

**CURRICULUM VITAE**  
**HELENE ELIZABETH STARKS**

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**PLACE OF BIRTH** Seattle, Washington

**EDUCATION**

- PHD** Health Services Research, School of Public Health, University of Washington, Seattle, WA.  
December 2004. Dissertation: *Dying on one's own terms: Access to care, timing of death, and effects on family members.*
- MPH** Policy & Administration, School of Public Health, University of California, Berkeley, CA. May 1989.
- BA** International Communications, School of Communications, University of Washington, Seattle, WA.  
June 1982.

**AWARDS/HONORS**

- 2003–2004 National Research Service Award (NRSA) Pre-doctoral Traineeship, Agency for Healthcare Research & Quality (AHRQ), Grant No. T32 HS-013853
- 2013 Outstanding Faculty Teaching Award, University of Washington School of Public Health

**FACULTY POSITIONS HELD**

- 2005–2010 **Assistant Professor**, Dept. of Bioethics and Humanities (formerly Dept. of Medical History & Ethics, through 10/08), University of Washington School of Medicine (UW SOM)
- 2005–2010 **Adjunct Assistant Professor**, Dept. of Health Services, UW School of Public Health (SPH)
- 2008–2011 **Associate Director of Graduate Studies**, Dept. of Bioethics & Humanities, UW SOM
- 2009–2015 **Auxiliary Faculty**, Institute for Public Health Genetics, UW SPH
- 2010–present **Associate Professor**, Dept. of Bioethics and Humanities, UW SOM
- 2010–present **Adjunct Associate Professor**, Dept. of Health Services, UW SPH
- 2011–2013 **Chair, Supervisory Board** (provided oversight for the Master of Arts in Bioethics program and completion of students' Masters Projects), Dept. of Bioethics & Humanities, UW SOM
- 2012-present **Adjunct Associate Professor**, Dept. of Family Medicine, UW SOM
- 2012-present **Director**, Metrics, Quality, and Evaluation Core, Cambia Palliative Care Center of Excellence, UW SOM
- 2013-present **Adjunct Associate Professor**, Dept. of Pediatrics, Division of Bioethics, UW SOM

**RESEARCH POSITIONS HELD**

- 1988–1989 **Research Assistant**, San Francisco Institute on Aging, Mount Zion Medical Center, San Francisco, CA
- 1989–1995 **Research Manager**, Dept. of Medicine, UW SOM
- 1992–1993 **Research Manager**, Dept. of Health Services, UW SPH
- 1995–1999 **Research Manager**, Health Services Research & Development (HSR&D), VA Puget Sound Health Care System (VAPSHCS) and Dept. of Medicine, UW SOM
- 1997–2001 **Co-Investigator/Research Manager**, Seattle Institute for Biomedical and Clinical Research, and Dept. of Medicine, UW SOM
- 2000–2001 **Dissemination and Administrative Coordinator**, HSR&D, VAPSHCS and Dept. of Health Services, UW SPH
- 2001–2002 **Research Manager**, Dept. of Medical Oncology, UW SOM
- 2001–2002 **Co-Investigator/Analyst**, HSR&D, VAPSHCS
- 2002–2004 **Research Manager**, Dept. of Medical Education & Biomedical Informatics, UW SOM

**CURRENT RESEARCH ACTIVITY**

Cambia Health Foundation: "Implementing and disseminating quality metrics for primary and specialty palliative care in inpatient and outpatient settings." J. Randall Curtis, MD MPH, Ruth Engelberg, PhD, & Helene Starks, PhD MPH (Co-PIs). 07/01/14-06/30/17. Role: Co-Principal Investigator.

National Institute on Aging, R24 AG044300: "Enhancing research capacity in geriatric palliative care." R. Sean Morrison, MD (PI). 09/30/13—08/31/18. Role: Consultant.

Stupski Foundation: "Implementation evaluation of home-based palliative care ACO pilot program." Gary Bacher, JD (PI). 02/15/17—03/01/19. Role: Co-Investigator and PI on UW subcontract.

**RESEARCH PROPOSALS UNDER REVIEW**

NIH: "Genes, the Environment, and Me: Health and STEM Network (GEMNET)." Maureen Munn, PhD, & Helene Starks, PhD MPH (Multiple PIs). Role: Co-Principal Investigator. Resubmitted for 2<sup>nd</sup> review, 06/16.

NIH: "Precision medicine and population health: public deliberation and priority setting." Erika Blacksher, PhD (PI). Role: Co-investigator. Resubmitted for 2nd review, 11/16.

Cambia Health Foundation: "Building on success: Advancing the Cambia quality metrics program and the Cambia Palliative Care Training Center." J. Randall Curtis, MD MPH & Ardith Doorenbos, PhD (Co-PIs). Role: Co-investigator. Under review, 02/17.

**COMPLETED RESEARCH**

National Center for Research Resources, 1 R25 RR032147: "Genes, the Environment, and Me." Maureen Munn, PhD, & Helene Starks, PhD MPH (Multiple PIs). 09/01/11-06/30/16. Role: Co-Principal Investigator.

Cambia Health Foundation: "Helping meet the palliative care workforce needs in Washington with a community/academic partnership." Ardith Doorenbos, PhD and Larry Mauksch, MEd (Co-PIs). 07/01/13-06/30/16. Role: Co-investigator.

National Institutes of Nursing Research Grant No. R01 NR011179, "Improving family outcomes with a communication intervention in the pediatric ICU." Ross Hays, MD (PI). 09/30/09-06/30/15. Role: Co-Investigator (and PI on UW subcontract).

National Human Genome Research Institute Grant No. P50 HG 3374: "Center for genomics and healthcare equality." Wylie Burke, MD PhD (PI). 04/01/10-03/31/15. Role: Co-Investigator & Director of Graduate Training.

National Human Genome Research Institute, R01 HG 005221: "Ethics of dissemination: Communicating with participants about genetic research." Bert Boyer, PhD & Wylie Burke, MD PhD (Dual PIs). 07/01/10-02/28/14. Role: Co-Investigator.

National Institute for General Medical Sciences, Grant No. U01 GM 092676: "Pharmacogenetics in rural and underserved populations." Ken Thummel, PhD & Wylie Burke, MD PhD (Dual PIs). 06/01/10-10/31/13. Role: Co-Investigator.

National Human Genome Research Institute, P20 HG005551: "Interdisciplinary center on epigenetics, science and society." Nancy Press, PhD (PI). Role: Consultant. 05/11/10-03/30/13

Patient-Centered Outcomes Research Institute: "Engaging stakeholders to improve depression management in a tribal health system." Renee Robinson, PharmD MPH (PI). 10/31/12-11/30/13. Role: Co-Investigator.

National Human Genome Research Institute, ARRA Challenge Grant RC1 MD 004304-03, "Engaging tribal participation in research through priority setting and regulation." Ron Whitener, JD (PI). 09/30/09-06/30/13. Role: Co-Investigator.

National Center on Minority Health Disparities Grant No. P20 MD 000173 to the Center for Native and Pacific Health Disparities Research. Center subproject: "Familial cardiomyopathy among Native Hawaiians," Todd Seto, MD (PI). 11/01/09-10/30/11. Role: Consultant.

National Palliative Care Research Center, "Palliative care consults: A mixed methods evaluation of referral processes and outcomes." Helene Starks, PhD MPH (PI). 09/01/07-09/30/10. Role: Principal Investigator.

- National Human Genome Research Institute Grant No. P50 HG 3374, "Genomic health care and the medically underserved." Wylie Burke, MD PhD (PI). 01/01/06-03/31/10. Role: Co-investigator and Director of Training.
- UW School of Nursing, Research & Intramural Funding Program, "Disclosure and stigma in Chinese HIV-positive women," Wei-Ti Chen, RN, CNM, DNSc (PI). 04/01/09-03/31/10. Role: Consultant.
- National Cancer Institute Grant No. 2R44-CA097592, "EOL Care Companion II," Eileen vanSchaik, PhD (PI). 08/09/06-12/31/09. Role: Consultant.
- U.S. Dept. of Education, National Institute on Disability & Rehabilitation Research Grant No. H133-B031129, "National research and training center on multiple sclerosis." George Kraft, MD (PI). 02/01/06-06/15/08. Role: Co-investigator (PI on sub-project on caregiving and MS).
- National Institute of Mental Health Grant No. R01 MH058986, "Peer & pager support to enhance antiretroviral adherence." Jane Simoni PhD, (PI). 10/16/06-08/31/07. Role: Co-investigator.
- National Institute on Aging Grant No. K23 AG19635, "Understanding and implementing end-of-life preferences." Elizabeth Vig, MD MPH (PI). 03/01/05-06/30/07. Role: Co-investigator and Mentor.
- National Institute of Mental Health Grant No. R34 MH074364, "Adherence research in China." Jane Simoni, PhD (PI). 07/16/05-04/30/06. Role: Co-investigator.
- Office of Research Integrity Grant No. R01 NS-44486, "Motivating integrity on research with human subjects." Wylie Burke, MD PhD (PI). 01/01/05-12/31/05. Role: Co-investigator.
- Agency for Healthcare Research & Quality Grant No. R01 HS-13172, "Effects of establishing focus in the medical interview." Lynne Robins, PhD (PI). 10/01/02-12/31/04. Role: Research Manager.
- Veterans Health Administration Clinical Initiative Grant, "Palliative care for cancer initiative." Anthony Back, MD (PI). 04/01/01-09/30/02. Role: Co-investigator.
- National Cancer Institute Grant No. R25 CA-92055, "End-of-life communication skills for medical oncology fellows." Anthony Back, MD (PI). 07/01/01-09/30/02. Role: Research Manager.
- Veterans Affairs Grant No. IHS 99-233, "Ischemic Heart Disease Quality Enhancement Research Initiative (IHD-QUERI)." Anne Sales, MSN PhD (PI). 10/01/00-09/30/01. Role: Dissemination and Administrative Coordinator.
- The Greenwall Foundation and Walter & Elise Haas Fund, "Insights into hastened death." Robert Pearlman, MD MPH (PI). 07/01/97-06/30/01. Role: Co-investigator & Research Manager.
- VA Investigator Initiated Research (IIR) Grant No. 96-047, "Evaluation of a comprehensive advance care planning intervention," Robert Pearlman, MD MPH (PI). 4/01/97 – 9/30/99. Role: Research Manager.
- VA IIR Grant No. 94-050, "Development of an advance care planning workbook," Robert Pearlman, MD MPH (PI). 4/01/95 – 3/31/97. Role: Research Manager.
- Agency for Health Care Policy & Research Grant No. HS-06343, "Long-term stability of treatment preferences," Robert Pearlman, MD MPH (PI). 09/30/89-3/31/95. Role: Research Manager.

## PUBLICATIONS

### Peer Reviewed (\* indicates mentee)

1. Pearlman RA, Cain KC, Patrick DL, **Starks HE**, Appelbaum-Maizel M, Jecker NS, Uhlmann RF. Insights pertaining to patient assessments of states worse than death. *Journal of Clinical Ethics* 1993; 4(1):33-41.
2. Patrick DL, **Starks HE**, Cain KC, Pearlman RA, Uhlmann RF. Measuring preferences for health states worse than death. *Medical Decision Making* 1994; 14(1):9-18.
3. Pearlman RA, Cole W, Patrick DL, **Starks HE**, Cain KC. Advance care planning: Eliciting patient preferences for life-sustaining treatment. *Patient Education and Counseling* 1995; 26(1-3):353-61.
4. Back AL, Wallace JI, **Starks HE**, Pearlman RA. Physician-assisted suicide and euthanasia in Washington state: Patient requests and physician responses. *JAMA*, 1996; 275(12):919-25.
5. Patrick DL, Richardson M, **Starks HE**, Rose MA, Kinne S. Rethinking prevention for people with disabilities Part II: A framework of designing interventions. *American Journal of Health Promotion*, 1997; 11(4):261-3.
6. Patrick DL, Pearlman RA, **Starks HE**, Cain KC, Cole WG, Uhlmann RF. Validation of preferences for life-sustaining treatment: Implications for advance care planning. *Annals of Internal Medicine* 1997; 127(7):509-17.

7. Pearlman RA, Cain KC, **Starks H**, Cole WG, Uhlmann RF, Patrick DL. Preferences for life-sustaining treatments in advance care planning and surrogate decision making. *Journal of Palliative Medicine* 2000; 3(1):43-54.
8. Back AL, **Starks H**, Hsu C, Gordon JR, Bharucha A, Pearlman RA. Clinician-patient interactions about requests for physician-assisted suicide: A patient and family view. *Archives of Internal Medicine*, 2002; 162(11):1257-65.
9. Ho PM, Maynard C, **Starks H**, Sun H, Sloan K, Sales A. Outcomes in patients with coronary heart disease who do not undergo lipid testing. *Journal of American Cardiology*, 2003; 91(8):986-8.
10. Bharucha AJ, Pearlman RA, Back AL, Gordon JR, **Starks H**, Hsu C. The pursuit of physician-assisted suicide: Role of psychiatric factors. *Journal of Palliative Medicine*, 2003; 6(6):873-83.
11. Sharp ND, Pineros SL, Hsu C, **Starks H**, Sales AE. A qualitative study to identify barriers and facilitators to implementation of pilot interventions in the Veterans Health Administration (VHA) Northwest Network. *Worldviews in Evidence-based Nursing*, 2004; 1(2):129-39.
12. Pearlman RA, **Starks H**, Cain KC, Cole WG. Improvements in advance care planning in the VA: Results of a multifaceted intervention. *Archives of Internal Medicine*, 2005; 165(6):667-74.
13. Pearlman RA, Hsu C, **Starks H**, Back AL, Gordon JR, Bharucha A, Koenig BA, Battin MP. Motivations for physician-assisted suicide: Patient and family voices. *Journal of General Internal Medicine*, 2005; 20(3):234-39. PMID: PMC1490083
14. **Starks H**, Pearlman RA, Hsu C, Back AL, Gordon JR, Bharucha A. Why now? Timing and circumstances of hastened deaths. *Journal of Pain and Symptom Management*, 2005; 30(3):215-26.
15. \*Vig EK, **Starks H**, Taylor JS, Hopley EH, Fryer-Edwards KA, Pearlman RA. How do surrogate decision-makers describe hospice? Does it matter? *American Journal of Hospice and Palliative Medicine*, 2006; 23(2):91-99.
16. \*Vig EK, Taylor JS, **Starks H**, Hopley EH, Fryer-Edwards KA. Beyond substituted judgment: How surrogates navigate end-of-life decision making. *Journal of the American Geriatrics Society*, 2006; 54(11):1688-93.
17. \*Deming N, Fryer-Edwards K, Dudzinski D, **Starks H**, Culver J, Robins L, Burke W. Incorporating principles and practical wisdom in research ethics education: A preliminary study. *Academic Medicine*, 2007; 82(1):1-7.
18. **Starks H**, Back AL, Koenig BA, Pearlman RA, Hsu C, Gordon JR, Bharucha A. Family member involvement in hastened death. *Death Studies*, 2007; 31(2)105-130.
19. \*Vig EK, **Starks H**, Taylor JS, Hopley EK, Fryer-Edwards K. Surviving surrogate decision making: What helps and hampers the experience of making medical decisions for others. *Journal of General Internal Medicine*, 2007; 22(9):1274-9. PMID: PMC2219771
20. **Starks H**, Trinidad SB. Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative Health Research*, 2007; 17(10):1372-80.
21. \*Chen WT, **Starks H**, Shiu CS, Fredriksen-Goldsen K, Simoni J, Zhang F, Pearson C, Zhao H. Chinese HIV-positive patients and their health care providers: Contrasting Confucian vs. Western notions of secrecy and support. *Advances in Nursing Science*, 2007; 30(4):329-42. PMID: PMC3583193
22. **Starks H**, Simoni J, Zhao H, Huang B, Fredriksen-Goldsen K, Pearson C, Chen WT, Lu L, Zhang F. Conceptualizing antiretroviral adherence in Beijing, China. *AIDS Care*, 2008; 20(6):607-14. PMID: PMC3530611
23. \*Valencia-Garcia D, **Starks H**, Simoni J, Strick L. After the fall from grace: Negotiation of new identities among HIV-positive Peruvian women. *Culture, Health and Sexuality*, 2008; 10(7):739-752. PMID: PMC2704982
24. Kraft GH, Johnson KL, Yorkston K, Amtmann D, Bamer A, Bombardier C, Ehde D, Fraser R, **Starks H**. Setting the agenda for multiple sclerosis rehabilitation research. *Multiple Sclerosis* 2008; 14(9):1292-7. [Not NIH funded]
25. **Starks H**, Diehr, P, Curtis JR. The challenge of selection bias and confounding in palliative care research. *Journal of Palliative Medicine*, 2009; 12(2):181-187. PMID: PMC2982715

26. \*Chen WT, Shiu CS, Simoni J, Fredriksen-Goldsen K, Zhang F, **Starks H**, Zhao H. Attitudes toward antiretroviral therapy and complementary and alternative medicine in Chinese patients infected with HIV. *Journal of the Association of Nurses in AIDS Care* 2009; 20(3):203-17. PMID: PMC2684986
27. \*Strong LL, **Starks HE**, Meischke H, Thompson B. Perspectives of mothers in farmworker households on reducing the take-home pathway of pesticide exposure. *Health Education and Behavior* 2009; 36(5):915-29. [Not NIH funded]
28. **Starks H**, Morris MA, Yorkston K, Gray R, Johnson K. Being in- or out-of-sync: A qualitative study of couples' adaptation to change in multiple sclerosis. *Disability and Rehabilitation* 2010; 32(3):196-206. [Not NIH-funded]
29. Lemke AA, Trinidad SB, Edwards KL, **Starks H**, Wiesner GL and the GRRIP Consortium. Attitudes toward genetic research review: Results from a national survey of professionals involved in human subjects protection. *Journal of Empirical Research on Human Research Ethics* 2010; 5(1):83-91. PMID: PMC2902178
30. \*Vig EK, **Starks H**, Taylor JS, Hopley EK, Fryer-Edwards K. Why don't patients enroll in hospice? Can we do anything about it? *Journal of General Internal Medicine* 2010; 25(10):1009-19. PMID: PMC2955487
31. \*Meacham M, **Starks H**, Burke W, Fryer-Edwards K. Researcher perspectives on disclosure of unanticipated findings in genetic research. *Journal of Empirical Research on Human Research Ethics* 2010; 5(3):31-41. PMID: PMC3413406
32. Edwards KL, Lemke AA, Trinidad SB, Lewis SM, **Starks H**, Quinn Griffin M, Wiesner GL and the GRRIP Consortium. Attitudes toward genetic research review: Results from a survey of human genetics researchers. *Public Health Genomics* 2011; 14(6):337-45. PMID: PMC3221257
33. Fredriksen-Goldsen K, Shiu CS, **Starks H**, Chen WT, Simoni J, Pearson C, Zhao H, Zhang F. "You must take the medications for you and for me": Family caregivers in China promoting HIV medication adherence. *AIDS Patient Care and STDs* 2011; 25(12):735-41. PMID: PMC3263300
34. Lemke, AA, Smith, ME, Wolf, WA, Trinidad, SB, and the GRRIP Consortium. Broad data sharing in genetic research: views of IRB professionals. *IRB: Ethics and Human Research* 2011; 33(3):1-5. PMID: PMC3394177
35. \*Walker LE, **Starks H**, West KM, Fullerton SM. dbGaP data access requests: A call for greater transparency. *Science Translational Medicine*; 2011; 3:113cm34. PMID: PMC3432400
36. \*Dressler LG, Smolek S, Ponsaran R, Markey J, **Starks H**, Gerson N, Lewis S, Press N, Juengst E, Wiesner GL, GRRIP Consortium. IRB perspectives on the return of individual results from genomic research. *Genetics in Medicine*; 2012; 14(2):215-22. PMID: PMC3493147
37. Edwards KL, Lemke AA, Trinidad SB, Lewis SM, **Starks H**, Snapinn KW, Wiesner GL, Burke W, GRRIP Consortium. Genetic researchers' and IRB professionals' attitudes toward genetic research review: A comparative analysis. *Genetics in Medicine*; 2012; 14(2):236-42. PMID: PMC3448270
38. Kelley M, Edwards K, **Starks H**, Fullerton SM, Goering S, Holland S, James R, Burke W. Values in translation: How asking the right questions can move translational science toward greater health impact. *Journal of Clinical and Translational Science*, 2012; 5(6):445-451. PMID: PMC3561695
39. \*Lee HH, Lewis CW, Saltzman B, **Starks H**. Visiting the emergency department for dental problems: Trends in utilization, 2001 to 2008. *American Journal of Public Health*, 2012; 102(11):e77-83. PMID: PMC3477981
40. Doorenbos AZ, Lindhorst T, **Starks H**, Aisenberg E, Curtis JR, Hays R. Palliative care in the pediatric ICU: Challenges and opportunities for family centered practice. *Journal of Social Work in End-of-Life and Palliative Care*, 2012; 8(4):297-315. PMID: PMC3647033
41. \*James R, **Starks H**, Segrest V, Burke W. From leaky pipeline to irrigation system: Minority education through the lens of community-based participatory research. *Progress in Community Health Partnerships*, 2012; 6(4):471-479. PMID: PMC3951382.
42. Doorenbos AZ, **Starks H**, Bourget E, McMullan DM, Lewis-Newby M, Rue TC, Lindhorst T, Aisenberg E, Oman N, Curtis JR, Hays R and the Seattle Ethics in ECLS Consortium. Examining palliative care team involvement in automatic consultations for children on extracorporeal life support (ECLS) in the pediatric ICU. *Journal of Palliative Medicine*, 2013; 16(5):1-4. PMID: PMC3705963.

43. Loggers ET, **Starks H**, Shannon-Dudley M, Back AL, Appelbaum FR, Stewart FM. A comprehensive cancer center's approach to physician-assisted death. *New England Journal of Medicine*, 2013; 368(15):1417-1424. [Not NIH-funded]
44. \*Hiratsuka V, Delafield R, **Starks H**, Ambrose AJ, Mau MM. Patient and provider perspectives on using telemedicine for chronic disease management among Native Hawaiian and Alaska Native people. *International Journal of Circumpolar Health*, 2013; 72: 21401 - <http://dx.doi.org/10.3402/ijch.v72i0.21401> PMID: PMC3751232.
45. \*Kaci A, **Starks H**. Caring for the elderly in Algeria within the discourse of traditionalism and modernism: Is there a Kabyle "women problem?" *International Journal of Feminist Approaches to Bioethics*, 2013; 6(2):160-178. [Not NIH-funded]
46. **Starks H**, Wang S, Farber S, Owens DA, Curtis JR. Cost savings vary by length of stay for in-patients receiving palliative care consult services. *Journal of Palliative Medicine*, 2013; 16(10):1215-20. PMID: PMC3837564
47. \*Lee H, **Starks H**, Milgrom P, Burke W. Trends in death associated with pediatric dental sedation and general anesthesia. *Paediatric Anesthesia*, 2013; 23(8):741-6. PMID: PMC3712625.
48. \*Shaw JL, Robinson R, **Starks H**, Burke W, Dillard DA. Risk, reward and the double-edged sword: Views of pharmacogenetic testing among Alaska Native/American Indian people. *American Journal of Public Health*, 2013; 103(12):2220-5. PMID: PMC3828986.
49. \*Rosenberg AR, **Starks H**, Jones B. "I know it when I see it." The complexities of measuring resilience in pediatric cancer. *Supportive Care in Cancer*, 2014;22(10):2661-8. DOI: 10.1007/s00520-014-2249-5. PMID: PMC4264630
50. James R, Tsosie R, Sahota P, Parker M, Dillard D, Sylvester I, Lewis J, Klejka J, Muzquiz L, Olsen P, Whitener R, Burke W; Kiana Group (**Starks H** is a member). Exploring pathways to trust: a tribal perspective on data sharing. *Genetic Medicine*. 2014;16(11):820-6. doi: 10.1038/gim.2014.47. Epub 2014 May 15. PMID: PMC4224626.
51. **Starks H**, Shaw JL, Hiratsuka V, Dillard DA, Robinson R. Engaging stakeholders to develop a depression management decision support tool in a tribal health system. *Quality of Life Research Journal*, 2015;24(5):1097-105. doi: 10.1007/s11136-014-0810-9. PMID: 25246185. [Not NIH-funded]
52. \*Burns M, Baylor C, Dudgeon BJ, **Starks H**, Yorkston K. Asking the stakeholders: Perspectives of individuals with aphasia, their family caregivers, and physicians regarding communication in medical interactions. *American Journal of Speech Language Pathologists*. 2015 Mar 10. doi: 10.1044/2015\_AJSLP-14-0051. [Epub ahead of print]. PMID:25760479 [Not NIH-funded]
53. \*Barata LP, **Starks H**, Kelley M, Kuszler P, Burke W. What DNA can and cannot say: Perspectives of immigrant families about the use of genetic testing in immigration. *Stanford Journal of Law, Science & Policy*. 2015; 26(2):597-638. PMID: PMC4743036.
54. **Starks H**, Doorenbos AZ, Bourget E, Lindhorst T, Aisenberg E, Oman N, Rue TC, Curtis JR, Hays R. The Family Communication Study: A randomized trial of prospective pediatric palliative care consultation, study methodology and perceptions of participation burden. *Contemporary Clinical Trials*. 2016;49:15-20. doi 10.1016/j.cct.2016.05.004. PMID in progress.
55. \*Coats H, Paganelli T, **Starks H**, Lindhorst, T, Starks Acosta A, Mauksch L, Doorenbos A. A community needs assessment for the development of a an interprofessional palliative care training curriculum. *Journal of Palliative Medicine*, 2016; Nov 1, epub ahead of print. PMID: 27802069, DOI:[10.1089/jpm.2016.0321](https://doi.org/10.1089/jpm.2016.0321)
56. \*Richards C, **Starks H**, O'Connor MR, Doorenbos AZ. Elements of family-centered care in the pediatric intensive care unit: An integrative review. *Journal of Palliative Care Nursing*, 2017; in press.
57. \*Coats H, Bourget E, **Starks H**, Oman N, Lindhorst T, Curtis JR, Hays R, Doorenbos AZ. "There's gotta be some balance." Nurse reflections on the benefits and challenges of implementing family-centered care in the PICU. *American Journal of Critical Care*, 2017; in press.

**Book Chapters**

58. Pearlman RA, **Starks H**. Quantitative surveys. In *Methods in Medical Ethics*, J. Sugarman and D. Sulmasy, eds. Georgetown University Press, Washington D.C., 2001; Revised 2<sup>nd</sup> edition, 2010.
59. Pearlman RA, **Starks H**. Why do people seek physician-assisted death? In *Physician-assisted Dying: The Case for Palliative Care and Patient Choice*, Quill TE, Battin MP, eds. Johns Hopkins University Press, Baltimore, 2004.
60. Pearlman RA, **Starks H**, Cain KC, Cole WG, Patrick DL, Uhlmann RF. Integrating preferences for life-sustaining treatments and health state ratings into meaningful advance care discussions. In *Bioethics: An introduction to the history, methods and practice*, Jecker NS, Jonsen AR, Pearlman RA, eds. Jones and Bartlett Publishers, Boston, 2<sup>nd</sup> edition, 2007; Revised 3<sup>rd</sup> edition, 2011.
61. **Starks H**, Vig EK, Pearlman RA. Advance care planning. In *Palliative Care: Core Skills and Clinical Competencies*. Emanuel, L.L. and Librach, S.L., eds. Saunders-Elsevier, Philadelphia, 2007; Revised 2<sup>nd</sup> edition, 2011.
62. James RD, **Starks H**. Bringing the “best science” to bear on youth suicide: Why community perspectives matter. In *Achieving Justice in Genomic Translation: Rethinking the Pathway to Benefit*. Burke W, Edwards K, Goering S, Holland S, Trinidad S, eds. Oxford University Press, New York, 2011.

**Editorials/Commentaries**

63. **Starks H**, Curtis JR. Is withholding life support associated with a premature death? If so, what does this mean for ICU practice? [Editorial] *Chest*, 2008; 33(6):1298-1300.
64. Burke W, Holland S, Kuzler P, **Starks H**, Press N. Translational genomics: Seeking a shared vision of benefit. [Commentary] *American Journal of Bioethics*, 2008; 8(3):54-6. PMID: PMC2633471

**Other Publications**

65. Work groups on prevention for people with disabilities, Center for Disability Policy and Research. *Promoting the Health of People with Disabilities: Protocols for Prevention Interventions*. Seattle, WA: Center for Disability Policy and Research, 1996.
66. Pearlman R, **Starks H**, Cain K, Cole W, Rosengren D, Patrick D. *Your Life, Your Choices. Planning for future medical decisions: How to prepare a personalized living will*. On the web at: [http://www.rihlp.org/pubs/Your\\_life\\_your\\_choices.pdf](http://www.rihlp.org/pubs/Your_life_your_choices.pdf). First posted 1995.
67. Pearlman RA, **Starks H**, Cain KC, Cole WG, Patrick DL, Uhlmann RF. Integrating preferences for life-sustaining treatments and health state ratings into meaningful advance care discussions. In *Proceedings from the Royal Netherlands Academy of Arts and Sciences Colloquium on Epidemiological and Clinical Aspects of End-of-life Decision-making*, P.J. van der Maas, ed. 2001.
68. Vig EK, **Starks H**, Taylor JS, Hopley EH, Fryer-Edwards KA. Cognitive screening raises fears of identify theft. [Letter to the Editor] *J Am Geriatr Soc*, 2004;52(12):2147-8.
69. **Starks H**, Hays R. Teaching research in pediatric palliative care. Module for EPEC Curriculum for Pediatric Oncologists. December 2011.

**Manuscripts Under Review/in Progress**

1. **Starks H**, Coats H, Paganelli T, Mauksch LB, van Schaik E, Lindhorst T, Hurd C, Doorenbos A. Pilot study of an interprofessional palliative care curriculum: Course content and participant-reported learning gains. Under review, *American Journal of Hospice and Palliative Medicine*.
2. **Starks H**, Doorenbos AZ, Curtis JR, Rue TC, Lindhorst T, Bourget E, Oman N, Aisenberg E, Hays R. Using length of stay as a trigger for automatic palliative care consults in the PICU: A randomized trial of a prospective intervention to decrease family stress.

**ABSTRACTS PRESENTED AT NATIONAL MEETINGS**

Pearlman RA, **Starks HE**, Powell-Cope G, Shalit P. “Perception of quality of life: Influence on advance care plans.” American Public Health Association 119th Annual Meeting, Atlanta, GA. Nov. 10-14, 1991.

- Pearlman RA, **Starks HE**, Cain KC, Cole WG, Patrick DL. "Physician communication and advance care planning." Presented as part of a symposium on ethical issues in the doctor-patient relationship. Gerontological Society of America 47th Annual Meeting, Atlanta, GA. Nov. 18-22, 1994.
- Starks HE**. "Applications of time trade off, standard gamble, and visual analog scales in clinical trials." Preference-based Quality of Life Assessment in Clinical Trials: Methodologic Issues and Applications, Montreal, Quebec. Oct. 12-13, 1995.
- Pearlman RA, **Starks HE**, Cain KC, Cole WG. "Positive effects of a workbook-centered advance care planning intervention." Department of Veterans Affairs Health Services Research & Development (DVA-HSR&D) Annual Meeting, Washington, DC. Feb. 24-26, 1999.
- Starks HE**, Sullivan J, Pineros S. "Human subjects issues: Operational lessons in conducting multi-site and multi-institutional studies." DVA-HSR&D Annual Meeting, Washington, DC. Feb. 14-16, 2001.
- Starks HE**. "Phenomenology, hermeneutics, and grounded theory: Differences in philosophy, methodology, method, and product." International Institute of Qualitative Methodology: Fifth Advances in Qualitative Research Methods Conference, Edmonton, AL, Canada. Jan. 29-31, 2004.
- Starks H**, Zimmerman FJ. "Home care use at the end of life: Evidence from MEPS." NRSA Trainees Research Conference, AcademyHealth Annual Research Meeting, San Diego, CA. June 5-8, 2004.
- Starks H**, Fryer-Edwards K, Hopley E, Taylor J, Vig E. "Appropriate use of surrogates in end-of-life decision-making." American Society for Bioethics and Humanities (ASBH) Annual Meeting, Philadelphia, PA. Oct. 28-31, 2004.
- Starks H**, Pearlman RA, Hsu C, Back AL, Gordon J, Bharucha A. "Why now? Timing and circumstances of hastened deaths." Association of Hospice and Palliative Medicine/Hospice and Palliative Nurses Association (AAHPM/HPNA), Annual Meeting, New Orleans, LA. Jan. 19-23, 2005.
- Starks H**, Lauer J, Johnson K, Yorkston K, DiGiacomo A. "Caregiving and multiple sclerosis." State of the Science in MS Rehabilitation Research, Washington DC. Sept. 18-19, 2006.
- Gotlib A, **Starks H**, Meghani Z, Reiheld A. "Justice and caregiving: Familial, national, and transnational perspectives." Panel Presentation, ASBH Annual Meeting, Denver, CO. Oct. 26-29, 2006.
- Starks H**. "Data ownership: Preserving reputations and relationships when data get pulled without warning." Office of Research Integrity, 2006 Research on Research Integrity Conference, Tampa, FL. Dec. 1-3, 2006.
- Starks H**. "Overview of surrogate decision making." American Geriatrics Society, Annual Meeting, Seattle, WA. May 3-5, 2007.
- Starks H**. "Palliative care consults: A mixed methods evaluation of referral processes and outcomes." National Palliative Care Research Center (NPCRC) 1<sup>st</sup> Annual Meeting and Research Consortium, Park City, UT. Sept. 17-19, 2007.
- Starks H**, Morrison RS. "Computing and using propensity scores in palliative care research." AAHPM/HPNA Annual Meeting, Tampa, FL. Jan. 30-Feb. 2, 2008; NPCRC 2<sup>nd</sup> Annual Meeting and Research Consortium, Park City, UT. Sept. 16-18, 2008.
- Kuzler P, Burke W, **Starks H**, for the Translational Research Working Group, Center for Genomics and Healthcare Equality. "The translational cycle in genomic research." Translating "ELSI": Global Perspectives in Research on the Ethical, Legal and Social Implications of Human Genome Research. 2008 ELSI Congress, Cleveland, OH; May 1-3, 2008.
- \*Laberger A, Kuzler P, **Starks H**, Burke W. "The standard of care for genetic tests: What role do clinical practice guidelines play?" Translating "ELSI": 2008 ELSI Congress, Cleveland, OH; May 1-3, 2008.
- Starks H**. "Ethics of the use and non-use of a continuum of therapies at the end of life." Panel presentation on Enhancing care at the end of life: Optimizing palliative care and dignity preserving interventions at end of life. Washington State Medical Association Annual Meeting, Spokane, WA. Sept. 26-27, 2008.
- Starks H**, Schwarz J, Battin MP, Doukas D, Pearlman R. "Dying behind closed doors: Bringing hidden consequences of illegal aid-in-dying to light." Panel Presentation, ASBH Annual Meeting, Cleveland, OH. Oct. 23-26, 2008.
- Starks H**. "Words that work: Useful phrases and expressions in palliative care consultations." Poster Presentation, AAHPM/HPNA Annual Meeting, Austin, TX. March 25-28, 2009.



- Starks H.** “Exploring predictors of referral to inpatient palliative care consult services: A mixed methods analysis.” Poster Presentation, NPCRC 3<sup>rd</sup> Annual Kathy Foley Palliative Care Research Retreat and Symposium. Greensboro, GA. Oct. 13-15, 2009.
- Starks H,** VandeKieft G, Farber S. “What should I say when... Words that work in palliative care consults.” Educational Session, AAHPM/HPNA Annual Meeting, Boston, MA. March 3-6, 2010.
- Hays R, **Starks H,** Aisenberg E, Bourget E, Curtis JR, Doorenbos A, Lindhorst T, Oman N, Rue T. “Improving family outcomes with a communication intervention in the pediatric ICU.” 18<sup>th</sup> International Congress on Palliative Care. Montreal, Canada. October 5-8, 2010.
- Starks H.** “Predictors & cost outcomes of referrals to inpatient palliative care consult services.” Poster presentation, NPCRC 4<sup>th</sup> Annual Kathy Foley Palliative Care Research Retreat and Symposium, Sundance, UT. October 12-14, 2010.
- Starks H,** Farber S, Vig E, VandeKieft G. “Words that work: Patient-centered strategies for difficult conversations.” Half-day, pre-conference workshop, AAHPM/HPNA Annual Meeting, Vancouver, BC. February 16-19, 2011; Ernest Becker Foundation, Seattle, WA. July 29, 2011.
- Starks H,** Wang S. “Predictors of referrals to an inpatient palliative care consult service.” Paper presentation, AAHPM/HPNA Annual Meeting, Vancouver, BC. February 16-19, 2011.
- Holland S, **Starks H,** Fullerton SM, Burke W. “Justice in translation: Achieving benefit for all from genomic science.” Exploring the ELSI Universe, 2011 ELSI Congress, Chapel Hill, NC. April 12-14, 2011.
- Starks H,** West KM, Walker L. “Stakeholder views on data sharing policies: Who wins, who loses, and why?” Exploring the ELSI Universe, 2011 ELSI Congress, Chapel Hill, NC. April 12-14, 2011.
- Starks H,** Carlson M, Hanson LC, Prommer E, Steinhauer KE, Prince-Paul MJ. “Writing an NIH research proposal.” Half-day, pre-conference workshop, AAHPM/HPNA Annual Meeting, Denver, CO. March 7, 2012.
- Starks H,** Wang S. “Cost savings vary by length of stay for in-patients receiving palliative care consult services.” Paper presentation, AAHPM/HPNA Annual Meeting, Denver, CO. March 7-10, 2012.
- Carlson M, Lunney J, Tulsy J, **Starks H,** Baggs J. “Mock study section: An inside look at how your grant is reviewed.” AAHPM/HPNA Annual Meeting, New Orleans, LA. March 13, 2013.
- Starks H,** Bourget E, Oman N, Rue T, Doorenbos A, Lindhorst T, Curtis JR, Aisenberg E, Hays R. “Family participation in a communication and support intervention study in the PICU: Low burden and tangible benefits.” Paper presentation, University of Washington Palliative Care Conference, Seattle, WA. April 28-29, 2014.
- Starks H,** Lindhorst T, Bourget E, Oman N, Rue T, Doorenbos A, Curtis JR, Aisenberg E, Hays R. “A systems approach to family stress in the pediatric ICU.” Paper presentation, University of Washington Palliative Care Conference, Seattle, WA. April 28, 2014.
- Caga-anan EC, Dawson L, Edwards K, Helmers KF, Merritt M, **Starks H.** “Navigating federal funding for bioethics research: From soup to nuts.” Half-day, pre-conference workshop, ASBH Annual Meeting, Washington, DC. October 6, 2016.

#### INVITED TALKS/EXPERT WITNESS

##### *End-of-life Issues/Palliative care/Assisted dying/Communication & Decision making*

- “How to choose a surrogate decision maker and what they should know about your health care wishes.” Hamilton House Senior Center, June 20, 2005.
- “Communication strategies for talking with your health care provider.” Hamilton House Senior Center, August 29, 2005.
- “Lessons from the Schiavo family for end of life care.” St. Mark’s Cathedral, Scientific Epiphanies Winter Lecture Series, February 1, 2006.
- “Possibilities and pitfalls of surrogate decision making: What you and your surrogate need to know about making advance care planning work for you.” University Rotary Club, April 20, 2007.
- “Understanding and responding to requests for a hastened death.” Evergreen Healthcare & Hospice, December 19, 2007.

- “Medical decision making at the end of life.” University of Puget Sound, Religion and ethics course, April 9, 2008.
- “Physician-assisted death and euthanasia: What's the difference and why does it matter?” NW Association for Biomedical Research, Ethics in the Science Classroom, Midwinter High School Science Teachers Reunion, January 13, 2009.
- “Responding to requests for physician-assisted death under the Washington Death with Dignity Act.” Grand Rounds, Polyclinic-Northgate, February 18, 2009; Polyclinic-First Hill, February 19, 2009.
- “The Washington Death with Dignity Act: What does this mean for VA providers in Washington?” Chief of Medicine Rounds, VA Puget Sound Health Care System, April 14, 2009.
- “Washington Death with Dignity Act: Implications for practice.” Panel Discussion with Hope Weckin and Thomas Preston. Swedish Hospital Cherry Hill Family Practice Residency Program, April 21, 2009.
- “Passage of the Washington Death with Dignity Act (I-1000): What does this mean for health care providers in Washington?” Ethics Lecture Series, Madigan Army Medical Center, May 26, 2009; Elder Care and the Law Symposium, November 6, 2009; American College of Physicians, Washington Chapter Annual Meeting, November 6, 2009; Puget Sound Oncology Nursing Society Chapter Annual Meeting, April 9, 2010.
- “Washington’s Death with Dignity law: Health and legal issues every person should know.” Panel discussion with Patricial Kuszler, MD JD, Terry Price, JD, and Thomas McCormick, D.Min. UW School of Law Alumni-Faculty Breakfast, May 27, 2009.
- “Euthanasia, assisted dying and YOU.” University of Arizona School of Medicine, Ethics at the End of Life (course for 2<sup>nd</sup> year medical students), Jason Robert, PhD, Course chair, January 21, 2010.
- “Washington Death with Dignity Act: Overview of the law and report of 1<sup>st</sup> year (2009) data.” Panel discussion with Denise Dudzinski, PhD MTS, Rabbi Moshe Kletenik, and Stuart Farber, MD. National Undergraduate Bioethics Conference, University of Puget Sound, March 26, 2010.
- “Words that work: Talking with patients about miracles and hope.” Panel presentation with Stuart Farber, MD and Gregg VandeKieft, MD MA, Understanding Palliative Care – What is it? Who is it for? Palliative Care Symposium, Swedish Medical Center, September 17, 2010; UW Palliative Care Grand Rounds, November 30, 2010.
- Expert Witness for the Plaintiffs, *Carter v. Canada* (case before the Supreme Court of British Columbia challenging the Criminal Code prohibiting physician-assisted dying). Testimony given November 17, 2011.
- “Should Arizonans have the right to die with dignity?” Panelist, Lincoln Center for Applied Ethics, Arizona State University, Tempe, AZ, September 30, 2014.
- “Making visible the invisible: Developing quality measures for palliative care.” Plenary speaker, Noon conference, Hospitalist/Palliative care service, SUNY Downstate, Brooklyn, NY, March 2, 2015.
- “Cambia Palliative Care Center of Excellence Metrics, Quality & Evaluation Core: Measurement Update and Progress on Developing Palliative Care Quality Dashboards at UW Medicine.” Presentation for the American Academy of Hospice and Palliative Medicine Quality Committee, Virtual meeting, December 8, 2015.
- “Using a narrative ethics approach to assess requests for physician-assisted dying.” Panelist, End of Life Option Act Response Conference, San Francisco, CA, December 12, 2015.
- “Washington’s experience with the Death with Dignity Act 2009-2014.” Harborview Ethics Forum, April 13, 2016.
- “Spring policy forum on the End of Life Option Act.” Panelist, Institute for Health & Aging, University of California at San Francisco, San Francisco, CA, May 10, 2016.
- “Lessons on dying in Washington.” Panelist, End-of-Life Discussion Series: Inaugural Event. Stanford University, Palo Alto, CA, May 12, 2016.

#### *Bioethics/Research Ethics*

- “Challenges with surrogate decision making: Balancing patient and family interests.” Valley General Hospital Ethics Committee Grand Rounds, Monroe WA, April 6, 2005.
- “Women and aging: Ethical implications for 2005 and beyond.” Panelist, Women’s Bioethics Project & SAGE Crossroads, June 8, 2005.

- “Substituted judgment vs. best interest standards.” Conference on end of life issues and decision making, King County State Bar Association, October 26, 2005.
- “Gender differences in aging.” St. Mark’s Cathedral, SAGE (Simeon & Anna Guild of Elders) group, November 2, 2005.
- “Ethical dilemmas in hospice settings.” New volunteer training, Evergreen Healthcare & Hospice, June 26, 2008; January 31, 2009.
- “Balancing tensions in data and decision making in the context of uncertainty.” Closing plenary speaker, Society for Critical Care Medicine, Research Summit, Atlanta, GA, April 10-11, 2014.

#### *Research Methods*

- “Qualitative methods in CAM research.” Keynote Speaker, Post-doctoral Fellows Retreat, Bastyr Research Institute, Bastyr University, September 23, 2010.
- “Observational and quasi-experimental research methods.” Workshop co-leader, Kathleen Foley Palliative Care Retreat, Park City, UT, October 20, 2014.
- “Qualitative research methods.” Workshop co-leader, Kathleen Foley Palliative Care Retreat, Quebec City, Canada, October 25, 2016.
- “Moving forward into the future with health services research.” Akron Children’s Hospital, Akron, OH, December 6, 2016.

#### **MEMBERSHIP IN PROFESSIONAL SOCIETIES**

American Academy of Hospice and Palliative Medicine  
American Society of Bioethics and Humanities

#### **TEACHING**

##### **Formal Courses**

- **Advanced Qualitative Methods** (4 cr). Depts of Medical History & Ethics and Health Services, (MHE 597/HSERV 590 D), Winter 2006; Dept of Medical History & Ethics (MHE 552), Winter 2008, Dept of Bioethics and Humanities (BH552), Winter 2010, Winter 2012, Winter 2014, Winter 2016.
- **Research Ethics and Regulations** (3 cr). Depts of Medical History & Ethics and School of Law (MHE 536/LAW H 536), Winter 2007.
- **Introduction to Research Methods** (3 cr). Taught at Northwest Indian College through a collaboration with the UW Center for Genomics and Healthcare Equality [CGHE] (BIOL 188), Spring 2007.
- **Center for Genomics & Healthcare Equality (CGHE) Summer Seminar** (2 cr). Dept of Medical History & Ethics/Bioethics & Humanities (MHE 597 B; BH560) Community based participatory policy making in Indian country, Summer 2007; Building and measuring capacity for research-community partnerships, Summer 2008 (BH 597 B); Examining benefits and harms of genomic research for underserved communities, Summer 2009; Data sharing policies, Summer 2010.
- **CGHE RA Seminar: Focus on qualitative methods** (1-2 cr). Dept of Bioethics and Humanities (BH 600), Fall 2008; Winter 2009; Spring 2009; Winter 2011, Fall 2011, Winter & Spring 2014.
- **Research Methods in Bioethics** (3 cr). Dept of Bioethics and Humanities (BH 527), Survey course on normative and empirical methods for bioethics research, Spring 2010, Winter 2011, Spring 2012, Spring 2013, Spring 2014.
- **Palliative Care Graduate Certificate Program** (15 cr). Co-sponsored with School of Nursing (BH 566, 567, 568; NSG 526, 527, 528) this 3 quarter series (5 credits/quarter) is focused on clinician skills training in narrative and patient-centered communication, interprofessional team practice, and palliative care quality metrics and system integration. Lead faculty for Spring quarter 2017 (BH 568/NSG 528).

##### **Guest Teaching/Lectures in University of Washington Courses, Seminars and Grand Rounds**

###### *End-of-life Issues/Palliative care/Assisted dying*

- “Clinician-patient interactions about physician-assisted suicide: A patient and family view.” April 1, 2002 Doctoral Seminar (HSERV 592H), Dept. of Health Services

- “Physician-assisted suicide,” Current Topics in Clinical Ethics I (MHE 549), Dept. of Medical History and Ethics, January 16, 2003; April 5, 2005.
- “Relational autonomy and physician-assisted suicide: Effects on families of participating in a hastened death.” Research presentation for the Faculty Search Committee of the Dept. of Medical History and Ethics, April 8, 2004.
- “Responding to requests for aid-in-dying.” Internal Medicine Residents Ethics Conference, School of Medicine, June 16, 2004.
- “Why now? Timing and circumstances of hastened deaths.” Medical Ethics Brown Bag Series, Dept. of Medical History and Ethics, August 13, 2004.
- “Caring for patients with life threatening illness: Responding to requests for assisted dying.” Discussion leader, Integrated Clinical Medicine II, School of Medicine, February 28, 2005; February 27, 2006; February 25, 2008; March 3-4, 2009; March 11, 2010.
- “Terri Schiavo: How did we get here and why does it matter to you?” Tri-beta Honors Biology Seminar, Dept. of Biology, April 7, 2005.
- “The Terri Schiavo case: What should physicians consider?” Alpha Epsilon Delta Pre-Med Ethics Forum, April 13, 2005.
- “Responding to requests for physician-assisted suicide after Gonzales v. Oregon.” Harborview Ethics Forum, March 8, 2006; Medical History & Ethics Brown Bag, July 26, 2006.
- “Decision making at the end of life: Issues and impacts for patients, family members, and clinicians.” Social & Behavioral Sciences Seminar, Dept. of Health Services, November 20, 2006.
- “Ethical issues around behaviors that may shorten life.” Preclinical Hospice Volunteer Training (FAMED 546/MHE 517), January 17, 2008; January 15, 2009; January 14, 2010; January 27, 2011; January 26, 2012; January 31, 2013; Palliative Care Clerkship, 3<sup>rd</sup> year medical students, September 22, 2008.
- “Communication skills to elicit goals of care at the end of life.” Advanced Practicum in Parent & Child Nursing (NCLIN 512), May 22, 2008.
- “Pros and cons of physician aid-in-dying and euthanasia—weighing the moral arguments.” Introduction to Bioethics (MHE 411), June 2, 2008.
- “Patient and family perspectives on physician aid-in-dying.” Legal issues at the end of life (Law H 509), February 26, 2009; February 23, 2011; February 23, 2012; January 30, 2013
- “Passage of the Washington Death with Dignity Act (I-1000): What does this mean for health care providers in Washington?” Harborview Ethics Forum, January 14, 2009; UW Medicine Spiritual Care Dept, March 2, 2009; Geriatrics Grand Rounds, April 3, 2009; Palliative Care Conference, April 28, 2009, Social Work Grand Rounds, June 9, 2009.
- “Washington Death with Dignity Act, Part II: Evaluating and responding to requests.” Neurology Ground Rounds, February 19, 2009.
- “Lessons for the Washington Death with Dignity Act from the Insights into Hastened Death study.” End of Life: Rights and Choices (Law H 509), February 26, 2009; February 23, 2011; February 23, 2012; January 30, 2013; February 18, 2015; February 2, 2016.
- “The joys, challenges and skills of doctoring at the end of life.” Integrated Clinical Medicine II, School of Medicine, February 25, 2010.
- “Predictors & outcomes of referrals to UWMC inpatient palliative care consult service.” UW/HMC Palliative Care Research Conference, June 15, 2010.
- “Cost savings vary by length of stay for in-patients receiving palliative care consult services.” UW/HMC Palliative Care Research Conference, September 20, 2011.
- “What to consider when choosing outcomes in palliative care.” UW/HMC Palliative Care Research Conference, April 17, 2012.
- “Talking about death, dying & quality of life: Can’t we talk about something more *pleasant*?” Guest lecture, BH 411, June 2, 2014.
- “Ethics at the end of life: Surrogate decision making.” Guest lecture, IS 290, November 26, 2014; BH 201, April 21, 2015; April 12, 2016, BH 311, June 1, 2015; May 16, 2016.

- “Washington’s experience with the Death with Dignity Act 2009-2014.” Harborview Ethics Forum, April 13, 2016.

#### *Qualitative methods*

- “The ‘essence’ of three methodological approaches: Comparisons between phenomenology, grounded theory and hermeneutics.” April 23, 2003. Doctoral Seminar (HSERV 592 H), Dept. of Health Services
- “Qualitative research: Ethical issues and human subjects reviews.” Interdisciplinary Qualitative Research Group Quarterly Lecture Series, May 20, 2003.
- “Understanding phenomenology.” Narrative and Narrativity (SW 585), Dept. of Social Welfare, February 19, 2004.
- “Thinking qualitatively.” Social & Behavioral Sciences Seminar (HSERV 592G), February 23, 2004; March 6, 2006. Maternal & Child Health Seminar, January 22, 2007; International Health Seminar, February 2, 2007, February 13, 2008; February 10, 2009; International Health Seminar on the Responsible Conduct of Research (EPI 586), September 16, 2009; September 13, 2010; September 12, 2011. COPHP Seminar (HSERV592D) October 15, 2013.
- “Introduction to Qualitative Methods.” Workshop for Masters’ Students (4 two-hour sessions), Dept. of Health Services, Winter 2005.
- “Different qualitative methods: What they can add to your research.” Health Policy and Research Seminar (HSERV 592), Dept. of Health Services, March 28, 2005; March 26, 2007, November 4, 2008. Social Welfare Extended Degree Program, January 9, 2010; January 12, 2011; Investigative Skills (MEDEX 528/588), June 27, 2011; Developmental & Rehabilitation Medicine Fellows Conference, June 10, 2014.
- “Grounded theory and coding.” Qualitative Research Methods for Public Health (HSERV 526), Dept. of Health Services, May 24, 2005; May 25, 2006; May 22, 2007; May 29, 2008; May 28, 2009; March 1, 2010; February 23, 2011; February 15, 2012; February 20, 2013; November 5, 2014; November 16, 2015.
- “Introduction to Atlas.ti.” Faculty/Staff training, June 9, 2005; November 15, 2006.
- “Writing qualitative and mixed methods papers: Tricks of the trade.” Doctoral Seminar (HSERV 592 H), Dept. of Health Services, May 21, 2008.
- “Coding qualitative data.” Research Design in Anthropology (ANTH 551), February 9, 2011; February 25, 2013.
- “Overview of qualitative research methods & participatory coding activity.” ITHS Summer Seminar (UConJ 517, August 15, 2013; July 17 2014; July 30, 2015.

#### *Research ethics*

- “Scholarly integrity and research ethics.” International Health Seminar on the Responsible Conduct of Research (EPI 586), September 20, 2007.”
- “Research ethics in global health.” Advanced Topics in Global Health (Med 560), January 11, 2008; International Health Seminar on the Responsible Conduct of Research (EPI 586), Sept. 12, 2008; Sept. 16, 2009.
- “How does community consent work in practice: Lessons from the GOCADAN study.” Research Ethics (MHE 536/Law H 536), February 3, 2009; January 26, 2010.
- “Community consent in the context of community-based participatory research.” Communications Proseminar (COM 594), March 2, 2011.
- “Authorship and publication issues in research.” Reflections on Research, Responsibility and Society (BH 460), November 12, 2015.

#### *Other topics*

- “Measuring patient preferences: Use of visual analog scales, standard gamble, and time trade off methods to obtain utilities.” Pharmacoeconomics, Genetics, and Healthcare (Pharm 436/PHG 537), Depts. of Pharmacy and Public Health Genetics, May 20, 2003.
- “Dysfunctional families or devoted caregivers? Rethinking health care from 'an ethic of accommodation'.” Teaching Seminar, Dept. of Medical History and Ethics, April 9, 2004.
- “Constructing a patient narrative.” Discussion leader, Chronic Care Clerkship, School of Medicine, March 7, 2005.

- “Intrafamilial justice and relational autonomy: Rethinking the family conference.” Faculty Forum, Dept. of Medical History and Ethics, June 8, 2005.
- “Experiences of interviewing for a faculty job.” Doctoral Seminar (HSERV 592 H), Dept. of Health Services, February 11, 2009.
- “Career pathways for communications graduates.” Communications Pro-seminar (COM 594), November 29, 2010.
- “Career pathways for health services PhD graduates.” Doctoral Seminar (HSERV 592 H), Dept. of Health Services, April 6, 2011; May 22, 2013.
- “Policy 101.” Professional development seminar, Palliative care fellows, June 24, 2012.
- “Stakeholder analysis.” Palliative Care Training Center online seminar, August 3, 2015.

### **Mentoring Activities**

#### **Current Student Supervision**

##### Masters Project, Thesis, Capstone, or Doctoral Dissertation Committee Chair/Member

1. Danae Dotolo, MSW, MA, PhC, School of Social Work, Dissertation Committee Member, May 2013-present.
2. Claire Richards, RN, PhC, Dept of Biobehavioral Nursing and Health Systems, Dissertation Committee Member, ITHS TL1 Primary Mentor (TL1TR000422, UW ITHS Mentored Clinical Research Scholars Program), October 2014-present.
3. Abby Rosenberg, MD, MPH, MA in Bioethics student, Dept. of Pediatrics & Hematology-Oncology, Seattle Children’s Hospital, Mentor on K-award (KL2TR000421, UW ITHS Mentored Clinical Research Scholars Program, July 2014), June 2012-present. Masters Project Advisor, February 2016-present.
4. Anna Snyder, MD/MA in Bioethics student, Masters Project Advisor, April 2016-present.

##### Graduate School Representative

5. Stephanie Cruz, PhC, Dept. of Anthropology, February 2014-present.

#### **Current Fellows & Junior Faculty**

6. Ann Long, MD, Senior Fellow, Division of Pulmonary & Critical Care, Dept. of Medicine. December 2013-present.

#### **Completed Student Supervision**

##### Masters Project or Thesis/Doctoral Dissertation Committee Chair/Member

7. Larkin Strong, PhD, Dept. of Health Services. Dissertation Committee Member, July 2005-June 2006. Dissertation title: *Identifying strategies to promote adoption of pesticide safety practices in farmworkers and their families.*
8. Heather Linn Culley, MA, Dept. of Medical History & Ethics. Masters Project Advisor, September 2005-June 2006. Project title: *The making of a conflicted scientist: How different structures and aspects of the research process create conflict for a scientist.*
9. Grace Wang, PhD student, Institute for Public Health Genetics. Dissertation Committee Member, August 2006-March 2007.
10. Becca Sillifant Snyder, MSN, Dept. of Biobehavioral Nursing and Health Systems, School of Nursing. Masters Project Supervisor, November 2006-June 2007. Project title: *Exploring reasons and timing of referrals to the palliative care consult service.*
11. DeAnn Crompton, MPH, Dept. of Health Services, Social and Behavioral Sciences Track. Masters Thesis Committee Member, November 2006-July 2007. Thesis title: *Barriers and facilitators to smoking cessation among homeless populations.*
12. Anne-Marie Laberge, MD PhD. Institute for Public Health Genetics. Dissertation Committee Member, August 2006-August 2008. Dissertation title: *Clinical practice guidelines and their impact on the use of genetic tests in practice and on the definition of the standard of care.*
13. Nicole White, MD MA. Dept. of Bioethics and Humanities. Masters Project Committee Member, October 2008-June 2009. Project title: *Adolescent decision-making: Does a minor have a right to decide?*

14. Meredith Meacham, MPH, Institute for Public Health Genetics. Masters Thesis Committee Member, April 2009-July 2009. Thesis title: *Research perspectives on disclosure of incidental findings in genetic research.*
15. Heidi Montoya, PhD, Dept. of Psychology. Dissertation Committee Member, April 2006-August 2010. Dissertation title: *Ni Hombre, Ni Macho: The relationship between gender norms and risky sexual behavior.*
16. Teresa Madrid, MPH, Institute for Public Health Genetics, Thesis Committee Chair, September 2009-August 2010. Thesis title: *Assessing the motivational, educational and training experiences of underrepresented minorities who participated in a genomic scientific research training program at the University of Washington.*
17. Celeste Chung, MPH, Dept. of Health Services, May 2009-December 2010. Thesis Committee Member. Thesis title: *Bridging the gap: A process evaluation of a patient navigator program for families with limited English proficiency in a pediatric hospital.*
18. Amber Harmon, MPH, Institute for Public Health Genetics. Thesis Committee Chair, February 2011-August 2011. Thesis title: *Indigenous protection of traditional knowledge: A case study of genetically modified taro in Hawaii.*
19. Ariana Kaci, MA, Dept of Bioethics and Humanities. Masters Project Advisor, July 2009-Dec. 2011. Masters Project title: *Caring for the elderly in Algeria within the discourse of traditionalism and modernism: The Kabyle "women problem."*
20. Angela Anderson, MPH, Extended Degree Program. Thesis Committee Chair, August 2011-March 2012. Thesis title: *Research code toolkit for AI/AN communities: Fostering health research and trust in American Indian and Alaska Native communities.*
21. Llilda Barata, PhD, Institute for Public Health Genetics. Dissertation Committee Chair, August 2008-August 2012. Dissertation title: *Genetic testing in immigration for family reunification: Ethical, legal and social implications.*
22. Lorelei Walker, MPH, Institute for Public Health Genetics. Thesis Committee Chair, February 2011-December 2012. Thesis title: *Exploring discourses of allostasis to further transdisciplinary research.*
23. Jessica Turnbull, MD MA, Dept. of Bioethics and Humanities. Masters Project Advisor, January 2012-June 2013. Project title: *Determining eligibility criteria for pediatric ECLS: How do physicians decide?*
24. Sara Crumb, MPH, Institute for Public Health Genetics. Thesis Committee Member, November 2011-December 2013. Thesis title: *An evaluation framework to assess educational genetic websites: Are they meeting public needs?*
25. F.J. "Gino" Gianola, MA, Dept. of Bioethics and Humanities. Masters Project Advisor, November 2012-December 2013. Project title: *A duty to create pathways and prioritize veterans who were medics and corpsmen in application for admissions to Physician Assistant programs*
26. Andrea Corage Baden, MPH PhD, Dept. of Social and Behavioral Sciences, University of California, San Francisco. External Advisory Committee Member, May 2009-March 2014.
27. Emmi Bane, MPH PhD student, Institute for Public Health Genetics. Dissertation Committee Member, August 2013-April 2014.
28. Diana Vinh, MPH student, Community-Oriented Public Health Practice, Capstone Project Advisor, October 2013-April 2014.
29. Danae Dotolo, MSW, MA, Dept. of Bioethics and Humanities. Masters Project Advisor, May 2013-June 2014. Project title: *Intersections of recognition theory and social work: Justice, misrecognition and LGBTQ surrogate decision makers.*
30. Katherine L. Kwong, MPH, Institute for Public Health Genetics, Thesis Committee Chair, October 2013-June 2014. Thesis title: *Comparing genomic data sharing policies from the National Institutes of Health, Global Alliance, and Reg4All: Common ground and future directions.*
31. Megan Hawthorne, MPH, Institute for Public Health Genetics, Thesis Committee Member, April 2014- June 2014. Thesis title: *Evaluating the "sensitivity and specificity" of the newborn screening debate: How tradeoffs between population and individual benefit are shaping the conversation between public health and genetic advocates.*

32. Flavia Chen, MPH, Institute for Public Health Genetics, Thesis Committee Member, November 2013-December 2014. Thesis title: *23andMe and the FDA: Negotiating conceptions of benefit in the direct-to-consumer genetic testing regulatory debate.*
33. Krysta Shutske, PhD MPH, Institute for Public Health Genetics. Dissertation Committee Member, August 2009-June 2015. Dissertation title: *Genetic testing for Autism Spectrum Disorder (ASD): Evaluating the challenges of genomic translation.*
34. Ali Adem, MPH, Dept of Global Health, Thesis Committee Member, April 2014-June 2015. Thesis title: *Exploring the similarities and differences of the perceptions of participation in clinical research in the East African community in King County, Washington.*
35. Kelson Okimoto, BS, Health Informatics & Health Information Management, Capstone supervisor. December 2014-June 2015.
36. Lorelei Walker, PhD MPH, Institute for Public Health Genetics. Dissertation Committee Member, January 2013-August 2015. Dissertation title: *The importance of environmental embodiment for public health professionals: Stress triggers, environmental toxicants, and strategies for education.*
37. Cara Friang, MA, Dept of Bioethics & Humanities, Master's Project Advisor, August 2014-November 2015. Thesis title: *Measuring moral distress in critical care nurses.*

#### Independent Study/III

38. Nicole Deming, MA Student, Dept. of Medical History and Ethics (MHE). Independent study on relational autonomy, Spring 2005.
39. Michael Nguyen, MHE Minor Student. Independent study on understanding behaviors that shorten life: physician-assisted suicide and euthanasia, Winter 2006 & Spring 2006.
40. Nicholas Wysham, MD student, School of Medicine. III Supervisor, May 2006-October 2008. Paper title: *Recognizing and responding to existential suffering: A review of philosophical, psychological and medical literatures.*
41. Dellanira Valencia-Garcia, PhD, Dept. of Psychology. Manuscript mentor/co-author, September 2006-June 2008. Paper title: *After the fall from grace: Negotiation of new identities among HIV-positive Peruvian women.*
42. Christine Bachman, MPH student, Dept. of Health Services, International Health track. Independent study on qualitative and community-based participatory research methods, Summer 2007.
43. Garland Wood, PhD student, Dept. of Biomedical Informatics. Independent Study, Spring 2008.
44. Lesley Richardson, MD student, School of Medicine, III Supervisor, July 2009-February 2010.
45. Max Hunter, MA student, Dept. of Bioethics & Humanities. Independent study, Winter 2012; Spring 2012.
46. Sayward Nelson, BH minor student. Independent study on narrative medicine, Winter 2016 (3 credits).

#### Graduate School Representative

47. Jen-Yu Chou, PhD, Dept. of Anthropology. October 2006.
48. Michele Bedard, PhD, Dept. of Psychology, April 2007-July 2009.
49. Joseph D. Tariman, PhD, Dept. of Biobehavioral Nursing and Health Systems, September 2007-February 2011.
50. Carrie Moylan, PhD, School of Social Work, May 2008-May 2012.
51. Sergio Casillas, PhC, Dept. of English, September 2008-June 2010.
52. Meghan H. Green, DNP, Dept. of Biobehavioral Nursing and Health Systems, February 2009-June 2010.
53. Sarah M. Magnuson-Whyte, DNP, Dept. of Family and Child Nursing, May 2009-June 2010.
54. Elizabeth Circo, PhC, School of Social Work, May 2010-June 2012.
55. Michael Burns, PhD, Dept. of Rehabilitation Medicine, May 2010-December 2013.
56. Christopher C. Imes, PhD, School of Nursing, Dept. of Family and Child Nursing, April 2012-June 2012.
57. Katharine Gries, PhD, Dept. of Pharmaceutics, October 2011-August 2014.
58. Anne Poppe, PhD, School of Nursing, Dept. of Biobehavioral Nursing and Health Systems, July 2014.
59. Renuka K. Garg, PhD, Dept. of Epidemiology, July 2015- August 2015.

#### **Fellows & Junior Faculty**

60. Elizabeth K. Vig, MD, Assistant Professor, Dept of Medicine, Division of Gerontology & Geriatric Medicine. July 2002-July 2007. Supported by K23AG019635, *Understanding and Implementing End of Life Preferences.*



61. Rosalina James, PhD, Senior Fellow, Dept. of Bioethics & Humanities, January 2006-October 2009. Supported by P50HG3374, Center for Genomics and Healthcare Equality, Wylie Burke, MD PhD, PI.
62. Wei-Ti Chen, RN, CNM, DNSc, Research Assistant Professor, Dept. of Family & Child Nursing, March 2009-February 2010.
63. Sabine Thomas, ND, Senior Fellow, Bastyr University Research Institute, August 2009-September 2012. Supported by T32AT000815, Training In Complementary and Alternative Medical Research, Leanna Standish, PI.
64. Ron Whitener, JD, Assistant Professor, Native American Law Center, School of Law, October 2007-July 2013.
65. Helen Lee, MD MPH, Acting Assistant Professor, Dept. of Anesthesiology, May 2010-December 2013. Supported by T32GM086270, Anesthesiology & Perioperative Medicine Research Training, Tonya Palermo, PI.
66. Michelle Montgomery, PhD, Center for Genomics and Healthcare Equality, July 2010- December 2013. Supported by P50HG3374, Center for Genomics and Healthcare Equality, Wylie Burke, MD PhD, PI.
67. Rebecca O'Connor, PhD RN, Assistant Professor, Dept. of Family & Child Nursing, School of Nursing. March 2014-June 2015.
68. Kara von Zyclin, MD, Senior Fellow, Dept. of Pediatrics & Critical Care Medicine, Seattle Children's Hospital, May 2014-June 2016.
69. Andrea Corage-Baden, PhD. Post-doc working on her own to publish her dissertation on health equity, June 2014-January 2015.

#### **NATIONAL/INTERNATIONAL SERVICE**

##### ***National Committee Membership***

- |               |   |
|---------------|---|
| 2009-2011     | Scientific Review Committee, National Palliative Care Research Center   |
| 2009-2013     | Research Committee, American Academy of Hospice and Palliative Medicine (AAHPM)   |
| 2010- present | Annual Assembly Scientific Review Subcommittee, AAHPM   |
| 2011-2012     | Abstract Reviewer, American Society of Bioethics and Humanities   |
| 2013-present  | Member, National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Data Safety Monitoring Board; <i>Fibromyalgia Activity Study with TENS (FAST)</i> , Kathleen Sluka (PI) |
| 2017-2019     | Member, Quality Committee and Clinical Quality Measures Working Group, AAHPM  |

##### ***External Reviewer***

##### Journals

- |      |                                      |
|------|--------------------------------------|
| 2004 | Archives of Internal Medicine        |
| 2005 | Social Science and Medicine          |
| 2007 | Disability and Rehabilitation        |
| 2008 | Journal of General Internal Medicine |
| 2008 | Journal of Palliative Medicine       |
| 2008 | Public Health Genomics               |
| 2009 | Palliative Care                      |
| 2009 | BMC Medical Ethics                   |
| 2011 | Intensive Care Medicine              |
| 2011 | Genome Medicine                      |
| 2015 | Academic Medicine                    |
| 2016 | JAMA Internal Medicine               |

##### Reports

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|------|---|
| 2003 | <i>Patterns of Health Care Use and Cost at the End of Life</i> , Manitoba Centre for Health Policy, Dept. of Community Health Sciences, Faculty of Medicine, University of Manitoba |
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##### Books

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|-----------|-------------------|
| 2007-2009 | Sage Publications |
|-----------|-------------------|

Grants

2007	Seattle Aging & Cancer Program (SCAP), Seattle Cancer Care Alliance
2007	University of Washington (UW) Research Royalty Fund (RRF)
2008-present	UW Institute for Translational Health Sciences (ITHS) Small Grants Program
2011	Wellcome Trust
2016	Multiple Sclerosis Society

**COMMUNITY SERVICE**

1982–2001	Founding Board Member and Treasurer, Washington DOC (Doctors Ought to Care, a tobacco prevention and advocacy group)
1984–1987	Peace Corps Volunteer, Community Health Sector (water/sanitation and maternal and child health projects), Kadiolo & Bamako, Mali (West Africa)
2003–2008	Hospice Volunteer, Evergreen Healthcare & Hospice, Kirkland, WA
2004	Member, Women’s Bioethics Project, Seattle, WA

**UW SERVICE**

2001–2015	Founding Member, Qualitative Methods in Health Research Writing Group
2003–2005	Advisory Board Member, UW Interdisciplinary Qualitative Research Group
2005–2011	Co-Chair, Quarterly Faculty Forum, Dept. of Bioethics & Humanities
2005–present	Discussion Leader, Biomedical Research Integrity Summer Training Program, Dept. of Bioethics & Humanities, School of Medicine
2005–2008	Co-Director, Critical Medical Humanities Research Cluster, Simpson Center for the Humanities
2007	Advisory Board Member, Oversight Committee for International Research Ethics Certificate Program, Dept. of Bioethics & Humanities
2007–2012	Member, Curriculum Committee, Dept. of Bioethics & Humanities
2008–2009	Member, Faculty Search Committee, Dept. of Bioethics & Humanities
2009–2013	Member, Committee to Promote Minority Student Recruitment, School of Medicine
2009–2013	Member, Council on Research and Graduate Education, School of Medicine
2012–2013	Chair/Member, Faculty Search Committees (n=2), Dept. of Bioethics & Humanities
2014–2015	Member, Faculty Search Committee, Dept. of Pediatrics, Division of Bioethics, Treuman Katz Center for Pediatric Bioethics, Seattle Children’s Hospital
2015	Member, Faculty Search Committee, Dept of Medicine, Division of Gerontology & Geriatric Medicine
2015-present	Member, Advance Care Planning Strategic Workgroup, UW Medical Center
2016-present	Member, Post Acute Care Committee, Data and Analytics Sub-committee, UW Medicine