An Intimate History, Part 2: <https://www.genome.gov/outreach/the-gene-an-intimate-story>

DUE TODAY: Pecha Kucha Presentations

Required reading:

- Werner-Lin, A., Doyle, M. H., Merrill, S. L., Gehlert, S. (2019). Social work and genetics. In S. Gehlert & T. Arthur Browne. Handbook of Health Social Work, 2nd Ed. (pp. 499-534). Wiley & Sons, San Francisco, CA
- Collins, F. S., & Varmus, H. (2015). A new initiative on precision medicine. *New England Journal of Medicine*, 372(9), 793-795.
- McDaniel, S. H., Doherty, W. J., & Hepworth, J. (2014). *Medical family therapy and integrated care*. American Psychological Association. (Chapter 12, pp. 239-253)
- NASW Standards for Integrating Genetics into Social Work Practice <http://www.naswdc.org/practice/standards/geneticsstdfinal4112003.pdf>

Recommended:

- Skloot, R., & Turpin, B. (2010). *The immortal life of Henrietta Lacks* New York: Crown Publishers.

TUESDAY NOVEMBER 23RD: THE GENOMIC REVOLUTION (CONTINUES....)

DUE TODAY: Pecha Kucha Presentations

DUE TODAY: Simulation Reflection Paper