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RAISING VOICES:

THE ETHICS OF DIALOGUE AND COMMUNICATION IN HEALTHCARE

APRIL 11 & 12, 2019

29TH ANNUAL KINSMAN STATEWIDE CONFERENCE

EUGENE, OREGON

Sponsored By:
OHSU Center for Ethics in HealthCare
PeaceHealth Eugene
University of Oregon

Raising Voices: The Ethics of Dialogue and Communication in Health Care

Keynote Speaker:

Autumn Fiester, Ph.D. – University of Pennsylvania

Conference Co-Chairs:

John Holmes, Ph.D., H.E.C.-C. – PeaceHealth Eugene
Lynn A. Jansen, Ph.D., R.N. – OHSU Center for Ethics in Health Care
Nicolae Morar, Ph.D. – University of Oregon

Target Audience:

Our audience includes dental, social work, medical, nursing, chaplaincy and public health professionals, as well as anyone who wishes to broaden their knowledge of current ethical issues and controversies associated with the promotion of health and well-being.

Learning Objectives:

1. Discuss the role traditional organizational health care structures, and social determinants of health, play in marginalizing the voices of under-represented and/or vulnerable patients.
2. Explore how innovative ethical, spiritual, and cultural analysis can offer insight into emerging ethics issues in communication and dialogue among individuals who work in and access health care systems.
3. Identify effective ethical strategies to assist healthcare professionals, patients and families elevate marginalized voices within the modern health care setting.
4. Learn novel policies and practices which aim to address health care advocacy and access for under-represented and/or vulnerable patients whose voices may not be part of the traditional structure of health care systems.

Credit Statement:

Accreditation

Oregon Health & Science University School of Medicine is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians.

Credit OHSU School of Medicine designates this live activity for a maximum of 13.75 *AMA PRA Category 1 Credits™.* Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Nursing Contact Hours

Participants can earn 14.08 continuing nursing education contact hours.

This continuing nursing education activity was approved by Oregon Nurses Association, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation.

Approval valid through: 4/12/2021
OCEAN ID: #2019-16

Requirements for Successful Completion of this CNE Activity

In order to obtain a Certificate of Successful Completion for this activity, the learner must complete the following criteria:

- Sign the attendance sheet.
- Attend the entire (two-day) conference.
- Complete the anonymous course evaluation prior to leaving on the second day.
- Return course evaluation in exchange for the printed conference certificate.

Participants who successfully complete the above requirements will receive a Certificate of Successful Completion before you leave on the second day of the conference.

Conflict of Interest Disclosures

The planners for this CNE activity declare no conflicts of interest in the development and implementation of this educational activity.

All presenters declare no conflicts of interest in the development and implementation of this educational activity.

Pharmacy:
This conference is approved for 13.75 continuing education (CE) license renewal requirements. The Oregon Board of Pharmacy recognizes CME designated as *AMA PRA Category 1 Credits™* to count towards pharmacist and certified pharmacy technician continuing education (CE) license renewal requirements. ***Retain the conference certificate for proof of attendance.***

Nursing Home Administrators: This conference is approved for 14.0 general hours, Agency approval number: 2019-01.

Social Work:
This course is approved for 14.50 continuing education credits. Social workers have the option to choose between the (a) Clinical Track or (b) Ethics Track depending on the breakout sessions (A, B, C, D, and E) individually chosen. Certificates will be awarded at the end of the conference. Social workers can request a personalized conference certificate indicating which track was chosen; the clinical or ethics track. To request this, email Molly Willis (willima@ohsu.edu).

Acknowledgments:

Special appreciation goes to John Kinsman for the endowment he established to provide partial support for this conference and The Kinsman Foundation for their support to help underwrite this conference. The conference organizers express their appreciation to Salem Health and the OHSU Center for Ethics in Health Care for their support in co-hosting this year's conference.

Raising Voices:

The Ethics of Dialogue and Communication in Health Care

FACULTY

Robin Baker, M.S., Ph.D.	**Melissa Monner, M.S.**
Oregon Health and Science University	*Oregon Health and Science University*
Kristen Beiers-Jones, R.N., M.N.	**Nicolae Morar, Ph.D.**
Oregon Health and Science University	*University of Oregon*
Daniel Bissell, M.D.	**Molly Osborne, M.D., Ph.D.**
Portland Street Medicine	*Portland VA Medical Center*
Clifford Coleman, M.D., Ph.D.	**Brian Park, M.D., M.P.H.**
Oregon Health and Science University	*Oregon Health and Science University*
Denise Dudzinski, Ph.D., M.T.S.	**Ryan J. Petteway, Dr.P.H., M.P.H.**
University of Washington	*Portland State University*
Autumn Fiester, Ph.D.	**Kelsey Priest, M.P.H.**
University of Pennsylvania	*Oregon Health and Science University*
Barbara Glidewell, M.B.S.	**Tera Roberts, D.N.P., F.N.P.-C.**
Oregon Health and Science University	*Virginia Garcia Memorial Health Center*
Drew Grabham, L.C.S.W.	**Berklee Robins, M.D., M.A.**
Oregon Health and Science University	*Oregon Health and Science University*
Melissa Graboyes, Ph.D., M.A., M.P.H.	**Camisha Russell, Ph.D.**
University of Oregon	*University of Oregon*
Barbara Hansen, M.A., R.N.	**F. Matthew Schobert, Jr. (Rev.) M.Div, L.C.S.W.**
Oregon Hospice and Palliative Care Association	*Portland VA Medical Center*
John Holmes, Ph.D., H.E.C.-C.	**William Toepper, M.D.**
PeaceHealth Eugene	*Portland Street Medicine*
Laura Hosford, M.A.	**Susan Tolle, M.D.**
PeaceHealth Eugene	*Oregon Health and Science University*
Lynn A. Jansen, Ph.D., R.N.	**Daniel Towns, D.O.**
Oregon Health and Science University	*Oregon Health and Science University*
Lauren Kaplan, P.M.H.N.P-BC	**Micki Varner, M.Div, B.C.C.**
Oregon Health and Science University	*Eugene PeaceHealth*
Caroline King, M.P.H.	**Chaplain Gregory Widmer, M.Div, B.C.C.**
Oregon Health and Science University	*Portland VA Medical Center*
Nicholas Luisi, M.S.N., R.N., C.C.R.N.	**Elizabeth Wheeler, Ph.D.**
PeaceHealth	*University of Oregon*
Lacey McCarley, R.N.	**Mary Wood, Ph.D.**
Portland Street Medicine	*University of Oregon*
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Oregon Health and Science University	*Oregon Health and Science University*
Jai Medina, M.A.	**Julia Zottola**
Two-Spirit Shamanic Healing	*Portland VA Medical Center*

Raising Voices:

The Ethics of Dialogue and Communication in Health Care

Thursday - Friday, April 11-12, 2019

FACULTY DISCLOSURE INFORMATION

In accordance with the requirements of the Standards for Commercial Support of the Accreditation Council for Continuing Medical Education, each instructor and member of the planning committee has been asked to disclose any relevant financial relationships with commercial interests (defined as: any entity producing, marketing, re-selling, or distributing health care goods or services consumed by, or used on, patients). The information disclosed for this activity is listed below.

In addition, the planners and instructors listed have agreed that all recommendations involving clinical medicine will be based on evidence that is generally accepted within the profession as adequate justification for their indications and contraindications in the care of patients; that all scientific research used in support or justification of a patient care recommendation will conform to the generally accepted standards of experimental design, data collection and analysis; and that material to be presented will be made available for advance peer review if requested.

Robin Baker, M.S., Ph.D.	Nothing to disclose
Kristen Beiers-Jones, R.N., M.N.	Nothing to disclose
Daniel Bissell, M.D.	Nothing to disclose
Clifford Coleman, M.D., Ph.D.	Nothing to disclose
Denise Dudzinski, Ph.D., M.T.S.	Nothing to disclose
Autumn Fiester, Ph.D.	Nothing to disclose
Barbara Glidewell, M.B.S.	Nothing to disclose
Drew Grabham, L.C.S.W.	Nothing to disclose
Melissa Graboyes, Ph.D., MA, M.P.H.	Nothing to disclose
Barbara Hansen, M.A., R.N.	Nothing to disclose
John Holmes, Ph.D., H.E.C.-C.	Nothing to disclose
Laura Hosford, M.A.	Nothing to disclose
Lynn A. Jansen, PhD, RN	Nothing to disclose
Lauren Kaplan, P.M.H.N.P-BC	Nothing to disclose
Caroline King, M.P.H.	Nothing to disclose
Nicholas Luisi, M.S.N., R.N., C.C.R.N.	Nothing to disclose
Lacey McCarley, R.N.	Nothing to disclose
Keren McCord, L.C.S.W., O.S.W.-C	Nothing to disclose
Jai Medina, M.A.	Nothing to disclose
Melissa Monner, M.S.	Nothing to disclose
Nicolae Morar, Ph.D.	Nothing to disclose
Molly Osborne, MD, PhD	Nothing to disclose
Brian Park, M.D., M.P.H.	Nothing to disclose
Ryan Petteway, Ph.D.	Nothing to disclose
Kelsey Priest, M.P.H.	Nothing to disclose
Tera Roberts, D.N.P., F.N.P.-C.	Nothing to disclose
Berklee Robins, M.D., M.A.	Nothing to disclose
Camisha Russell, Ph.D.	Nothing to disclose
F. Matthew Schobert Jr., (Rev.) M.Div, L.C.S.W.	Nothing to disclose

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William Toepper, M.D.	Nothing to disclose
Susan Tolle, M.D.	Nothing to disclose
Daniel Towns, D.O.	Nothing to disclose
Micki Varner, M.Div, B.C.C.	Nothing to disclose
Elizabeth Wheeler, Ph.D.	Nothing to disclose
Chaplain Gregory Widmer, M.Div., CCC	Nothing to disclose
Mary Wood, Ph.D.	Nothing to disclose
David Zonies, M.D., M.P.H.	Nothing to disclose
Julia Zottola	Nothing to disclose

PROGRAM PLANNING COMMITTEE	
John Holmes, Ph.D., H.E.C.-C	Nothing to disclose
Laura Hosford, M.A.	Nothing to disclose
Lynn A. Jansen, Ph.D., R.N.	Nothing to disclose
Keren McCord, L.C.S.W., O.S.W.-C	Nothing to disclose
Nicolae Morar, Ph.D.	Nothing to disclose
Berklee Robins, M.D., M.A.	Nothing to disclose
Camisha Russell, Ph.D.	Nothing to disclose
Susan Tolle, M.D.	Nothing to disclose
Micki Varner, M.Div., B.C.C.	Nothing to disclose

Raising Voices:
The Ethics of Dialogue and Communication in Health Care

Thursday, April 11, 2019

8:00 – 8:15	Welcome Nicolae Morar, Ph.D., University of Oregon Michael Schill, President, University of Oregon John Holmes, Ph.D., PeaceHealth Location: PLAYWRIGHTS			
8:15 – 9:30	Keynote: Weaponizing Principles: Clinical Ethics & the Plight of the Morally Vulnerable Autumn Fiester, Ph.D. Location: PLAYWRIGHTS			
9:30 – 9:40	Walk Time			
Obscured Voices in Healthcare				
9:40 – 10:50	A1 Medical Decision Making: Exploring Generational and Cultural Differences Using Graphic Narrative Molly Osborne, M.D., Ph.D. Julia Zottola Location: PLAYWRIGHTS	A2 Scrubs aren't Really Unisex: A Journey across Genders as a Patient, Nurse and Educator Nicholas X. Luisi, M.S.N, R.N., C.C.R.N., U.S. Army CPT (Ret.) Location: DIRECTORS	A3 The Lost Voice: Elderly Trauma Patients & The Downside of Presumed Consent Susan Tolle, M.D. David Zonies, M.D., M.P.H. Location: HANSBERRY	A4 Understanding & Addressing Gender Violence in Medical Training: An Ethical Imperative Caroline King, M.P.H. Kelsey Priest, M.P.H. Location: WILDER
10:50 – 11:10	Break (snack provided)			
Organizational and Structural Pressures which Interfere with Patient Voices				
11:10 – 12:20	B1 We TALK about Equity, but what do we DO about Equity? Organizing for all Oregonians to be able to read their pill bottles in a Language they Understand Kristen Beiers-Jones, R.N., M.N. Lauren Kaplan, P.M.H.N.P-B.C. Brian Park, M.D., M.P.H. Location: DIRECTORS	B2 You Only Die Once: How Health Care Providers May Contribute to a Less-Than-Perfect Death—by Creating Pressure to Have One! Barb Hansen, M.A., R.N. Location: PLAYWRIGHTS	B3 Coping with Moral Distress in Clinical Practice Denise Dudzinski, Ph.D., M.T.S. Location: HANSBERRY	B4 X-Ray This: Conceptual & Methodological Considerations for Connecting People, Place, & (Bio)Politics in Patient-Provider Settings Ryan Petteway, Dr.P.H., M.P.H. Location: WILDER
12:20 – 1:05	Lunch			
Extended Workshop: Ethical Issues in Dialogue and Communication in Healthcare				
1:05 – 2:40	Techniques for Effective Dialogue in Challenging Ethics Consultations Autumn Fiester, Ph.D. Location: PLAYWRIGHTS			
2:40 – 2:45	Walk Time			
2:45 – 3:45	Case A Bonnie: Bad News vs. Autonomy Barbara Glidewell, M.B.S. Location: DIRECTORS	Case B Mr. Williams: Decision-Making Capacity Laura Hosford, M.A. Location: PLAYWRIGHTS	Case C Mr. Brown: The Unrepresented Patient Keren McCord, L.C.S.W., O.S.W.-C. Location: HANSBERRY	Case D Patient Refusal of treatment Melissa Monner, M.S. Location: WILDER
3:45 – 4:00	Coffee break			
4:00 –5:00	Case Follow-up & Ethics Discussion Autumn Fiester, Ph.D. Location: PLAYWRIGHTS			
5:00	Thursday's reflection - Lynn A. Jansen, Ph.D., R.N.			

Friday, April 12, 2019

8:00 – 8:05	**Welcome Back** - Lynn A. Jansen, Ph.D., R.N. **Location:** PLAYWRIGHTS			
8:05 – 9:20	**Health Literacy & the Ethics of Clear Communication** Clifford Coleman, M.D., M.P.H. **Location:** PLAYWRIGHTS			
9:20 – 9:30	**Walk Time**			
Socially and Culturally Situated Voices in Healthcare				
9:30 – 10:40	C1 **Structural, Social, and Self Stigma: Ethical Dimensions of Health Disparities Experienced by Individuals who use Drugs** Robin Baker, M.S., Ph.D. **Location:** PLAYWRIGHTS	C2 **Bioethics and Culture: Implications in Immigrant and Refugee Mental Health** Daniel Towns, D.O. **Location:** DIRECTORS	C3 **Global Health Ethics: Appropriate Training for the Next Generation** Melissa Graboyes, Ph.D., M.A., M.P.H. **Location:** HANSBERRY	C4 **My Brain has a Pair of Scissors: Learning from the Stories of Patients with Disabilities** Elizabeth Wheeler, Ph.D. Mary Wood, Ph.D., M.A. **Location:** WILDER
10:40 – 11:00	**Break (snack provided)**			
Insights from Philosophical, Spiritual, and Cultural Analyses				
11:00 – 12:10	D1 **Beyond Biology or Disparity: A Harder Way of Thinking About Race** Camisha Russell, Ph.D. **Location:** PLAYWRIGHTS	D2 **Moral Injury: A Soulful Journey for Veterans, Providers, and Community Members** F. Matthew Schobert, M.Div, L.C.S.W. Gregory J. Widmer, M.Div, CCC **Location:** DIRECTORS	D3 **Bridging Indigenous Wisdom and Western Ways: Healing Practices for a Modern World** Jai Medina, M.A. **Location:** HANSBERRY	D4 **"Don't tell the Doctor this but…": Ethical Challenges in Medical Interpretation** Daniel Towns, D.O. **Location:** WILDER
12:10 – 1:00	**Lunch**			
1:00 - 1:55	**So Tired of Life: What Does Respect Require?** Lynn A. Jansen, Ph.D., R.N. **Location:** PLAYWRIGHTS			
1:55 – 2:05	**Walk Time**			
Meeting the Patient Where They Are				
2:05 – 3:30	E1 **Street Medicine: Bringing Care to our Neighbors who are Living on the Streets** Daniel Bissell, M.D. Drew Grabham, L.C.S.W. Lacey McCarley, R.N. William Toepper, M.D. **Location:** DIRECTORS	**This session is no longer available.**	E3 **Vulnerable & Marginalized Patients: Now you See Them, Now you Don't. How to Truly See & Hear Your Patients So that They will Come to See You.** Tera Roberts, D.N.P., F.N.P.-C. **Location:** HANSBERRY	E4 **Listening for Non-Religious Belief Systems in Healthcare Ethics Consultation** Micki Varner, M.Div, B.C.C. **Location:** PLAYWRIGHTS
3:30 – 3:45	**Coffee break**			
3:45 – 4:50	**Conference Wrap-Up: What was our vision? What did we achieve? What were the surprises?** John Holmes, Ph.D., H.E.C.-C. Nicolae Morar, Ph.D. **Location:** PLAYWRIGHTS			
4:50 – 5:00	**Thank you for joining us at this year's Kinsman Conference!**			

2019 Kinsman Bioethics Conference

Raising Voices:

The Ethics of Dialogue and Communication in Health Care

PLENARY SESSION	
Title	Health Literacy & the Ethics of Clear Communication
Speaker	Cliff Coleman, M.D., M.P.H
Date	Friday, April 12, 2019
Time	8:05 – 9:20 AM
Location	Playwrights Hall

PLENARY SESSION OBJECTIVES

- Recognize the prevalence of low health literacy among patient populations.
- Describe the imperative for using a "universal precautions" approach to health communication.
- List five best practices to help ensure clear communication with patients and caregivers.

PLENARY SESSION SPEAKER

Dr. Coleman is a national expert in the field of health literacy. His research and teaching focuses on improving health literacy and clear communication training for healthcare professionals. In 2010 and 2014 he was the principle investigator on a national consensus studies to identify a comprehensive set of health literacy educational competencies and clear communication practices for health professionals.

Cliff is an Associate Professor of Family Medicine at the Oregon Health & Science University (OHSU) School of Medicine, where he is responsible for the curriculum on health communication, professionalism and ethics. In 2014 he developed and implemented the first known health professions curriculum which integrates health literacy teaching as a running thread throughout the pre-clinical years. He also runs the curriculum on culturally responsive care. In 2018 he received the school's Excellence in Education Award for "outstanding efforts in leading educational endeavors, creating novel curriculum, and providing outstanding learning environments,"

Cliff practices at a Federally Qualified Health Center clinic, and attends on the OHSU inpatient Family Medicine service. His clinical interests include healthcare for medically complex individuals and underserved populations.

Cliff received his Bachelor's Degree in psychology from Dartmouth College, and his MD degree from Stanford University. He completed a dual residency in Family Medicine and Public Health & Preventive Medicine at OHSU, with a Master's of Public Health from Portland State University in 2004.

School of MEDICINE

OHSU

yourMD OHSU CURRICULUM TRANSFORMATION

Health Literacy & the Ethics of Clear Communication

Cliff Coleman, MD, MPH
Associate Professor of Family Medicine
Clinical Thread Director for Professionalism, Ethics, and Communication
Annual Kinsman Bioethics Conference
April 12, 2019

Disclosures/Conflict of Interest

I have no relevant financial relationships with commercial interests.

Session objectives

- ❑ Recognize the prevalence of low health literacy among patient populations.
- ❑ Describe the imperative for using a "universal precautions" approach to health communication.
- ❑ List 5 best practices to help ensure clear communication with patients. and caregivers

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Overview

- Literacy in America
- Health literacy
- Universal precautions for communication
- Best practices for spoken communication:

1. "Universal precautions"
2. Plain non-jargon language
3. Limit information to "need-to-know" items
4. Elicit questions in an open-ended manner
5. Use "teach back" to confirm adequate communication

Active Learning

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"The greatest problem with communication is the illusion it has occurred"

- Attributed to George Bernard Shaw

Does unequal access to complete and understandable health information drive all other healthcare inequities…?

Literacy in America

National Assessment of Adult Literacy, 2003

43%
of English-speaking US adults
have limited literacy skills

(Kutner et al, 2005)

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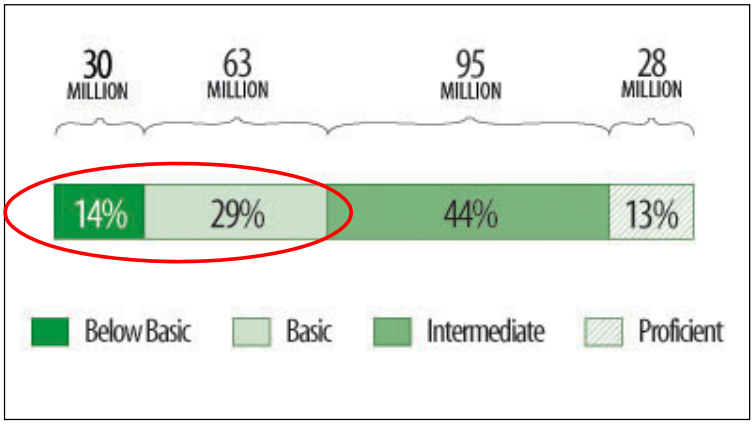
Percentage of U.S. adults (English- and Spanish-speaking) by literacy level



(Kutner et al, 2005)

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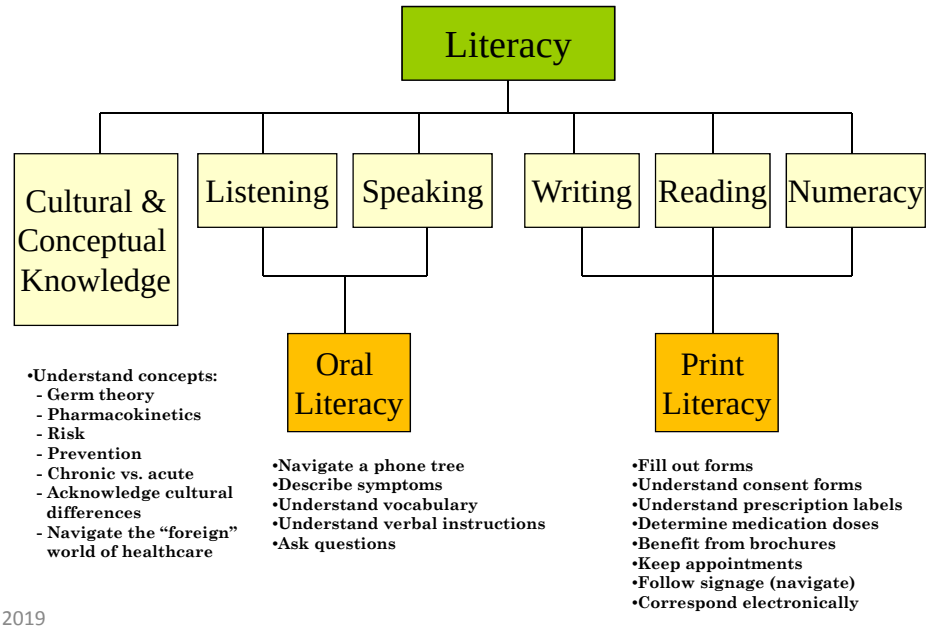
Literacy domains and examples of associated healthcare-related tasks



(Adapted from Neilsen-Bohlman et al, 2004)

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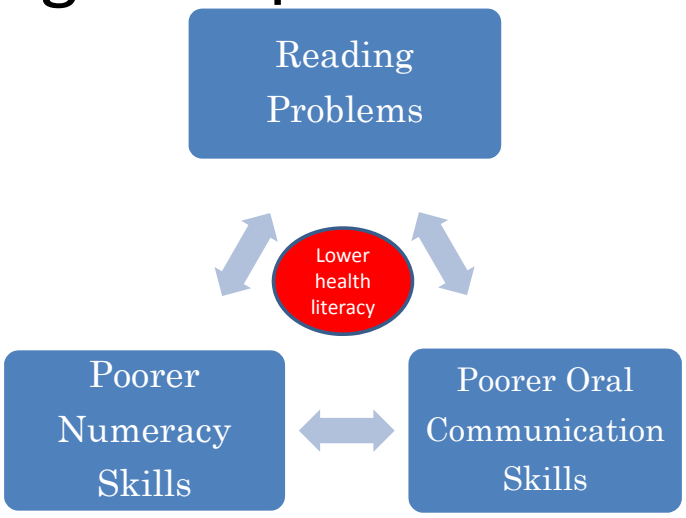
Reading skills predict other skills



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Reading ability vs. comprehension

- Most Americans can read (and write, speak, listen, and use numbers)
- The problem is language comprehension and utilization

Reading ability vs. comprehension

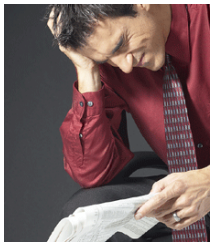
In a study of adults with literacy below the 6th grade level:

- 71% correctly read the instruction to "take two tablets by mouth twice daily"
- Only 35% could demonstrate the number of pills to actually take

(Davis et al, 2006)

Health literacy skills of US adults

- 42% of patients at two public hospitals misinterpreted directions to “take medication on an empty stomach”



(Williams et al, 1995)

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Please read this out loud…

"Do not tlit the nemiceps dnoyeb the stimil. Eseht sgnittes lliw erusne the reporp tnemngila of the refsnart rod nihtiw the elpmas redloh. Siht lliw osla tneverp a ylwen-decudortni elpmas morf gnikaerb the derettacskcab nortcele rotceted"

What does it mean?

Why is it hard to understand?

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The answer…

"Do not tilt the specimen beyond the limits. These settings will ensure the proper alignment of the transfer rod within the sample holder. This will also prevent a newly-introduced sample from breaking the backscattered electron detector."

Literacy is "context specific"

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Video excerpt: Health Literacy and Patient Safety

(AMA Foundation, 2008)

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Health Literacy

The degree to which individuals have the capacity to obtain, process, communicate and understand basic health information and services needed to make health decisions

(Somers & Mahadevan, 2010)

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Low health literacy is associated with...

- ↓ Use of preventive services
- ↓ Understanding of medication use and prescription label instructions
- ↓ Overall health status
- ↑ Use of emergency care
- ↑ Rates of hospitalization
- ↑ Mortality rates among seniors
- ↑ Racial health disparities

(Berkman et al, 2011)

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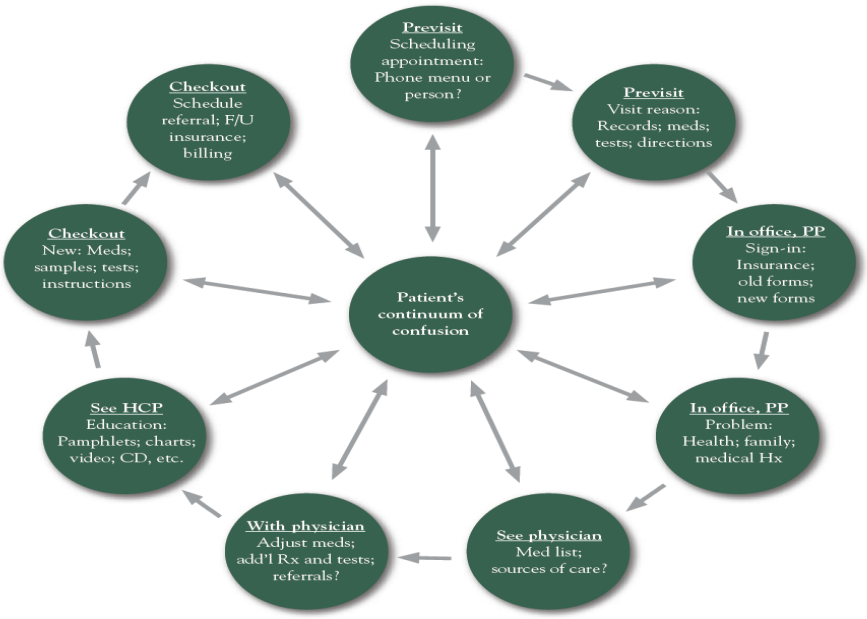
Figure 4. The continuum of confusion: "Now go home and safely manage your care"



ED—Emergency department
F/U—Follow up
HCP—Health care professional
PP—Prior to seeing physician

(AMA Foundation, 2007)

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The average Oregonian with low health literacy:

- White
- Born in U.S.
- Spoke English as first language

Disproportionately affected populations:

- Seniors
- People eligible for Medicaid
- Racial and ethnic minorities
- People who's first language was not English
- People with chronic diseases
- People with less education

(Kutner et al, 2005)

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Rapid Estimate of Adult Literacy in Medicine (REALM)

Fat	Fatigue	Allergic
Flu	Pelvic	Menstrual
Pill	Jaundice	Testicle
Dose	Infection	Colitis
Eye	Exercise	Emergency
Stress	Behavior	Medication
Smear	Prescription	Occupation
Nerves	Notify	Sexually
Germs	Gallbladder	Alcoholism
Meals	Calories	Irritation
Disease	Depression	Constipation
Cancer	Miscarriage	Gonorrhea
Caffeine	Pregnancy	Inflammatory
Attack	Arthritis	Diabetes
Kidney	Nutrition	Hepatitis
Hormones	Menopause	Antibiotics
Herpes	Appendix	Diagnosis
Seizure	Abnormal	Potassium
Bowel	Syphilis	Anemia
Asthma	Hemorrhoids	Obesity
Rectal	Nausea	Osteoporosis
Incest	Directed	Impetigo

# correctly pronounced	Grade reading level
0-18	≤3rd
19-44	4th-6th
45-60	7th-8th
61-66	≥9th

The average English-speaking U.S. adult reads at the 8th grade level (Kutner et al, 2005)

Source:
Davis, T., Crouch, M. & Long, S. (1993). Rapid Estimate of Adult Literacy in Medicine. Shreveport, LA: Louisiana State University Medical Center

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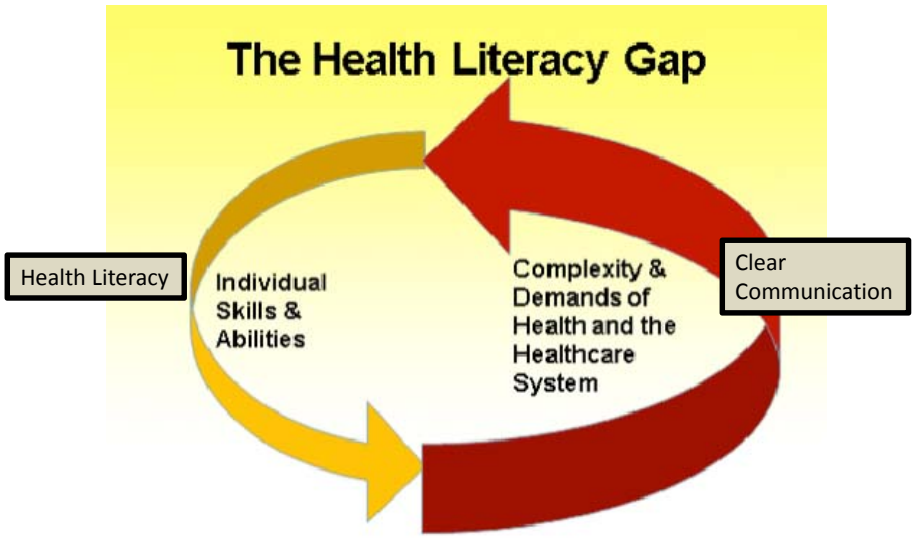

Adapted from Ruth Parker: http://www.iom.edu/~/media/Files/Activity%20Files/PublicHealth/HealthLiteracy/Parker.pdf

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Clear communication

Written or spoken communication which helps patients to understand and act on health care information

(Pfizer Inc., 2004)

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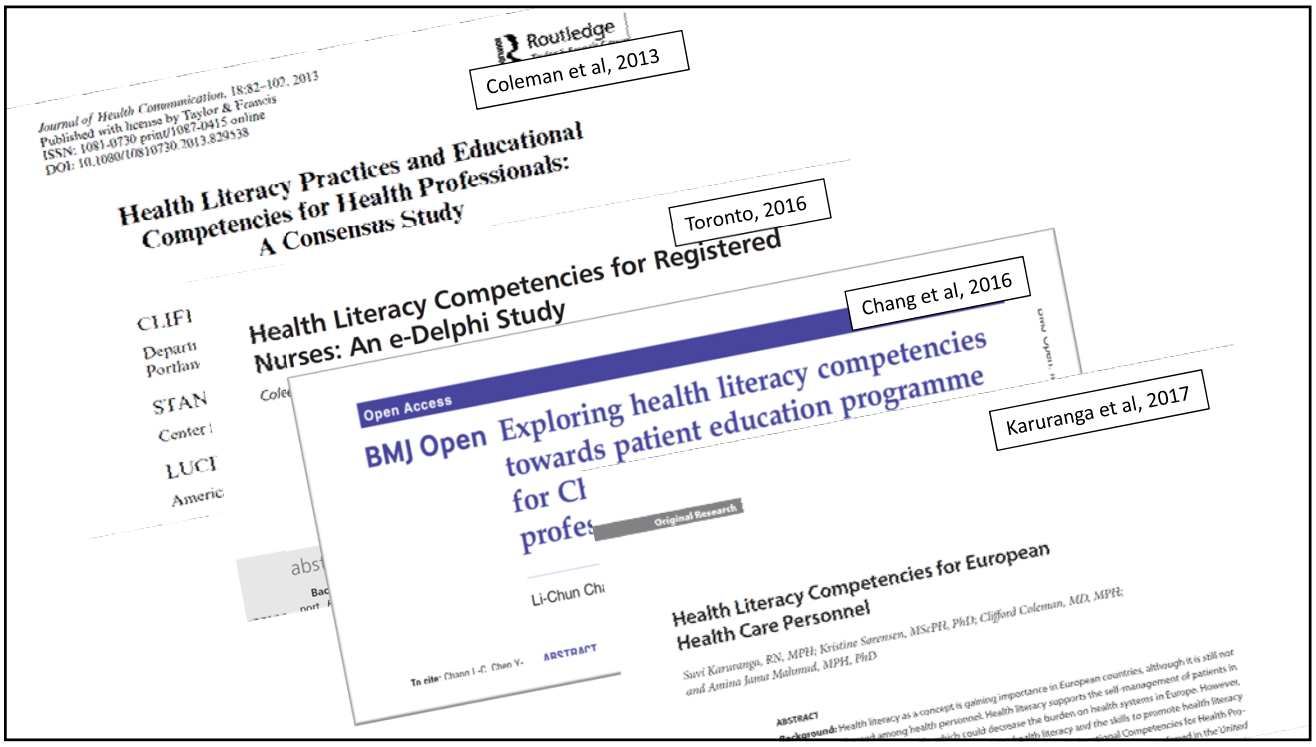

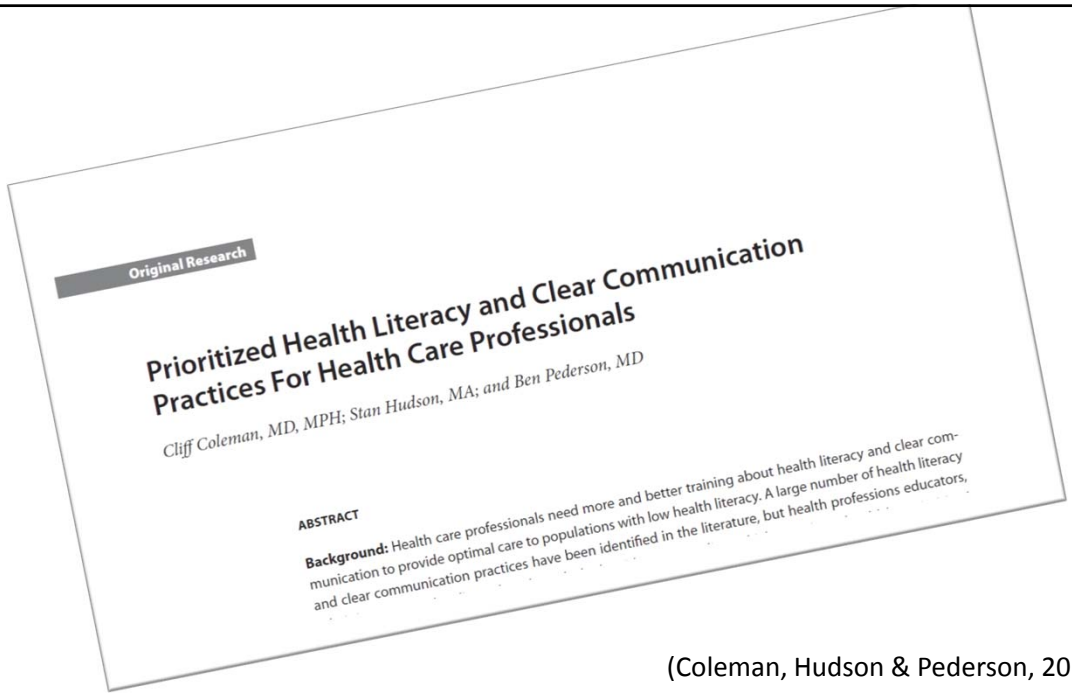

(Coleman, Hudson & Pederson, 2017)

Top 5 Best Practices

1. Practice “universal precautions” for health communication
2. Use plain non-jargon language to facilitate understanding
3. Limit information to 1-3 “need-to-know” items
4. Elicit questions in an open-ended manner
5. Use “teach back” to confirm adequate communication

(Coleman, Hudson & Pederson, 2017)

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Top 5 Best Practices

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(Coleman, Hudson & Pederson, 2017)

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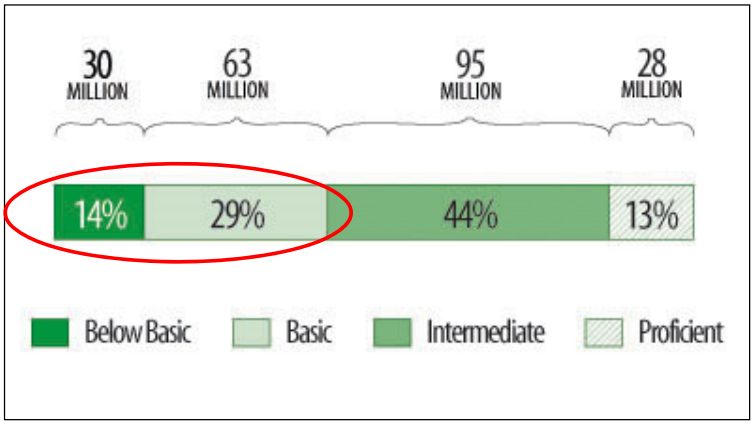
Low health literacy is ubiquitous



(Kutner et al, 2005)

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Shame

- Patients hide their literacy problems
  - "I forgot my glasses"
  - "I'm not going to fill out another one of these stupid forms."
  - "I'll read it with my husband when I get home."
- Over 60% have not told their spouse

(Parikh et al, 1996)

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"Red flags" are inadequate

- Forms incomplete or incorrectly filled out
- Non-adherence to medications
- Can't name, medications, their purpose, or how taken
- Frequently missed appointments
- "I forgot my glasses"
- Anger

(AMA Foundation, 2007)

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You can't tell by looking

- Physicians are poor at estimating patients' health literacy skills.

(Coleman, Hudson & Maine, 2013)

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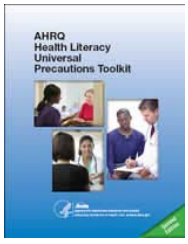
Screening is inappropriate

- Condition is too common.
- Screening is not acceptable to patients.
- Specific interventions are lacking.
- Risks outweigh benefits.

(Paasche-Orlow & Wolf, 2008)

"Universal precautions"

- Treat all patients with the same dignity and respect.
- Assume all are at risk for low health literacy in any given moment.
- Use clear communication best practices, including plain language, as your default style with all patients.



(Dewalt et al, 2010)

Won't some patients be offended?

- Studies show that all patients prefer clear communication.

(Kripalani & Weiss, 2006)

- Clear plain-language communication is not "dumbing down."

(HHS Office of Disease Prevention and Health Promotion, 2012)

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Top 5 Best Practices

1. Practice "universal precautions" for health communication
2. Use plain non-jargon language to facilitate understanding
3. Limit information to 1-3 "need-to-know" items
4. Elicit questions in an open-ended manner
5. Use "teach back" to confirm adequate communication

(Coleman, Hudson & Pederson, 2017)

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Use plain non-jargon language

- Even experienced clinicians use jargon

  (Castro et al, 2007)
- Jargon = Specialized words, phrases, or concepts, which might not be fully understood, or may be misinterpreted by the recipient

  (Nielsen-Bohlman et al, 2004)

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Jargon Blitz https://www.youtube.com/watch?v=uu7v4yRc4vw

Three types of medical jargon

Table 2: Medical Jargon

Jargon Type	Description	Examples		
		Words	**Phrases**	**Concepts**
Technical	Words, phrases or concepts with meaning only in a clinical context	• Glucometer • Cardiologist • Insomnia • Abdomen • Cath lab • Ortho • Hypertension • Hemoglobin A1c • Speculum	Acronyms: • GERD • COPD • UTI • IV fluid • Advance directive • After Visit Summary (AVS)	• Follow-up • Referral • Chronic • PRN • PCP • Contagious
Quantitative	Words, phrases or concepts requiring clinical judgment or knowledge	• Unlikely • Increased • Tablespoon • High fever	• Excessive wheezing • Twice daily	• Risk
Lay	Words, phrases or concepts with two or more meanings or interpretations, one of which is medical	• Stable • Abnormal • Stool • Frequency • Course • Positive • Negative • Tissue • Tongue blade • Admitted • Diet	Idioms: • Come down with • Break out • Run a fever • Stomach bug	• Take on an empty stomach

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(Coleman & Hadden, unpublished)

C. Coleman 2019 Health and the City https://www.youtube.com/watch?v=ux6c3wYzRJM

Write explicit instructions

Prescription labels often include technical, quantitative, and lay jargon terms, and require a high degree of numeracy

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Jargon – bottom line

- You cannot know what will be jargon to any given patient in any given situation
- The only solution is:

1. Use universal precautions, and
2. Check for understanding (see “teach-back” later)

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Top 5 Best Practices

1. Practice "universal precautions" for health communication
2. Use plain non-jargon language to facilitate understanding
3. Limit information to 1-3 "need-to-know" items
4. Elicit questions in an open-ended manner
5. Use "teach back" to confirm adequate communication

(Coleman, Hudson & Pederson, 2017)

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Limit information to 1-3 "need-to-know" items

- Patients typically retain < 50% of health information
- Illness and stress are major barriers to learning

❑Focus on what people need to <u>do</u>, not on facts

(Kripalani & Weiss, 2006 ; Schwartzberg et al, 2007)

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Top 5 Best Practices

1. Practice "universal precautions" for health communication
2. Use plain non-jargon language to facilitate understanding
3. Limit information to 1-3 "need-to-know" items
4. Elicit questions in an open-ended manner
5. Use "teach back" to confirm adequate communication

(Coleman, Hudson & Pederson, 2017)

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Invite real questions

Don't ask: *"Do you have any questions?"*

Closed-ended

- Implies that you expect them to "get it." If they don't, something must be wrong with them…
- Patients do not answer this honestly.

Ask: *"What questions do you have?"*

Open-ended

- Implies an expectation that patients should have questions!

(DeWalt et al, 2010)

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Top 5 Best Practices

1. Practice "universal precautions" for health communication
2. Use plain non-jargon language to facilitate understanding
3. Limit information to 1-3 "need-to-know" items
4. Elicit questions in an open-ended manner
5. Use "teach back" to confirm adequate communication

(Coleman, Hudson & Pederson, 2017)

Teach-back to confirm understanding

Don't ask: *"Do you understand?"*

- Implies that patients *should* understand. If they don't, something must be wrong with them…
- Patients do not answer this honestly.

Use: a "teach-back" or "show-me" technique. Say:

- *"I want to make sure I have explained things well. In your own words how are you going to use this medicine?"*
- *"How would you explain this plan to your partner?"*
- *"Show me how you use this inhaler."*

(Schillinger et al, 2003)

Teach Back http://www.nchealthliteracy.org/teachingaids.html

Research on "teach back"

- A "top safety practice."

(National Quality Forum, 2003)

- Associated with better glycemic control in people with diabetes.

(Schillinger et al, 2003)

- Does not take longer than standard care.

(Schillinger et al, 2003; Kripalani & Weiss, 2006)

Barriers to adopting clear communication

- An estimated $106 billion to $238 billion is “wasted” on low health literacy annually

(Vernon et al, 2007)

- But to health systems, this may just be profit…

Session objectives

☑ Recognize the prevalence of low health literacy among patient populations.

☑ Describe the imperative for using a “universal precautions” approach to health communication.

☑ List 5 best practices to help ensure clear communication with patients. and caregivers

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2019 Kinsman Bioethics Conference

Raising Voices:

The Ethics of Dialogue and Communication in Health Care

SESSION C1	
Theme	Socially and Culturally Situated Voices in Healthcare
Title	Structural, Social, and Self Stigma: Ethical Dimensions of Health Disparities Experienced by Individuals who use Drugs
Speaker(s)	Robin Baker, M.S., Ph.D.
Date	Friday, April 12, 2019
Time	9:30 – 10:40 AM
Location	Playwrights Hall

SESSION C1 OBJECTIVES

- Discuss the landscape of health services and the health disparities experienced by individuals who use drugs.
- Define stigma and distinguish the three types of stigma that impact access and quality of health services for individuals who use drugs.
- Interpret the health disparities experienced by individuals who use drugs and evaluate different approaches to treatment with an ethical lens.

SESSION C1 SPEAKER

Robin Baker, M.S., Ph.D.

Dr. Robin Baker is an Assistant Professor in the OHSU-PSU School of Public Health. Dr. Baker graduated with a doctorate in Health Systems and Policy and teaches courses in the Health Management and Policy, Primary Health Care & Health Care Disparities, and Public Health Practice MPH programs. Her research interests include evidence-based treatment for substance use disorders, integration of behavioral health and primary care, care management for individuals with mental illness, and systemic and organizational factors that impact quality and access of services.

OHSU Portland State University | SCHOOL OF PUBLIC HEALTH

National Drug Abuse Treatment Clinical Trials Network

Structural, social, and self stigma: Ethical dimensions of health disparities experienced by individuals who use drugs

ROBIN BAKER, PHD

APRIL 12, 2019

Who am I?

- PhD in Health Systems & Policy from the OHSU-PSU School of Public Health
- Assistant Professor in the OHSU-PSU School of Public Health
- Research experience includes:
  - Navigation of stigma and the resilience of formerly incarcerated women
  - Opportunities and challenges of integrating behavioral health and primary care
  - Implementation of MOUD in primary care, criminal justice settings, and HIV clinics

Learning Objectives

1. Discuss the landscape of health services and the health disparities experienced by people who use drugs
2. Define stigma and distinguish the three types of stigma that impact access and quality of health services for people who use drugs
3. Interpret the health disparities experienced by people who use drugs and evaluate different approaches to treatment with an ethical lens

Glossary

SUD – Substance Use Disorder

OUD – Opioid Use Disorder

MOUD – Medications for Opioid Use Disorders (often referred to as MAT)

PWUD – People Who Use Drugs

PWID – People Who Inject Drugs

IDU – Injection Drug Use

Tx – Treatment

CJ – Criminal Justice

HIV - Human Immunodeficiency Virus

HCV – Hepatitis C Virus

SMI – Serious Mental Illness

In 2016, ~48.5 million aged 12+ reported use of illicit drugs or misuse of prescription drugs in the past year [1]

The Continuum of Drug Use

No Use – person is not using a particular drug

Experimental Use – person tries a substance and may or may not use it again, use motivated by curiosity and peer influence

Social Use – use is irregular, usually confined to special occasions, availability, accessibility, and affordability influence use

Regular Use – use becomes more frequent, person still using in a controlled manner but use becomes a fairly integral part of their life

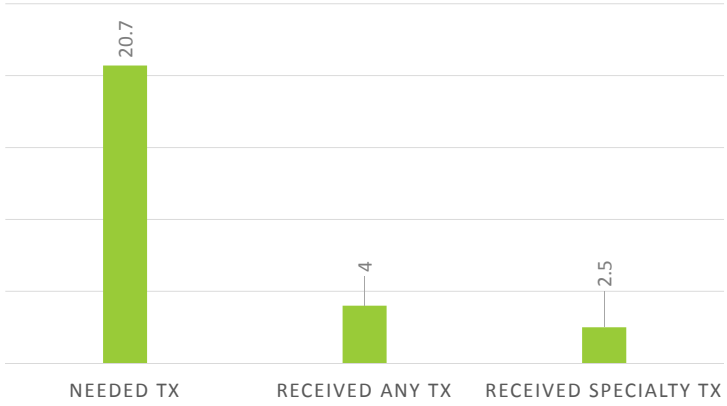
Problem Use – use tends to become excessive, using higher doses due to increased tolerance or trying stronger drugs, begins to compromise personal values and/or health

Dependence Use – a serious medical & psychological condition in which one is physically dependent on the substance to function

Public health concerns

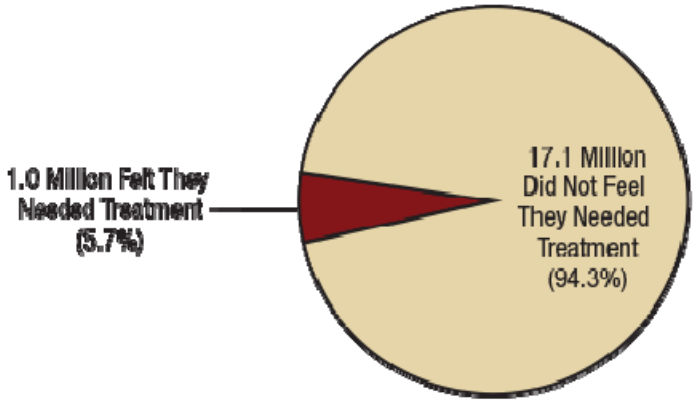
- In 2015, 9% of HIV infections were attributed to injection drug use [2]
- From 2010 to 2016, there was a ~3.5 fold increase in reported cases of acute HCV infection (850 to 2,967 reported cases) – the increase was associated with the rise in the number of PWID [3]
- In 2015, there were 547,543 emergency department visits for all drug-related poisonings [4]
- In 2016, 63,632 drug overdose deaths occurred – 66.4% involved prescription and/or illicit opioids [5]
  - Illicitly manufactured fentanyl (19,413 deaths)
  - Prescription opioids (17,087 deaths)
  - Heroin (15,469 deaths)

In 2017, 20.7 million people aged 12+ needed substance use treatment, but only 4 million people received any treatment in the past year and only 2.5 million received treatment at a specialty facility.



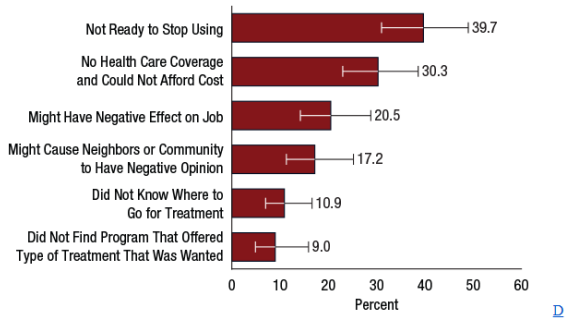
[6]

Perceived Need for Substance Use Treatment among People Aged 12 or Older Who Needed but Did Not Receive Specialty Substance Use Treatment in the Past Year: 2017



18.2 Million People Needed but Did Not Receive Specialty Substance Use Treatment

Figure 67. Reasons for Not Receiving Substance Use Treatment in the Past Year among People Aged 12 or Older Who Felt They Needed Treatment in the Past Year: Percentages, 2017



Note: Respondents could indicate multiple reasons for not receiving substance use treatment; thus, these response categories are not mutually exclusive.

[6]

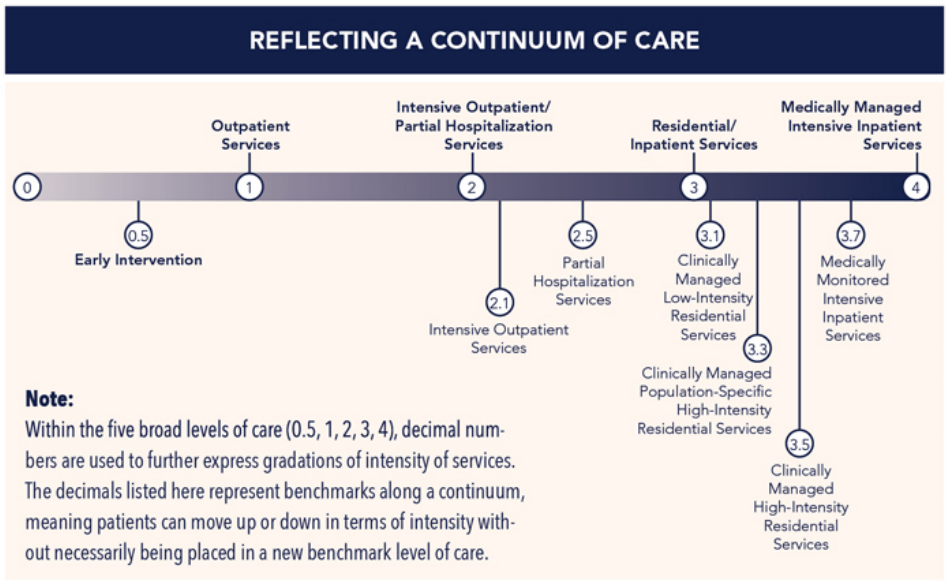
Disparities Experienced by PWUD

PWUD are at greater risk for contracting and spreading infectious diseases such as HIV and HCV, due to injection drug use and risky sexual behavior [7]

Use of some substances—including alcohol, heroin, prescription stimulants, methamphetamine, and cocaine—is associated with increased risk for cardiovascular and heart disease [8]

25% of people with SMI also have a SUD and 10% of people with SUD have SMI (SMI = includes major depression, schizophrenia, bipolar disorder, & other mental disorders that cause serious impairment) [9]

What is the ideal treatment system?



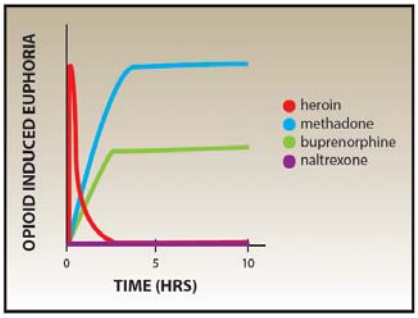
https://www.asamcontinuum.org/knowledgebase/what-are-the-asam-levels-of-care/

Medications for the Treatment of OUD

The Food and Drug Administration (FDA) has approved the following medications the treatment of OUD:

- Methadone
- Buprenorphine
- Naltrexone

The ASAM guideline recommends that all OUD medications be offered in conjunction with the appropriate level of psychosocial treatment, which is most often delivered in the context of outpatient treatment (either level 1 outpatient or level 2 intensive outpatient) [10]



What are barriers to treatment?

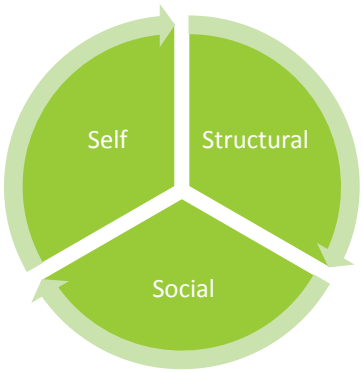
Insurance Barriers

- Lack of insurance
- Lack of awareness regarding parity
- Fail-first & prior authorization policies

Health System

- Fragmented health system
- Lack of education in SUD
- Lack of metrics or measures to assess quality
- Problematic treatment philosophies

Stigma is enacted at 3 levels



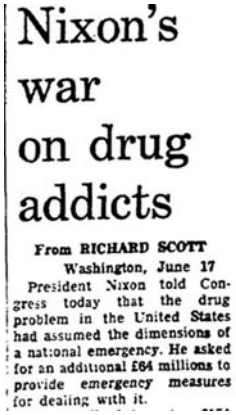
1. Structural Stigma – opportunities and resources denied or limited
2. Social Stigma – labelling and avoidance, isolation, humiliation
3. Self Stigma – individual psychological processes in response to stigma (i.e., shame, concealment, internalization)

Structural Stigma

Structural stigma are the societal-level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and wellbeing of the stigmatized [12]

As a society, we have moralized drug use – rather than dealing with it as a public health issue

The result has been policies that criminalize drug use and addiction → higher levels of incarceration and CJ involvement among PWUD

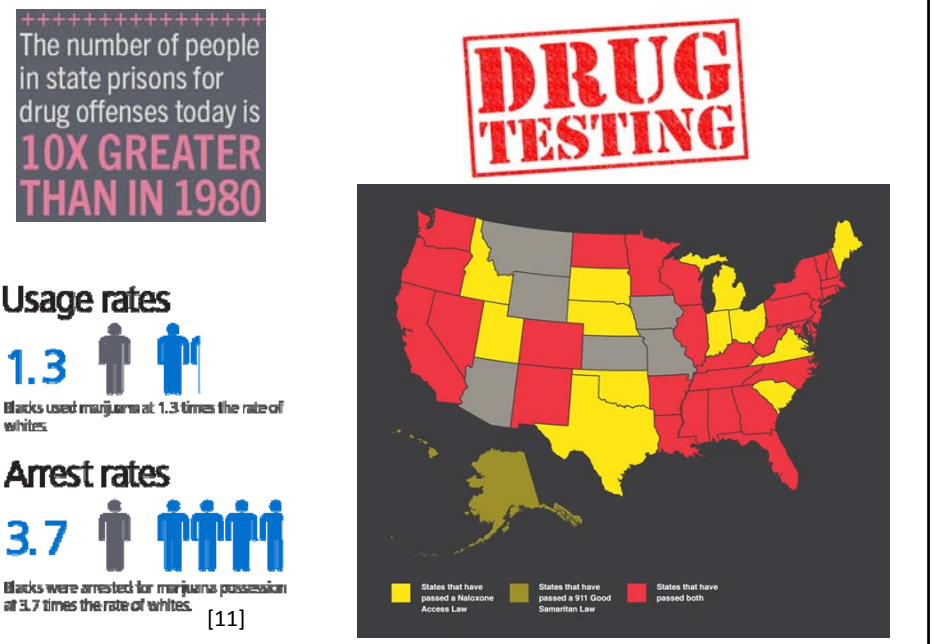


Nixon's war on drug addicts

From RICHARD SCOTT

Washington, June 17

President Nixon told Congress today that the drug problem in the United States had assumed the dimensions of a national emergency. He asked for an additional £64 millions to provide *emergency* measures for dealing with it.



[11]

Social Stigma

Social stigma refers to the attitudes and beliefs of individuals (i.e., the general public, health care providers, family, friends) towards PWUD

PWUD may experience social isolation as people avoid them

In health care settings, it can result in humiliating and dehumanizing interactions with health care professionals

"People say, well, oh my gosh, why would you want to do that? You're taking on all the addicts. People think that it's inviting addicts to your clinic as if that would be the worst thing that you could have happen."

Many healthcare professionals hold negative, stereotyped views of people who use illicit drugs.

The result is that PWUD are less likely to be offered help than are people with a mental illness or physical disability.

The way we talk about PWUD can create or uphold stigma. Words like 'crackhead' and 'junkie' dehumanize a person who may be struggling with a SUD.

"Well and here's the thing, nobody wants a bunch of addicts in the waiting room with grandma and her grandkids."

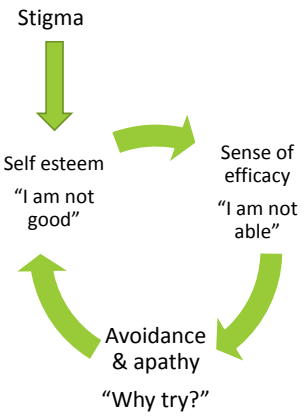
Self Stigma

Self stigma is the internalization of the negative stereotype, a resultant loss of self-esteem, and acting out the negative public image [13]

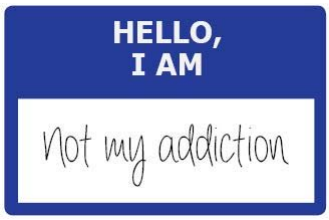
Those who experience stigma often report engaging in maladaptive emotion regulation strategies such as rumination and suppression as well as maladaptive coping behaviors such as smoking, drinking, and drug use. [14]

Exposure to chronic stress may lead to diastolic blood pressure reactivity and increased cortisol output. [14]

Those affected may isolate themselves (i.e., quit work, stop engaging in health care, stop engaging with family/friends) [14]

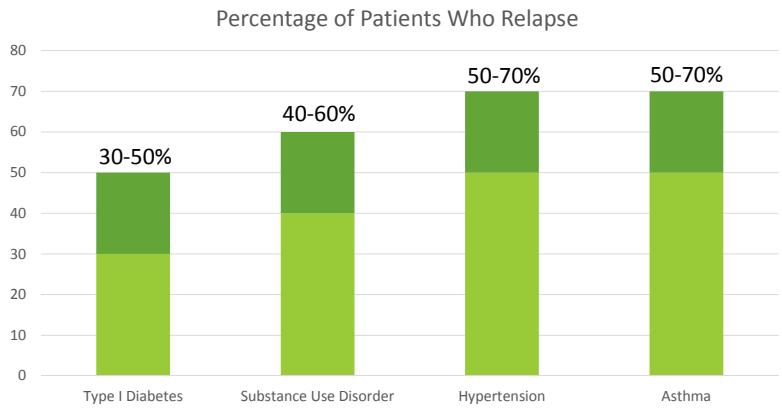


"Guilt and shame kept me out there [on the streets] for a lot of years. You know, I didn't feel like anything. I didn't want to feel anything."



"I just felt like maybe they were right, maybe I was just a junkie. I was out there choosing to use. Wasn't doing nothing good with my life and my family, they want nothing to do with me."

We evaluate SUD Tx differently.



Abstinence only Tx Philosophy

Drugs are not only viewed within a schema of facts, but of morality—an ideology that views psychoactive substances as fundamentally wrong.

~ Gopalan, 2017

- A treatment philosophy that embraces abstinence as the end goal or true measure of recovery
- Most common are programs that rely on the 12 steps such as Alcoholics Anonymous (AA) and Narcotics Anonymous (NA)
- Being drug free is the only measure of success and any level of use is unacceptable, this often includes MOUD
- Assumption that PWUD need to hit rock bottom before they are willing to make changes

Potential Consequences of Substance Use and SUD Tx relapse

Structural

- Loss of resources (i.e., health, social services)
- Discrimination (i.e., housing, employment)
- CJ involvement

Social

- Labelled as an addict and failure
- Loss of social support & isolation
- Dehumanizing and humiliating interactions

Self

- Concealment of drug use/relapse
- Internalized shame
- Withdrawal or lack of engagement with health services

Literature suggests that stigmatization may have direct negative effects on mental and physiological health. These effects are due to exposure to chronic stress including experience of discrimination.

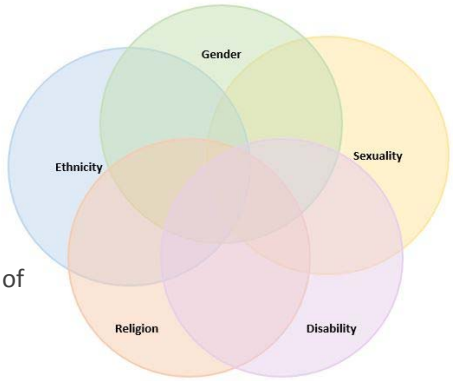
Layers of Disparities related to Drug Use Stigma

Not all drug use is equally stigmatized

- Crack vs Cocaine
- IV drug use vs Pills

Not all PWUDs are equally stigmatized

- Intersectional understanding of stigma



Is there another way?

What are the concerns?

- Negative consequences on health
- Safety concerns (self & others)
- Spread of infectious diseases

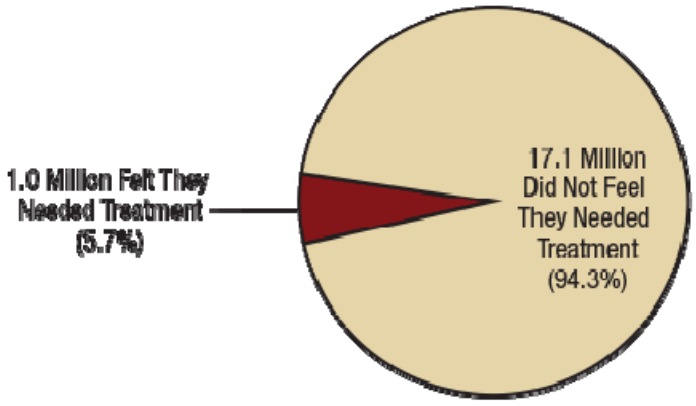
What are the goals?

- Improved individual health
- Prevention of fatal & non-fatal overdoses
- Improved community health

"Its time to change how we view addiction…not as a moral failing but as a chronic illness that must be treated with skill, urgency, and compassion. The way we address this crisis is a test for America."

~Surgeon General Dr. Vivek Murthy

Perceived Need for Substance Use Treatment among People Aged 12 or Older Who Needed but Did Not Receive Specialty Substance Use Treatment in the Past Year: 2017



16.2 Million People Needed but Did Not Receive Specialty Substance Use Treatment

Image from: https://habitslab.umbc.edu/the-model-2/

Harm Reduction

Harm Reduction is a perspective and a set of practical strategies to reduce the negative consequences of drug use.

- Moves past judgement of another person to address their drug use and sexual activity and the harm that's occurring to that person
- Incorporates a spectrum of strategies including safer techniques, managed use, and abstinence
- Meets people "where they are at" but doesn't leave them there

What Harm Reduction is NOT:

- Harm reduction does not mean "anything goes"
- Harm reduction does not condone, endorse, or encourage drug use or high risk behaviors
- Harm reduction does not exclude or dismiss abstinence-based treatment models as viable options

Harm reduction & bioethics?

1. Health and Dignity
2. Participant-Centered
3. Participant Involvement
4. Participant Autonomy
5. Intersectional
6. Pragmatism

Autonomy
Nonmaleficence
Beneficence
Justice

Bioethical principles

Autonomy is the principle that a person should be free to make his or her own decisions. It is the counterweight to the medical profession's long-practiced paternalism, wherein the provider acted on what they thought was "good" for the patient, whether or not the patient agreed.

Nonmaleficence is the philosophical principle that encompasses the medical student's principal rule, "first, do no harm." It derives from knowing that patient encounters with providers can prove harmful as well as helpful. This principle includes not doing harm, preventing harm, and removing harmful conditions.

Beneficence is the principle that health care providers have a duty to be of a benefit to the patient, as well as to take positive steps to prevent and to remove harm from the patient.

Justice has multiple dimensions. It can be described as the moral obligation to act on the basis of fair adjudication between competing claims. It is linked to fairness, entitlement and equality.

1. Health and Dignity

Harm reduction establishes the quality of individual and community life and well-being as the criteria for successful interventions and policies.

Treating PWUD—along with their families and communities—with compassion and dignity is integral.

Justice

Nonmaleficence

2. Participant-Centered

Autonomy

Calls for the non-judgmental, non-coercive provision of services and resources to people who use drugs and the communities in which they live

Recognizes that PWUD deserve to have their health needs met regardless of whether they choose abstinence or choose to continue to use drugs

Beneficence

Justice

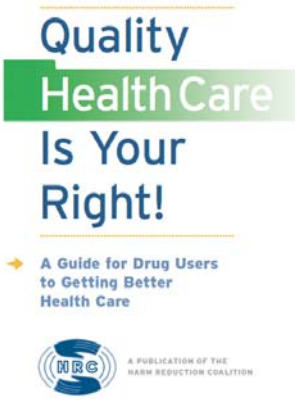


Image from www.harmreduction.org

3. Participant Involvement

Ensures that drug users and those with a history of drug use routinely have a real voice in the creation of programs and policies designed to serve them

Autonomy

Justice

http://www.oregonrecovers.org/

4. Participant Autonomy

Autonomy

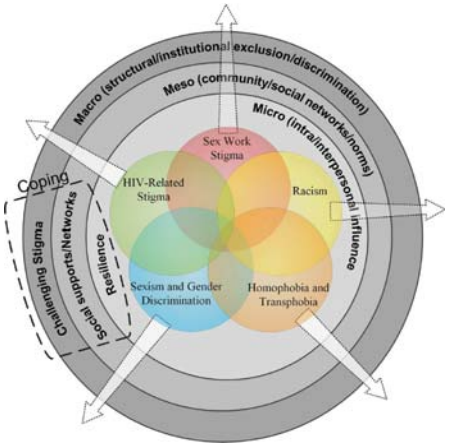
Recognizes PWUD are experts in their own lives. It is the individual who makes their own changes, when they feel they can make them, under their own circumstances.

Seeks to empower PWUD to share information and support each other in strategies which reduce the potential harm from their drug use.

Beneficence

5. Intersectional

Recognizes that the realities of poverty, class, racism, social isolation, past trauma, sex-based discrimination and other social inequalities affect both people's vulnerability to and capacity for effectively dealing with drug-related harm.



Justice

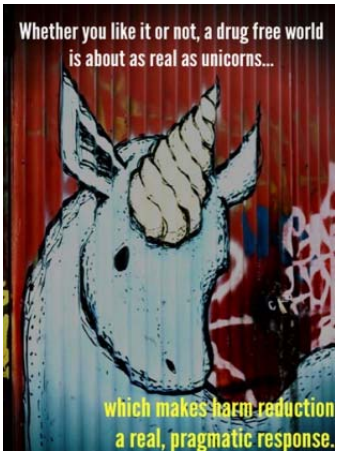
6. Pragmatism

Nonmaleficence

Accepts, for better or worse, that drug use is part of our world and chooses to work to minimize its harmful effects rather than simply ignore or condemn them

Acknowledges that some ways of using drugs are clearly safer than others

Does not attempt to minimize or ignore the real and tragic harm and danger associated with licit and illicit drug use



Beneficence

What are some harm reduction strategies?

Harm Reduction Strategies

Syringe exchange
- Storefront
- Street-based mobile out reach
- Secondary or peer-delivered
- Pharmacy

MOUD
- Methadone
- Buprenorphine
- Naltrexone

Distribution of and training to use Naloxone

Rapid HIV and HCV testing + linkage to resources and care

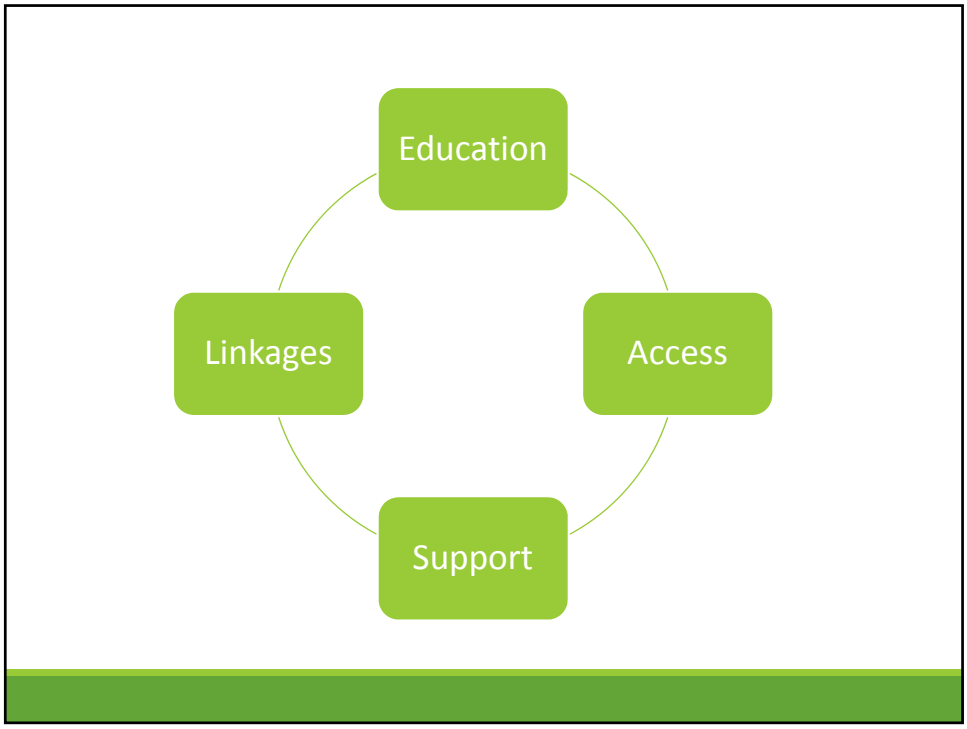
Education
- Safer drug use
- Safer sex practices

Motivational interviewing

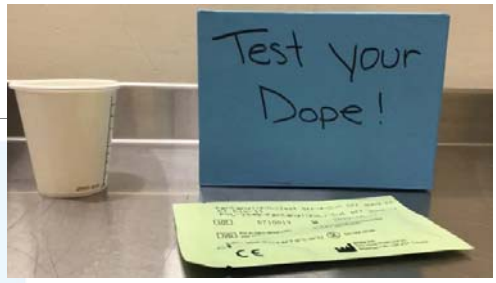
Peer support programs

Fentanyl test strips

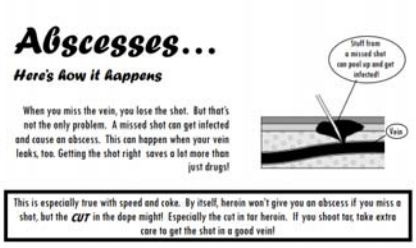
Safe Consumption Sites



Education



www.harmreduction.org



www.harmreduction.org

Access

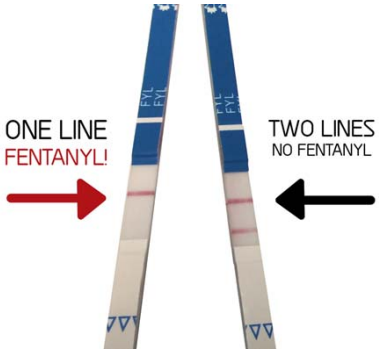
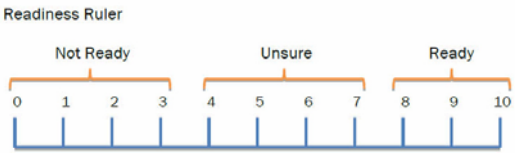
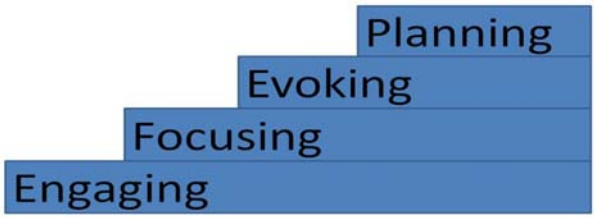


Image: Robert F. Bukaty/AP

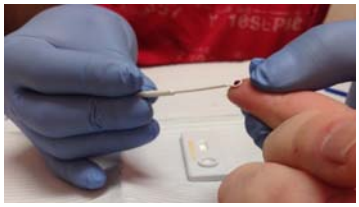
Support

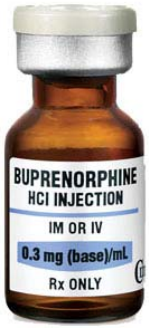




Linkages

http://www.seftonsupportedhousing.org.uk/housing-is-harm-reduction/



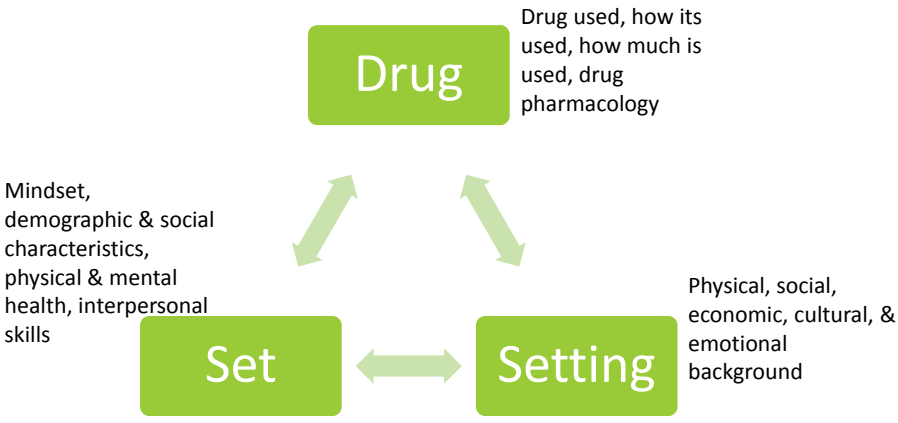


What does harm reduction look like in practice?

Harm Reduction interventions and policies should be designed to reflect specific individual and community needs.

There is no universal formula for implementing harm reduction.

The degree of harm associated with risk behavior varies based upon numerous factors, including drug, set, and setting.



Zinberg, 1984

Case Study

It's a busy day on the general surgery unit and it's Katherine's first day back after her days off. Katherine is a nurse who has been working on the unit for three months. One of her clients is Alex, a 35-year-old man, post-operative day three. During report, the night shift nurse reviews his post-op care, history, pain management and medical history including diabetes, asthma and substance use. "He has a history of using drugs. He's probably a drug addict and drug seeking. He keeps asking for PRN pain medications," the night shift nurse tells Katherine.

When Katherine checks in on Alex, he tells her that he is in incredible pain and once again restates his request for PRN pain medication.

Katherine is unsure how she should approach Alex's care. While she is uncomfortable with the night shift nurse's comments, she also hasn't cared for many clients with a history of substance use. Katherine understands that she is responsible and accountable for providing safe, competent, and ethical care, but given her limited experience, she wonders whether providing PRN pain medications will further encourage Alex's drug use.

Adapted from CARNA

Discussion

1. What might be motivating each person in the scenario (i.e., night shift nurse, Katherine, Alex)?
2. Why might Katherine be uncomfortable with the night shift nurse's comments?
3. What are the possible choices available to Katherine?
   a) What are the underlying assumptions of those choices?
   b) What are possible outcomes of those choices?
4. How could systems and processes be designed differently to better support all three individuals in this scenario?

What would be the biggest barrier to implementing harm reduction at your clinic/agency?

What components of harm reduction do you think you could implement into your daily work with clients/patients?

What good comes out of harm reduction?

Harm reduction directly challenges stigma

Harm reduction helps you increase trust with your clients/patients and fosters engagement

Harm reduction improves public health by supporting individuals and communities to reduce the spread of infectious diseases

Harm reduction literally saves lives

Questions

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2019 Kinsman Bioethics Conference

Raising Voices:

The Ethics of Dialogue and Communication in Health Care

SESSION C2	
Theme	Socially and Culturally Situated Voices in Healthcare
Title	Bioethics and Culture: Implications in Immigrant and Refugee Mental Health
Speaker(s)	Daniel Towns, D.O.
Date	Friday, April 12, 2019
Time	9:30 – 10:40 AM
Location	Directors

SESSION C2 OBJECTIVES

- Summarize the current state of displacement in the world and Oregon's role in refugee resettlement.
- Discuss the history and treatment model of the Intercultural Psychiatric Program in Portland, Oregon.
- Consider bioethical principles in working with diverse patient populations of multiple religions, belief systems, and cultural norms.
- Review several clinical examples in which ethical dilemmas arise in mental health care for immigrants and refugees.

SESSION C2 SPEAKER

Daniel Towns, D.O.

Dr. Towns is faculty psychiatrist at OHSU, where he works as the Medical Director at the Intercultural Psychiatric Program in the Department of Psychiatry. He received an undergraduate degree in History from Beloit College in Wisconsin, his medical degree from Des Moines University in Iowa, and completed his General Adult Psychiatry residency at OHSU in 2014. Since then, he has worked in a variety of settings, including in primary care / behavioral health integration, in Assertive Community Treatment teams, and in tele-psychiatry for the Oregon Department of Corrections. He now serves as a psychiatrist and the Medical Director at IPP, where he works with immigrants, refugees, and asylum-seekers from all over the world. He is also is the Director of the Torture Treatment Center of Oregon, which is embedded within IPP and is a federal grant program through the Office of Refugee Resettlement to support and provide holistic treatment to survivors of severe trauma and torture.

Bioethics and Culture: Implications in Immigrant and Refugee Mental Health

Daniel Towns

Kinsman Bioethics Conference

April 12, 2019

Disclosures / Conflicts of Interest

- None

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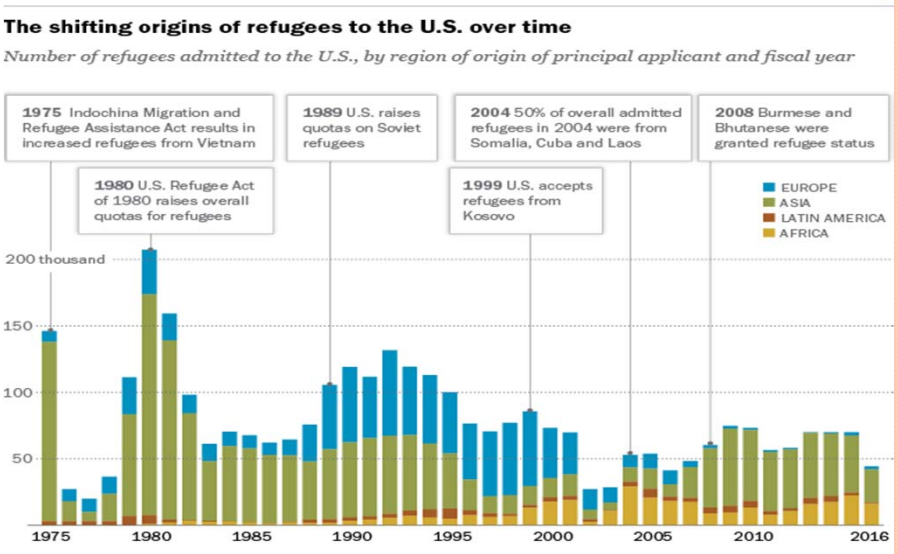
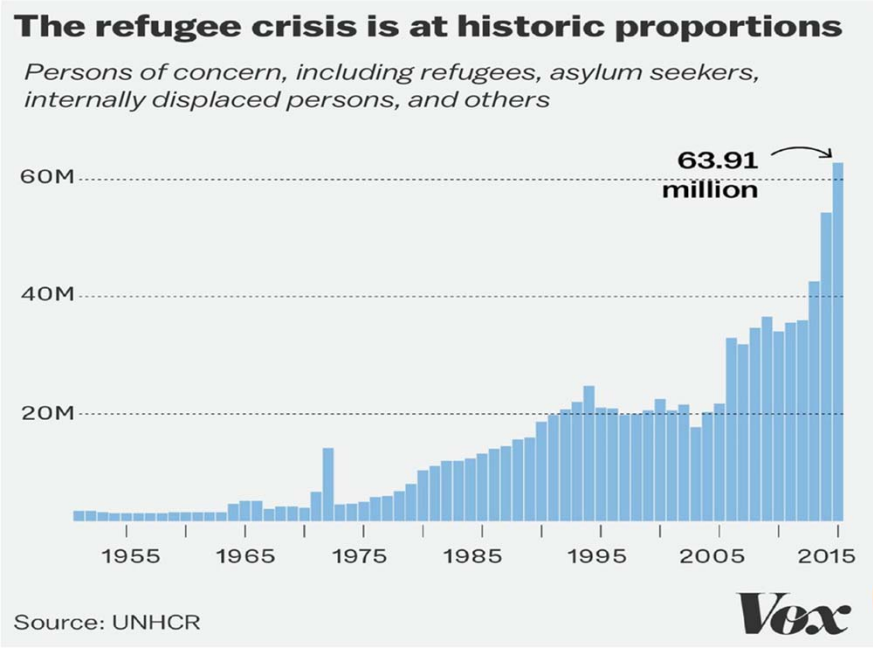


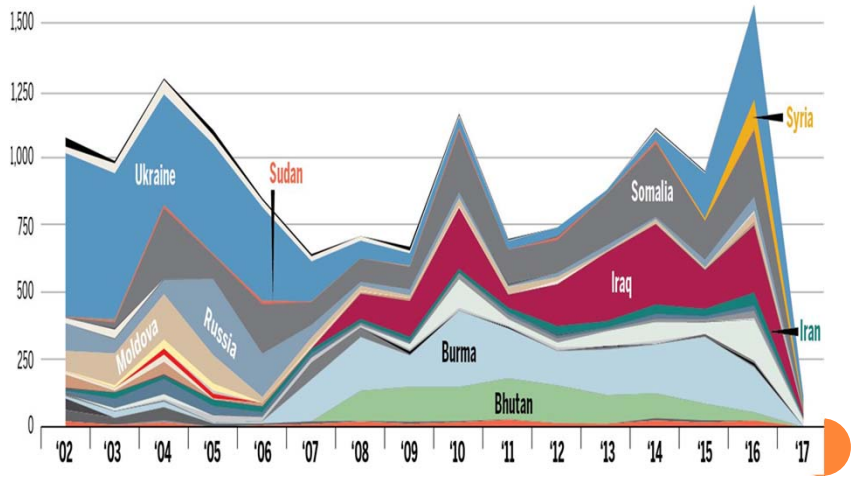
Current State of Displacement Crisis

- 68.5 million people forcibly displaced worldwide
  - 40 million internally displaced
  - 25.4 million refugees – only 102,800 refugees resettled
  - 3.1 million asylum-seekers
- 10 million stateless people
- 85% of the world's displaced people are in developing countries.
- Two-thirds of refugees worldwide come from five countries.
- Top refugee hosting countries are Turkey, Uganda, Pakistan, Lebanon, and Iran.

https://www.unhcr.org/figures-at-a-glance.html - June 2018 statistics



Refugee Admissions to Oregon



Top Refugee Cities

The Top 20 Cities for Refugee Resettlement and the Top 3 Origin Countries in Each City, 2006 to 2016

Rank	City and State	Total Refugees Settled	#1 Origin Country	#2 Origin Country	#3 Origin Country
1	Houston, Texas	20,069	Burma (4,606)	Iraq (4,420)	Bhutan (2,291)
2	Phoenix, Arizona	18,241	Burma (4,417)	Iraq (4,194)	Somalia (2,334)
3	Dallas, Texas	14,003	Burma (5,481)	Iraq (2,217)	Bhutan (1,924)
4	San Diego, California	13,401	Iraq (4,863)	Burma (1,987)	Somalia (1,828)
5	Buffalo, New York	12,685	Burma (4,531)	Somalia (2,094)	Bhutan (1,880)
6	Denver, Colorado	12,332	Burma (3,112)	Bhutan (2,554)	Iraq (1,611)
7	Glendale, California	12,187	Iran (10,874)	Iraq (1,128)	Syria (55)
8	Chicago, Illinois	12,069	Iraq (3,505)	Burma (2,713)	Bhutan (1,249)
9	El Cajon, California	11,586	Iraq (11,334)	Burma (97)	Palestine (60)
10	Indianapolis, Indiana	11,460	Burma (9,312)	Dem. Rep. Congo (536)	Somalia (382)
11	Columbus, Ohio	10,727	Somalia (4,616)	Bhutan (2,694)	Iraq (1,336)
12	Salt Lake City, Utah	10,312	Burma (2,263)	Somalia (2,111)	Iraq (1,490)
13	Fort Worth, Texas	10,288	Burma (3,436)	Bhutan (1,785)	Somalia (1,275)
14	Atlanta, Georgia	10,228	Burma (2,578)	Bhutan (1,815)	Dem. Rep. Congo (1,348)
15	Louisville, Kentucky	10,221	Bhutan (1,825)	Burma (1,752)	Somalia (1,635)
16	Syracuse, New York	9,568	Burma (2,464)	Bhutan (2,103)	Somalia (1,718)
17	Seattle, Washington	9,439	Somalia (2,034)	Burma (1,899)	Iraq (1,408)
18	Nashville, Tennessee	8,857	Burma (2,430)	Bhutan (1,719)	Somalia (1,350)
19	Tucson, Arizona	8,566	Somalia (1,547)	Iraq (1,534)	Bhutan (1,422)
20	Portland, Oregon	8,367	Burma (1,746)	Somalia (1,534)	Iraq (1,120)

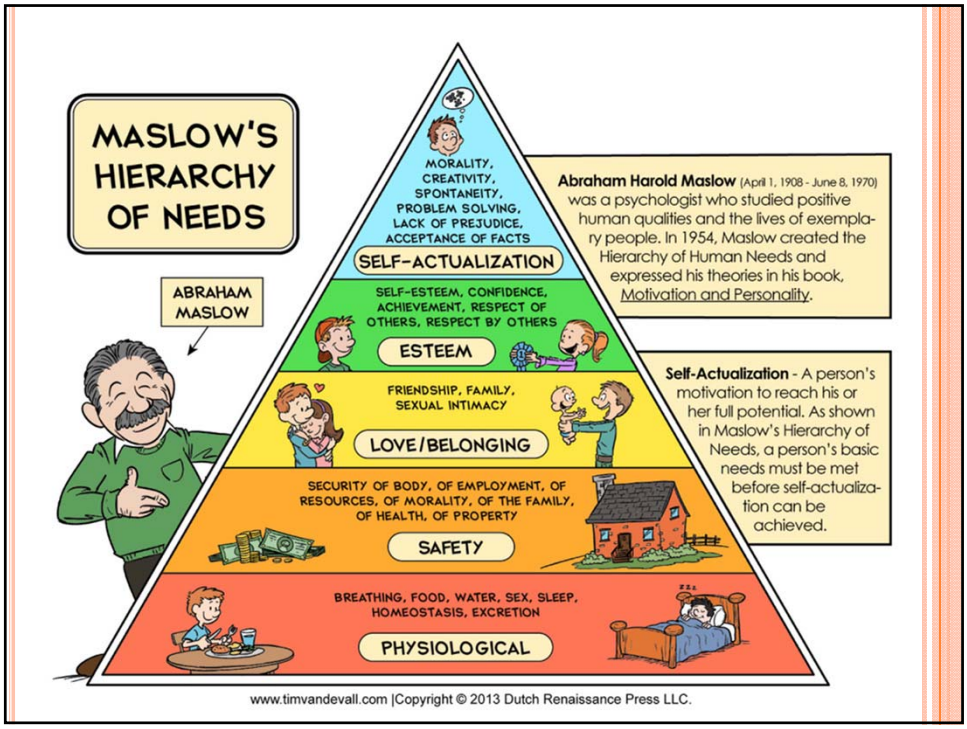
US Department of State: Worldwide Refugee Admission Processing

OHSU IPP Background

- Started in late 1970s following end of Vietnam War and conflict in Cambodia produced refugees.
- Working with refugees, immigrants, and those seeking asylum from many countries.
- More than 1,000 active patients currently.
  - About 250 of whom are torture survivors.
- Model of clinical team with psychiatrist and culturally and linguistically matched counselor.
  - 7 mostly part-time psychiatrists
  - 14 counselors
  - 3 administrative staff
- Part of the OHSU Department of Psychiatry.

OHSU IPP Background

- Four pillars
  - Clinical work / Education / Research / Advocacy
- Early goals of clinical work
  - Welcoming.
  - Establishing safety.
  - Engagement.
  - Instillation of hope. Re-imagining future.
  - Resources.
- Intermediate / longer-term clinical goals
  - Finding meaning.
  - Identity.
  - Family.
  - Roots.


MASLOW'S HIERARCHY OF NEEDS
ABRAHAM MASLOW
MORALITY, CREATIVITY, SPONTANEITY, PROBLEM SOLVING, LACK OF PREJUDICE, ACCEPTANCE OF FACTS
SELF-ACTUALIZATION
SELF-ESTEEM, CONFIDENCE, ACHIEVEMENT, RESPECT OF OTHERS, RESPECT BY OTHERS
ESTEEM
FRIENDSHIP, FAMILY, SEXUAL INTIMACY
LOVE/BELONGING
SECURITY OF BODY, OF EMPLOYMENT, OF RESOURCES, OF MORALITY, OF THE FAMILY, OF HEALTH, OF PROPERTY
SAFETY
BREATHING, FOOD, WATER, SEX, SLEEP, HOMEOSTASIS, EXCRETION
PHYSIOLOGICAL
Abraham Harold Maslow (April 1, 1908 - June 8, 1970) was a psychologist who studied positive human qualities and the lives of exemplary people. In 1954, Maslow created the Hierarchy of Human Needs and expressed his theories in his book, Motivation and Personality.
Self-Actualization - A person's motivation to reach his or her full potential. As shown in Maslow's Hierarchy of Needs, a person's basic needs must be met before self-actualization can be achieved.
www.timvandevall.com |Copyright © 2013 Dutch Renaissance Press LLC.

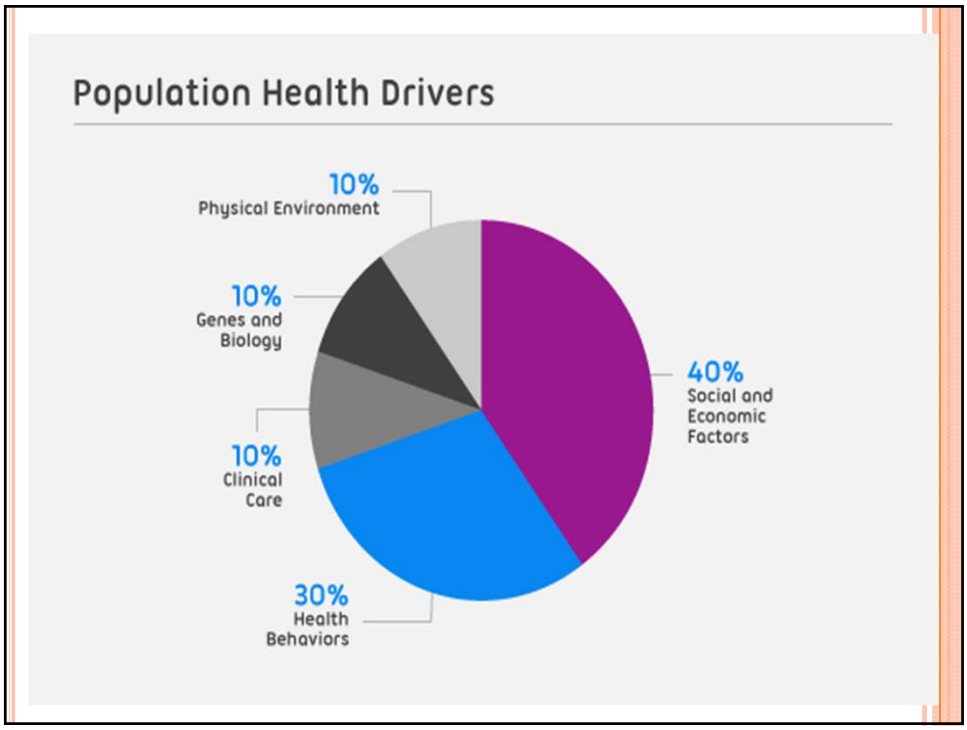

Population Health Drivers
10%
Physical Environment
10%
Genes and Biology
10%
Clinical Care
30%
Health Behaviors
40%
Social and Economic Factors

Figure 2

Social Determinants of Health

Economic Stability	Neighborhood and Physical Environment	Education	Food	Community and Social Context	Health Care System
Employment	Housing	Literacy	Hunger	Social integration	Health coverage
Income	Transportation	Language	Access to healthy options	Support systems	Provider availability
Expenses	Safety	Early childhood education		Community engagement	Provider linguistic and cultural competency
Debt	Parks	Vocational training		Discrimination	Quality of care
Medical bills	Playgrounds	Higher education			
Support	Walkability				

Health Outcomes
Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations

THE HENRY J. KAISER FAMILY FOUNDATION

Bioethics Basics - What should one do?

- Principles
  - Autonomy
  - Beneficence
  - Nonmaleficence
  - Justice

- Who gets what?
- Who makes the decisions?
- What matters most?
- What is "success?" How is it measured?
- What are the costs? Who pays?
- Who am I working for? And accountable to?

Paternalism and Patient-centered care

- How do we empower people in their health care when they are ones expecting doctors to make clinical decisions for them?
- Informed consent
  - Signing intake forms
  - Medications
    - Review of potential side effects.
    - Risks of addiction.
    - "Well, you're the doctor - you would know better."
- Experience with psychiatrists/psychiatry and how patients view the doctor.

Discussion and Treatment of Trauma

- Trauma-informed care
- Cultural differences in coping and processing of trauma.
- How should trauma be discussed? When in the treatment? What is best for that particular person?
  - How to discuss uncomfortable things in supportive, comforting way?
  - Torture treatment grant
- Evidence-based treatments for PTSD
  - Ethics of exposure therapies in such severe and complex trauma
  - Our treatment tends to be longer term, supportive, and generally oriented towards now and the future.

The role of the IPP counselor

- Serves as case manager, therapist, and interpreter. But also:
  - Coach
  - Community member
  - Advocate
  - Fellow immigrant/refugee
  - Gatekeeper
- Complex psychological experience of interpretation itself.
  - Therapeutic distance
- Identity and allegiances.
  - "Don't tell the Doctor this but…"

Advocacy, care, and respect

- How outspoken can one be in advocacy while doing this work?
  - Maintaining patient confidentiality.
  - Respecting patient wishes.
  - Allowing for flexibility and force while being always thoughtful and cautious.
- Telling one's story publicly, and being heard for once, can be very therapeutic for some people, yet can re-activate PTSD or memories of suffering.
  - How can we give people this opportunity while also supporting and protecting them?

Working with Displaced People in Transit or in Disaster Zones

- Basic necessities for survival take priority.
  - Including safety and security.
- Health as a relative priority.
- Exploration into and processing of emotions and losses actually may not be helpful in these circumstances.
  - Psychological First Aid
  - Critical Incident Stress Debriefing
- Distribution of resources
  - Rationing, triage, etc.
- Services comparable to those for native-born people in host country?
- When providing treatment and support to immigrants and refugees is dangerous.

Ethics at a Program Level

- How to manage referrals? Who is and who isn't accepted into the program?
- Cultural competence and risk of stereotyping.
  - Cultural humility.
- How do we tailor services to best meet the needs and wishes of immigrants/refugees, while also fulfilling our obligations to institution/state/funders?
  - Research protocols
  - Outcome measures

Ethics from a Public Health and Policy Standpoint

- When public policy does not promote improvements in public health.
- Recognition that conflict/war abroad results in refugees, some of whom come to the United States.
  - The United States is involved, or directly responsible, for some of these conflicts/wars.
- Hateful actions, fueled by extremism, result in traumatized people and has vast consequences regarding health and well-being.

All policy is health policy.

- Ethics at policy and government level
  - How much foreign aid in budgets?
  - How should refugees be treated? Resettlement, repatriation, prolonged refugee camp stay?
  - What is the importance of borders?
  - What immigrants should countries accept into their countries? How can it be fair for everyone?
- Considerations of multiple parties:
  - Host governments and people.
  - Immigrants and refugees themselves.
  - International organizations, the UN, humanitarian groups.
- Human rights.

Distributive Justice

- There is varying distribution of benefits and burdens across members in a society.
  - Economic, political, and social forces involved.
- Regarding refugees, what frameworks and distributions are morally preferable? What is fair?
  - Burden sharing of refugees based on wealth/resources of countries?
  - Who has responsibility for the conflict/war producing refugees?

What ultimately promotes healing?

- And how to achieve it with significant barriers and scarce resources…
  - Justice, punishment of perpetrators.
    - Truth and Reconciliation Commission
      - Focus on harmful systems promoting persecution.
    - Criminal Tribunals
  - Acknowledgement from others/society.
    - Museums, days of remembrance, etc
  - Prevention work. "Never again."
  - Promotion of resilience in people and communities.
  - Moving on with lives, treatment and rehabilitation, getting jobs, going home, etc.

SPECIFIC SITUATIONS TO DISCUSS

- Russian-speaking family giving their family member psychiatric medications without his knowledge.
- Divorced South Asian couple each coming for treatment without the other's knowledge.
  - Issues around confidentiality in small communities.
- Requests for writing letters or completing forms attesting to their disability.
- Adult males in family (fathers, sons, brothers, and husbands) speaking on behalf of the female patient.

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2019 Kinsman Bioethics Conference

Raising Voices:

The Ethics of Dialogue and Communication in Health Care

SESSION C3	
Theme	Socially and Culturally Situated Voices in Healthcare
Title	Global Health Ethics: Appropriate Training for the Next Generation
Speaker(s)	Melissa Graboyes, Ph.D., M.A., M.P.H.
Date	Friday, April 12, 2019
Time	9:30 – 10:40 AM
Location	Hansberry/Ferber

SESSION C3 OBJECTIVES

- Discuss some of the ethical challenges when determining how best to train future global health workers, including dilemmas around appropriate internship experiences and the values of clinical shadowing.
- Explore how an inter-disciplinary approach that fully integrates the humanities and social sciences can better train future global health workers.
- Present novel practices the UO's global health program has adopted in its goal of ethically training global health workers.

SESSION C3 SPEAKER

Melissa Graboyes, Ph.D., M.A., M.P.H.

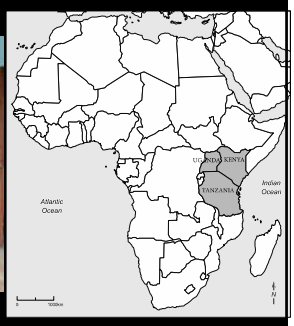
Melissa Graboyes is a historian of modern Africa who writes on topics of global health and medical ethics. She is currently an Assistant Professor in the Clark Honors College at the University of Oregon. Her research has an East Africa regional emphasis (Kenya, Tanzania, Uganda) and employs a variety of historical and anthropological methods. In 2015, she published *The Experiment Must Continue: Medical Research and Ethics in East Africa, 1920-2014* (Ohio UP), and is currently at work on a new book on the history of failed malaria elimination attempts in Africa. She earned a Ph.D. in History and a Master's in Public Health from Boston University, and has worked domestically as a health educator with Planned Parenthood, with international NGOs, and led health outreach and advocacy programs in Botswana and Tanzania. She is particularly committed to making research findings accessible and serving as a bridge to translate academic findings to practitioners working in the field.

Global Health Ethics:
Appropriate Training for the Next Generation

Melissa Graboyes, Ph.D., MPH
Assistant Professor, Clark Honors College
University of Oregon

Who am I?

- Faculty member at the Clark Honors College, Univ of Oregon. Teach medical history, global health, Africa-courses
- Trained as a historian of modern Africa (Ph.D. history) and as a public health practitioner (Masters in Public Health) with an emphasis on bioethics. Worked for global health organizations in US & Africa.
- First book on history of medical research in East Africa. Current NSF-funded work on the history of malaria elimination attempts in Africa.
- Worked in East Africa for 15+ years, fluent (but rusty) Swahili speaker
- Book chapter as part of *The Value of Stories: Narrative Ethics in Public Health.*



Agenda

Global Health & International Shadowing

Ethics Questions, Real Harms

Response: An Interdisciplinary Model

Learning Objectives:

1. Discuss some of the ethical challenges when determining how best to train future global health workers, including dilemmas around appropriate internship experiences and the values of clinical shadowing.

2. Explore how an inter-disciplinary approach that fully integrates the humanities and social sciences can better train future global health workers.

3. Present novel practices the UO's global health program has adopted in its goal of ethically training global health workers.

ALSO: Hear from practitioners about their experiences with students involved in shadowing; Consider how domestic shadowing experiences can increase students' ethical awareness of larger global health issues.

Thanks to Kristin Yarris (UO), Jessica Evert (Child Family Health International) for slides

What is Global Health?

"a field of study, research, and practice that places a priority of achieving equity in health for all people. Global health involves multiple disciplines within and beyond the health sciences, is a synthesis of population-base prevention with individual level clinical care, promotes interdisciplinary collaboration, and emphasizes transnational health issues and determinants."

Koplan et al. Consortium of Universities for Global Health Executive Board: Towards a common definition of global health. Lancet. 2009; 1993-1995.

OR….

"a concept fabricated by developed countries to explain what is regular practice in developing nations."

Consortium of Universities in Global Health. 2008. Annual Report.

"primarily a North American concept"… "a creation of the "resource-rich" world." –Johanna Crane, "Unequal Partners: AIDS, Academia, the Rise of Global Health" *Behemoth.* 2010.

What is “shadowing”?

Following a doctor or nurse-practitioner whose primary job is to provide care for patients—whether in a public hospital, teaching hospital, private clinic, community health center or in private homes.

Sometimes this is referred to as “clinical rotations,” “medical tourism,” or “voluntourism”

It typically involves students from richer countries (Global North) traveling to poorer countries (Global South) to gain clinical experience.`

Why be concerned about clinical shadowing?

Satirical

Not Satirical

Ethical Concerns with International Shadowing

Shadowing raises issues of
- Power Differentials
- Resource Inequality
- Cross-cultural (mis)communication

These are related to patients' ability to truly provide consent to being observed and students' ability to merely observe clinical interactions, without interfering in or participating in clinical care

- protecting students (to not be asked to do something illegal, inappropriate, unethical)
- protecting patients (who may not consent to being observed and/or may not be able to voice their discomfort about being observed).

Some Ethical Concerns with International Shadowing

- Being asked to do something not medically qualified to do
- Performing activities they're not medically qualified to do
- Having doctors/staff/patients believe they are doctors
- Observing without patient consent
- Inadvertently damaging the doctor-patient relationship
- Inadvertently decreasing the quality of patient care
- Taking away observational/apprenticeship opportunities from local medical students
- Drawing hospital/staff attention away from other priorities

- META: Conflating global health work with international medical work
- META: Contributing to the idea that global health work is done "over there" not here [More]

Not Just Hypothetical: Documented Harms

- Death of infant given wrong dose of medication.
- Pulling on breech babies during birth and potentially contributing to the baby's death.

- 20+ patients with malaria not diagnosed.
- Child put through spinal tap by inexperienced student, failed procedure, delayed diagnosis.
- Sticking infants 4x for a test that should require 1 poke and breaking needles in the process.

- Students writing prescriptions for 100x the appropriate dose.
- Students dispensing medications in "pop-up" clinics with no follow up to monitor side effects, adverse events, or complications.

Evert J, Todd T, Zitek P. "Do you GASP? How pre-health students delivering babies in Africa is becoming consequentially unacceptable." *The Advisor*. Dec 2015; 61-65.

Not Just Hypothetical: Student Experiences

In the past 4 years, UO undergrads without medical training have been asked to

- draw blood
- perform lab tests
- perform ultrasounds
- help with a pap smear
- initiate an IV line
- give injections
- assist with births

Distracted Doctors: *"a mother came in with her two year old son in the throes of cerebral malaria. He began seizing and emergency physician called us interns over for a teaching moment rather than tending to the baby. Mother was completely disregarded and shoved aside, told to be quiet when she cried. Nobody told her what was happening to her baby. Instead they were focused on telling us what was going on."*

Inappropriate Expectations: *"At one point I was shadowing an OB/GYN and he talked me through an ultrasound with one patient then left me in the room alone with the next patient as he went to do something else and told me to perform the ultrasound."*

Not Just Hypothetical: Student Experiences

- Unclear Identities and Qualifications: "*Everyone seemed nice but a few people laughed at us when we explained that we were just students who were there to shadow them. They believed we had training back home and we were at the hospital to practice what we had learned. We had to politely explain to them several times that we were just there to observe their daily interactions and see how the healthcare system works [here].*"

- Negatively Impacting Patient Care: "*we were placed in the eye clinic…the nurse showed us how to give an eye exam... Later in the day, our supervising nurse kept asking us to perform the exams on patients. At first we politely declined but it soon became more difficult to keep saying no because the nurse and patients would laugh at us. We figured there wasn't any harm in doing the eye exams while the nurse was watching us. Eventually, I realized that the exam we were giving the patients was what determined if they went back to see the doctor to get glasses or see the ophthalmologist for a consultation about glaucoma…I realized there were a few patients who were on the edge of that cut off, and if I hadn't given the exam correctly, they may not have received the glasses they needed or the glaucoma treatment they required.*"

- Denying Opportunities to Local Students*: "there was a birth that happened while I was there and physicians told [local] medical students that since they had already seen one, it was our (UO students) turn to observe since only two students could be in the room."*

Why is this important?

- Global Health is a growing field across American universities
- Many undergraduates are seeking out clinical experiences
- Clinical experiences are often rewarded by med schools

- Undergraduate training creates "norms" of the field

- We want students to be safe, have ethically appropriate experiences

- We do not want patients, doctors, and communities in the Global South to bear the burden of our students learning to "do" global health

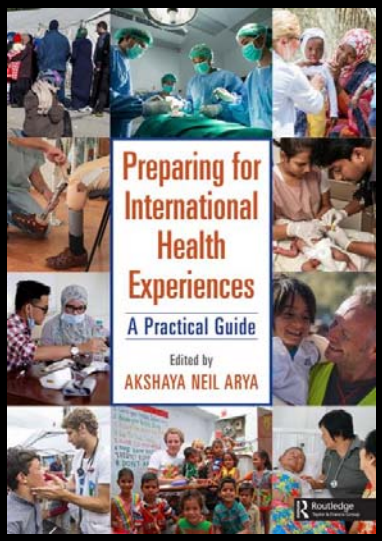
UO Responses: Better Prepare Students

1) Don't offer shadowing opportunities via our study abroad programs

2) Don't offer academic credit for shadowing

3) Require basic ethics training in global health classes and before going abroad through online programs such as:

- Univ of Minnesota, "Global Ambassadors for Patient Safety"—GAPS Online Workshop
- Johns Hopkins & Stanford: "Ethical Challenges in Short-Term Global Health Training"



UO Response: Inter-disciplinary academic training

- Stresses not just the medical component of global health
- Teaches students about these ethical challenges and various responses
- Humanities, social science, natural science training (2 classes in each area)
- Required Internship: local or global, real experience

UO Response: Convey Expectations Clearly & Repeatedly

- Teach in entry-level classes about the ethical challenges of global health and shadowing
- Explain to students why we don't support shadowing in classes, online, and in person
- Have students reflect on and share their experiences
- Share relevant and accessible articles (Wendland, Crane, Sullivan)
- Write about the UO's experience for a broader audience

How might we think differently about having students shadow here in the United States?

Larger Responses: Medical School Admissions & Sensitization

"We recently did not offer a student admission who had great test scores, grades, extracurricular activities, and was someone we would have otherwise accepted because she couldn't see the ethical issues with what she had done when she was on an international volunteer trip as a pre-med and she had done stuff that the admission committee had major concerns about."

-Medical School Admissions Dean

Larger Responses: Know & Follow Guidelines and Standards

Summary of Guidelines

1. Formal relationship mechanisms between school/institution and host site or facilitating organization.
2. Primary goal of experience is learning and appropriately scoped/supervised practice.* Patient and community safety is paramount, respecting continuity of care, patient safety, informed consent, etc.
3. Appropriate planning, pre-departure training, in-country support, safety/security, and post-experience multi-directional evaluation/assessment/feedback mechanisms.
4. Respect for local host, local health systems, and emphasis on local capacity building/integrity of workforce.
5. Reciprocity for host community, including recognition of true costs of receiving trainees, reciprocal benefits, and opportunities.

Is Global Health "Global"?

Crane, "Unequal Partners: AIDS, Academia, the Rise of Global Health" *Behemoth.* 2010.

- Mushtaque Chowdhury, Dean of the School of Public Health at BRAC University in Bangladesh, assured the audience that "what we do in Bangladesh is global health, though we don't call it global health."
- Mario Rodriguez-Lopez from the National Institute of Public Health in Cuernavaca, Mexico…recounted a conversation he had had the day before with Jeffrey Koplan, Vice President for Global Health at Emory University... Koplan had told him, "what you are doing in Mesoamerica is global health," to which Rodriguez-Lopez responded, "ah yes, I only just realized it!"
- Nelson Sewankambo, Principal of Makerere University College of Health Sciences in Kampala, Uganda and one of the first scientists to publish data on AIDS in Africa… "When you see it the way I see it, people are not discussing global health. […] How do our students learn global health? By coming North? By staying home? You need to examine what global health actually means from other countries' perspectives."

Such findings Raises questions about *how* we train our students, *where* we train them, the assumptions they have about what global health is…

2019 Kinsman Bioethics Conference

Raising Voices:

The Ethics of Dialogue and Communication in Health Care

SESSION C4	
Theme	Socially and Culturally Situated Voices in Healthcare
Title	My Brain has a Pair of Scissors: Learning from the Stories of Patients with Disabilities
Speaker(s)	Elizabeth A. Wheeler, Ph.D., M.Ed. Mary Wood, Ph.D., M.A.
Date	Friday, April 12, 2019
Time	9:30 – 10:40 AM
Location	Wilder

SESSION C4 OBJECTIVES

- To grasp the importance of listening to the ways patients with disabilities describe their own experience.
- To become aware of and self-reflective about clinician assumptions and pre-conceptions about people with disabilities.
- To learn about important texts and blogs by writers with disabilities that are good sources of stories about what it's like to be a patient with disabilities.

SESSION C4 SPEAKER

Elizabeth A. Wheeler, Ph.D., M.Ed.
is an Associate Professor of English and Director of the Disability Studies Minor at the University of Oregon, where she specializes in intersections of environmental and disability studies and post-1945 American literature and popular culture. Her book *HandiLand: The Crippest Place on Earth,* a study of young people with disabilities in contemporary literature for young readers, appears in August 2019 from the University of Michigan Press in the *Corporealities: Discourses of Disability* series. Her scholarship has appeared in *Children's Literature Quarterly, Disability Studies and the Environmental Humanities,* and *ISLE: Interdisciplinary Studies in Literature and the Environment.* Prof. Wheeler has just returned from Tübingen, Germany, where she held the Ottilie Wildermuth Chair Visiting Professorship at the University of Tübingen. She received the 2018 LILAC Award from the Lane Independent Living Alliance for her advocacy for independent living and community outreach to people with disabilities.

Mary Wood, Ph.D., M.A.
Mary Elene Wood is a Professor of English at University of Oregon with a specialization in Medical Humanities and Disability Studies. She regularly teaches an Introduction to Medical Humanities course for college undergraduate pre-med majors and has taught courses on Literature and Medicine, Madness and Literature, and Bioethics and Literature at every level, from lower-division classes to graduate seminars. She has published numerous articles as well as two books on the subject of mental illness (so-called) and autobiography--The Writing on the Wall (Univ. of Illinois Press, 1994) and Life Writing and Schizophrenia (Rodopi/Brill, 2013). She has also published memoir, personal essay, and fiction based on her family's experiences with schizophrenia and other health challenges (Missouri Review, British Journal of Medical Ethics, Capra Review). She is currently working on a

collaborative research project with a medical anthropologist on the complex history of the Morningside Psychiatric Hospital in Portland, Oregon, where patients were sent from the Alaska Territory during the first half of the twentieth century. The history of Morningside has much to tell us about conceptions of mental health and illness in the American imagination as well as in practice and state and federal practice and policy during the years leading up to deinstitutionalization of the mentally ill. By bringing a Disability Studies lens to this history, Mary Wood and her co-researchers hope to better understand how mental illness is seen today and how current treatment models can move towards greater self-determination for those diagnosed with mental illness.

This presentation does not have PowerPoint slides.

2019 Kinsman Bioethics Conference

Raising Voices:

The Ethics of Dialogue and Communication in Health Care

SESSION D1	
Theme	Insights from Philosophical, Spiritual, and Cultural Analyses
Title	Beyond Biology or Disparity: A Harder Way of Thinking about Race
Speaker(s)	Camisha Russell, Ph.D.
Date	Friday, April 12, 2019
Time	11:00 – 12:10 PM
Location	Playwrights Hall

SESSION D1 OBJECTIVES

- Familiarize participants with three typical ways of thinking about race (as biological, as socially constructed, as a driver of culture).
- Introduce a fourth way of understanding race, as an organizing social idea so pervasive that it influences the very framework of scientific theories.
- Offer examples of this framing power of race to urge participants take deeper account of its influence in their own research and professional practices

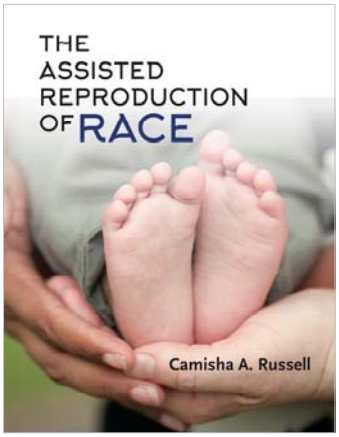
SESSION D1 SPEAKER

Camisha Russell, Ph.D.

Dr. Camisha Russell joined the Philosophy faculty at the University of Oregon in 2017. Her first book, The Assisted Reproduction of Race: Thinking Through Race as a Reproductive Technology (Indiana University Press, 2018) explores the role of race and racial identity in the ideas and practices surrounding assisted reproductive technologies. Her primary research and teaching interests are in Critical Philosophy of Race, Feminist Philosophy, and Bioethics. She received her PhD in Philosophy from Penn State University in 2013. Before attending graduate school, she served as a Peace Corps Volunteer for the Girls' Education and Empowerment program in Togo, West Africa. When not on campus, she enjoys the company of her wife and her energetic and loquacious 3-year-old.

Beyond Biology or Disparity: A Harder Way of Thinking about Race

Camisha Russell, PhD
Kinsman Bioethics Conference
April 12, 2019



What is "race"?

Outline

- Three approaches to race
  - Biological
  - Social constructivist
  - Cultural driver of history
- Implications of each approach:
  - For racism
  - For science and medicine
- An alternative approach: Race as organizing social idea
- Implications of this alternative
  - For science and medicine
  - For bioethics
- Example: Race and Assisted Reproductive Technologies

Three Approaches to Race

- Race is biological (or genetic)

Race as Biological

- More than the idea that physical traits are hereditary
- The idea that people can be meaningfully grouped biological/genetically
- The idea that racialized physical traits are markers of membership in discrete groups
- The idea that *the racial categories we use* are biologically or genetically meaningful
- In other words, racial categories are a feature of the natural world humans discover and that science allows humans to understand

Race as Biological: Implications for Racism

- What Paul Taylor calls "classical racialism":
  1. "The human race can be exhaustively divided into a few discrete subgroups"
  2. "Each of these smaller groups possesses a unique set of heritable and physiologically specifiable traits"
  3. "These distinctive sets of physiological traits vary with equally distinctive sets of moral, cognitive, and culture characteristics"
  4. These groups "can be ranked along graduated scales of worth and capacity"
  5. "The features that distinguish these races are passed down as part of a racial essence that shapes the character, conduct, potential, and value of each individual member of each race."

*Paul C. Taylor, *Race: A Philosophical Introduction* (Cambridge, UK: Polity, 2004), 47-8.

Race as Biological: Implications for Science/Medicine

- Prompts investigations of what race is, for example:
  - Is race real in the scientific sense?
  - What, if any, biological, physiological, or genetic features demarcate different racial categories?
  - What, if any, is the most scientifically accurate way to divide people into racial categories?
- Answers to which would shape scientific practices, as in:
  - How, if ever, should a concept of race be incorporated in human research?
  - Or pharmaceutical research?
  - Or medical practice?
  - For example, the use race-based medicine as proxy for personalized medicine

Three Approaches to Race

- ~~Race is biological~~ The science no longer supports this
- Race is a social construction

Race as Social Construction

- To be socially constructed is not necessarily *not* to be real
- Not a scientifically verifiable product of the natural world
- Analogy to money:
  - With money, societies take items found in nature (precious metals or paper) and assign them an exchange value that, though initially arbitrary, cannot be subsequently changed by individuals at will.
  - We must learn and use the rules of money to function in society.
  - With race, societies take natural physiological differences between people and assign them social meanings that, though initially arbitrary, cannot be easily changed or thrown off by individuals.
  - We must learn and use (at least to some degree) the rules of race to function in society.

Race as Social Construction: Implications for Racism

- Racism comes to be construed as irrational
- May seem to propose the solution to just stop talking about race
- Must keep money analogy in mind to how intractable a social construction can still be

Race as Social Construction: Implications for Science/Medicine

- As compared to white Americans, African Americans in particular experience:
  - poorer health
  - earlier death
  - reduced access to health care
  - inferior treatment when accessing health care
  - decreased likelihood of recovery from various illnesses

*LaVeist, Thomas A., ed. *Race, Ethnicity, and Health: A Public Health Reader*. San Francisco: Jossey-Bass, 2002.
*LaVeist, Thomas A., *Minority Populations and Health: An Introduction to Health Disparities in the United States*. San Francisco: Jossey-Bass, 2005.

Race as Social Construction: Implications for Science/Medicine

- Doctors and scientists can either help account for this issues or take these issues into account in their practices
- If the explanation is not biological, then causes are either:
  - socioenvironmental
    - social health risks
    - environmental toxins
    - lack of grocery stores and pharmacies
  - psychosocial/behavioral
    - the "weathering hypothesis"
    - "John Henryism"

*LaVeist, Thomas A., ed. *Race, Ethnicity, and Health: A Public Health Reader*. San Francisco: Jossey-Bass, 2002.
*LaVeist, Thomas A., *Minority Populations and Health: An Introduction to Health Disparities in the United States*. San Francisco: Jossey-Bass, 2005.

Three Approaches to Race

- ~~Race is biological~~ The science no longer supports this
- [Race is a social construction]
- Race is culturally and historically crucial for human well being and progress ⬅ White Nationalists ❤

Race as Cultural Driver of History

- The view that the temperaments and talents of certain races (and the nature of interactions between different races) determine the path of human progress (or decline)
- Historically important view of continuing relevance that rarely appears in these sorts of discussions
- More accurately describes thinking around the emergence of the race concept than the idea of race as biological
- Epitomized by British statesman Benjamin Disraeli's 1852 statement that: "All is race. In the structure, the decay, and the development of the various families of man, the vicissitudes of history find their main solution."*
- Remains quite present in the background of various nativist and white nationalist movements around the globe.

* Benjamin Disraeli, *Lord George Bentinck: A Political Biography* (London: Colburn, 1852), 331.

Race as Cultural Driver of History: Implications for Racism

- Connects race to other powerful concepts:
  - Cultural preservation
  - Cultural thriving
  - Patriotism
  - The Nation
  - National progress
  - National prosperity
- Makes the race idea a powerful political tool

Race as Cultural Driver of History: Implications for Science/Medicine

?

An Alternative Approach

Race is an organizing social idea

Race as Organizing Social Idea

- Takes seriously the second concept, social constructionism
- Keeps track of (and interrogates) the important effects of the first and third concepts
- Elsewhere in my work, I call this *race as technology*
- More simply put: shifting one's focus from questions about *what race is* to analyses of *what race does*.

Race as Organizing Social Idea

- Eric Voegelin, a German-born political theorist working in Austria during the rise of National Socialism, makes a useful distinction:
  - *race theory*: scientific theories of race in natural science
  - *race idea*: race as powerful political symbol used to define and shape communities
- Attempts to offer scientific theories of race persist (despite being discredited) because the sense of race as central and meaningful in our social relations endures the rise and fall of various racial theories.
- The essential task to undertake is to study systematically the way that the race idea operates in various contexts.

*Eric Voegelin, "The Growth of the Race Idea," *The Review of Politics* 2, no. 3 (1940): 283-4.

Race as Organizing Social Idea: Implications for Science/Medicine

- Explains why scientists continue to "look for" race
- Suggests it is not enough to pronounce race scientifically unreal
- Important work for scientists regarding race lies in making their own social positions as researchers more transparent to themselves in order to reflect critically on their deepest background assumptions and the very framing of their research questions.

Race as Organizing Social Idea: Implications for Bioethics

- Typical approach to bioethics:
  - focused on determining which practices are ethically permissible in biomedicine and biomedical research
  - thinking in terms of individually-conceived ethical rights, duties, obligations or prohibitions
  - limits of ethical permissibility involve specific harm to the personal freedom of other individuals
  - can easily recognize that racist policies or racial discrimination in medical or scientific research and practice are ethically impermissible due to the harm they cause the individuals targeted by the discrimination
  - but little to say about the idea of race itself

Race as Organizing Social Idea: Implications for Bioethics

- Suggests need to consider things like:
  - historical context
  - social values
  - often intangible harms to socially defined groups
  - even in areas they might consider purely objective and scientific
- Important work for bioethicists regarding race lies in making their own social positions as academics more transparent to themselves in order to reflect critically on their deepest background assumptions and the very framing of their ethical questions.

Bioethicists should be helping scientists think about race

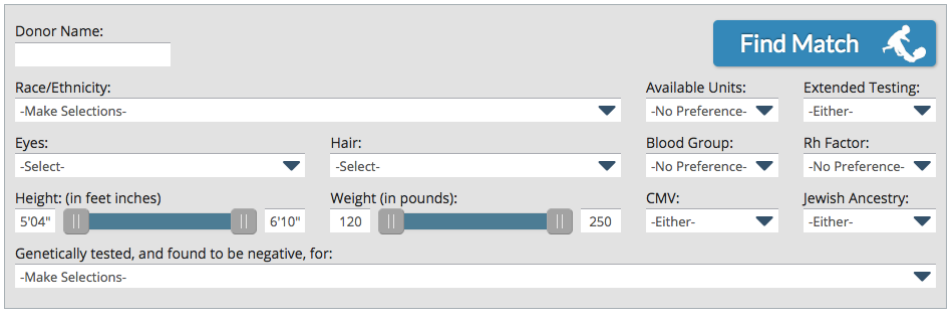
An Example: Race and Assisted Reproductive Technologies

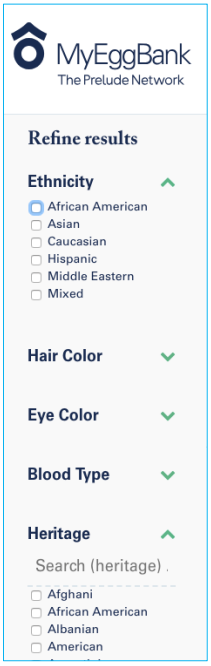
Diverse

Our frozen egg donors come from all over and reflect the diverse backgrounds that make up the United States

LEARN MORE

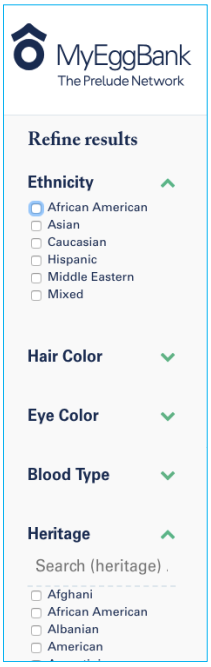
Instead of asking whether there is a scientific basis for the labeling of donor gametes with the self-reported racial identity of the donor





~~Instead of asking whether there is a scientific basis for the labeling of donor gametes with the self-reported racial identity of the donor~~

Explore why it is that people care so much about the supposed racial properties of donor eggs and sperm, and what effect that continued caring has on our popular understandings of race and racial identities



While questions of access to reproductive technologies for diverse social groups are important

~~While questions of access to reproductive technologies for diverse social groups are important~~

There are also crucial questions to be asked about which medical treatments and interventions get developed to treat which sorts of infertility problems and why

Traditional Division of Labor

Scientist	Bioethicist
What types of reproductive technologies *can* be developed and made safe?	When and how *should* such reproductive technologies be used?

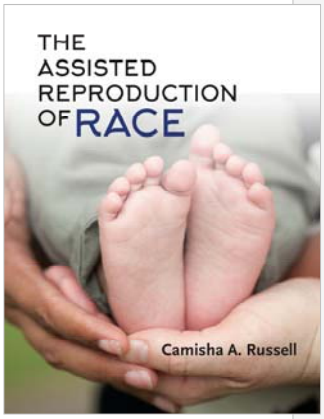
What are the social and historical contexts in which genetically-related children (or children that could pass for genetically related) are highly sought after and prized above all other forms of kinship?

Recap

- Three approaches to race
  - Biological
  - Social constructivist
  - Cultural driver of history
- Implications of each approach:
  - For racism
  - For science and medicine
- An alternative approach: Race as organizing social idea
- Implications of this alternative
  - For science and medicine
  - For bioethics
- Example: Race and Assisted Reproductive Technologies

Bioethicists should be helping scientists think about race

Questions?



CAS Department of Philosophy

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Camisha Russell

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Affiliated Departments: Disability Studies
Interests: Critical Philosophy of Race, Ethics (esp. Bioethics), African American Philosophy, Feminist Theory
Curriculum Vitae

Course Links

Fall 2018
PHIL 307 Social and Political Philosophy
PHIL 407/507 Critical Epistemology

Spring 2019
PHIL 103 Critical Reasoning

2019 Kinsman Bioethics Conference

Raising Voices:

The Ethics of Dialogue and Communication in Health Care

SESSION D2	
Theme	Insights from Philosophical, Spiritual, and Cultural Analyses
Title	Moral Injury: A Soulful Journey for Veterans, Providers, and Community Members
Speaker(s)	Chaplain Gregory Widmer, M.Div., C.C.C. F. Matthew Schobert, Jr., (Rev.) M.Div, L.C.S.W.
Date	Friday, April 12, 2019
Time	11:00 – 12:10 PM
Location	Directors

SESSION D2 OBJECTIVES

- Participants will describe the characteristics and impact of Moral Injury with combat Veterans.
- Participants will recognize the unique role and contribution that Veterans, health care providers, helping professionals, Native American Healers, and community partners bring to addressing combat Veteran's healing from trauma.
- Participants will understand the tools, techniques, and interventions of the VA Portland Health Care System's *Compassionate Warrior Training & Reintegration* program that facilitates the healthy reintegration of combat Veterans into the civilian community.

SESSION D2 SPEAKERS

Matthew Schobert (Rev.) M.Div., LCSW

Matthew is the Director of Chaplain & Social Work Professional Services and the Social Work Executive at the VA Portland Health Care System (VAPORHCS) in Portland, Oregon. Matthew earned a Bachelor of Arts degree (1995) from Union University in Jackson, TN, where he double majored in religion and history and double minored in English and philosophy. He earned a Master of Divinity degree (1999) in theology from Baylor University, completed two units of Clinical Pastoral Education at Hillcrest Baptist Medical Center, and then earned a Master of Social Work degree (2002) in healthcare from Baylor University.

Matthew is administratively responsible for the overall management and operations of staff and programs in two clinical sections – chaplaincy and social work – and their associated graduate and post-graduate training programs. He is also responsible for five Veteran and family lodging programs. He represents and oversees the professional practice of over 200 social workers throughout the health care system. Matthew is an active member of St. James Evangelical Lutheran Church (ELCA) in downtown Portland. He is joyfully married, the very proud parent of three young children, a Big Ten football fan, and a diaspora Texan.

Gregory J. Widmer (Rev.) M.Div., CCC

Greg is an Integrative Health Chaplain for VA Portland Health Care System (VAPORHCS) in Vancouver, WA. Greg earned a Bachelor of Arts degree (2010) from Moody Bible Institute in Chicago, IL, where

he majored in International Ministries. He earned a Master of Divinity degree (2015) from Denver Seminary and completed four units of Clinical Pastoral Education at Sioux Falls VA Medical Center in Sioux Falls, SD. Greg is a Certified Clinical Chaplain through the National Association of Veterans Affairs Chaplains (NAVAC), certified Whole Health Coach, and an endorsed Interfaith member of the Federation of Christian Ministries.

Greg is a two-tour Iraq War Veteran serving there from 2006-2007 and 2009-2010. He supervised and managed 18 soldiers as a Squad Leader. Greg was awarded the Army Commendation Medal for exceptional interpersonal skills with Iraqi Correctional Officers. Greg is married to his partner Tami and has two young girls at home.

Moral Injury: A Soulful Journey for Veterans, Providers, and Community Members

Rebecca M. Morris, (Rev.), MDiv
F. Matthew Schobert, Jr., (Rev.), MDiv, LCSW
Gregory J. Widmer, (Rev.), MDiv, CCC

Moral Injury

The Impact of Moral Injury

- Greg Widmer
  Staff Sergeant
- Saddam Hussein's Throne
  Baghdad, Iraq
- 2007

How are Moral Injury and PTSD Related?

- ❑ Sleep problems
- ❑ Nightmares/Flashbacks
- ❑ Hypervigilance
- ❑ Driving/Road Anxiety/Rage
- ❑ Anxiety in crowds
- ❑ Trust issues
- ❑ Withdrawn/Isolates
- ❑ General anxiety/worry
- ❑ Racing thoughts
- ❑ Impatience
- ❑ Low tolerance level
- ❑ Irritable
- ❑ Mood swings
- ❑ Cognitive distortions and changes
- ❑ Feelings of worthlessness
- ❑ Avoidance/Numbing
- ❑ Recklessness, adrenaline rush
- ❑ Surreal feeling
- ❑ Guilt
- ❑ Remorse
- ❑ Shame
- ❑ Euphoria
- ❑ Risk taking
- ❑ Anger & Rage
- ❑ Increased substance use/abuse
- ❑ Physical pain & ailments
- ❑ Loss of time
- ❑ Auditory hallucinations
- ❑ Denial
- ❑ Loss of sense of meaning
- ❑ Poor memory/forgetful
- ❑ Easily frustrated
- ❑ Panic attacks
- ❑ Obsessive checking
- ❑ Hopeless, thoughts of suicide

Faces of Moral Injury

"I am not the person I used to be."

"No one can understand."

"Meds can't take away this kind of pain."

"I used to have a purpose…who am I now?"

"God can never forgive me…"

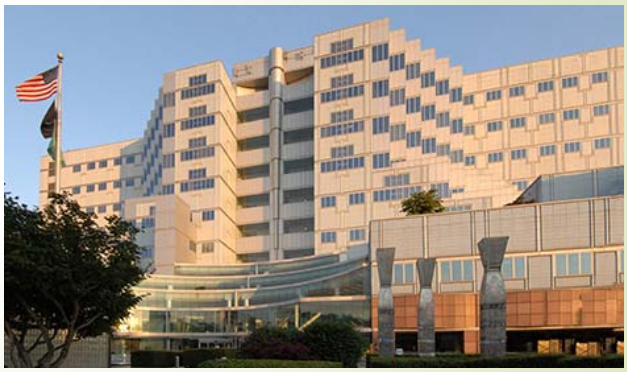
"I can't trust anyone."

Compassionate Warrior Training & Reintegration (CWTR)

Clinical Healthcare Chaplaincy
Ancient & Innovative

VA Portland Health Care System

- Level 1a Tertiary Care Facility
- 95,000+ Unique Veterans
- 950,000+ Outpatient Visits
- 12 Sites of Care
- 4,000+ Employees
- 1,500+ Trainees
- Integrated Health Care System
- Whole Health Flagship Site



From Complementary & Integrative Health to Compassionate Warrior Training & Reintegration

2015-2016
- Clinical Pastoral Education (CPE) CIH Mental Health Fellowship
- ACT for Moral Injury

2016-2017
- Compassionate Warrior Training Reintegration (CWTR) Program
- Blanketing Ceremony – May 2017

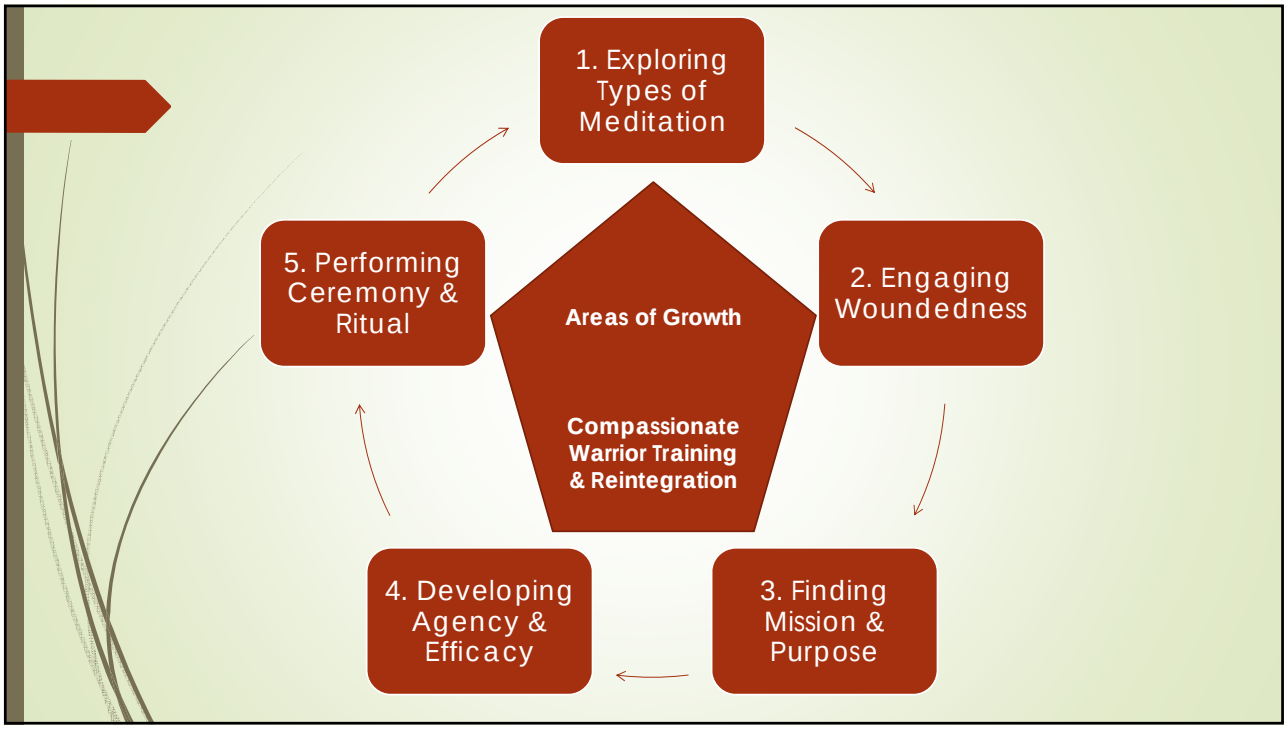
2017-2018
- Compassionate Warrior Training Reintegration (CWTR) Program
- 1.0 CIH MH Chaplain FTEE – Rev. Morris

2018-2019
- Compassionate Warrior Training Reintegration (CWTR) Program
- 2nd CIH MH Chaplain FTEE – Rev. Widmer

Voices from Our Healers

Compassionate Warrior Training & Reintegration

Engagement & Stabilization	Trauma Processing	Reintegration
Phase 1: Purification & Story Telling PTSD & Spirituality; Women's Council; Grief & Loss; Inpatient, Residential, & Outpatient Spiritual Skills Groups	**Phase 2: Story Telling & Restitution** ACT for Moral Injury: Perpetration & Betrayal	**Phase 3: Initiation** Compassionate Warrior Training for Reintegration (CWTR)
Phase 1: Death Lodge & Grieving	Phase 2: Whole Health Programming	Phase 3: Self-Designed Ceremony/Self-Project
• Veterans consolidate work they have done in mental health and chaplaincy services, revisiting what they have lost, grieving, and making room for new beginnings.	• Veterans work on a progression from grief to healing using a whole-health coaching framework.	• Self-designed ceremony and welcome home ritual with community support. • Through ceremony and ritual, Veterans intentionally reintegrate into communities and offer their gifts to others.



Voices from Our Veterans

Conversation & Discussion

Contact Us!

Rebecca.Morris5@va.gov Matthew.Schobert@va.gov Gregory.Widmer@va.gov

2019 Kinsman Bioethics Conference

Raising Voices:

The Ethics of Dialogue and Communication in Health Care

SESSION D3	
Theme	Insights from Philosophical, Spiritual, and Cultural Analyses
Title	Bridging Indigenous Wisdom and Western Ways: Healing Practices for a Modern World
Speaker(s)	Jai Medina, M.A.
Date	Friday, April 12, 2019
Time	11:00 – 12:10 PM
Location	Hansberry/Ferber

SESSION D3 OBJECTIVES

- Participants will be able to identify differences and places of convergence between ancient/indigenous ways of healing and modern medicine and psychology.
- Participants will gain effective strategies to increase cultural competency in clinical practice.
- Participants will learn about "wounded healer syndrome", and be given practical tools to support their own wellness.

SESSION D3 SPEAKER

Jai Medina, M.A.

Jai is the founder of the Balanzu Way, a shamanic healing tradition based in their Mexican/indigenous ancestry. Jai also helps facilitate a spiritual community called TRiBE that strives to re-weave the hoop of indigenous wisdom for a modern world.

Jai has been teaching and practicing energy work for more than fifteen years; they regularly see clients in their private practice, Two-Spirit Shamanic Healing. They have been an ordained interfaith minister since 2007, and have lead hundreds of public rituals, meditations, and private rites of passage. Jai also regularly teaches apprentices, offers workshops, and has spoken at conferences and gatherings around the country.

Jai received their M.A. in Counseling Psychology from Lewis and Clark College, and completed their clinical internship at NARA, where they supported the wellness of Native people recovering from drugs and alcohol. They currently work with Native elders from many different cultures, to learn from and preserve ancient healing methods, so they're not lost to our modern world.

This presentation does not have PowerPoint slides.

2019 Kinsman Bioethics Conference

Raising Voices:

The Ethics of Dialogue and Communication in Health Care

SESSION D4	
Theme	Insights from Philosophical, Spiritual, and Cultural Analyses
Title	"Don't tell the Doctor this but…": Ethical Challenges in Medical Interpretation
Speaker(s)	Daniel Towns, D.O.
Date	Friday, April 12, 2019
Time	11:00 – 12:10 PM
Location	Wilder

SESSION D4 OBJECTIVES

- Review current literature on the benefits of interpreters in health care settings for those with limited English proficiency.
- Discuss the different roles interpreters often assume in their work and the complications which may result for clients, family, and staff.
- Describe the general method of interpretation used at our program and the rationale behind it.

SESSION D4 SPEAKER

Daniel Towns, D.O.

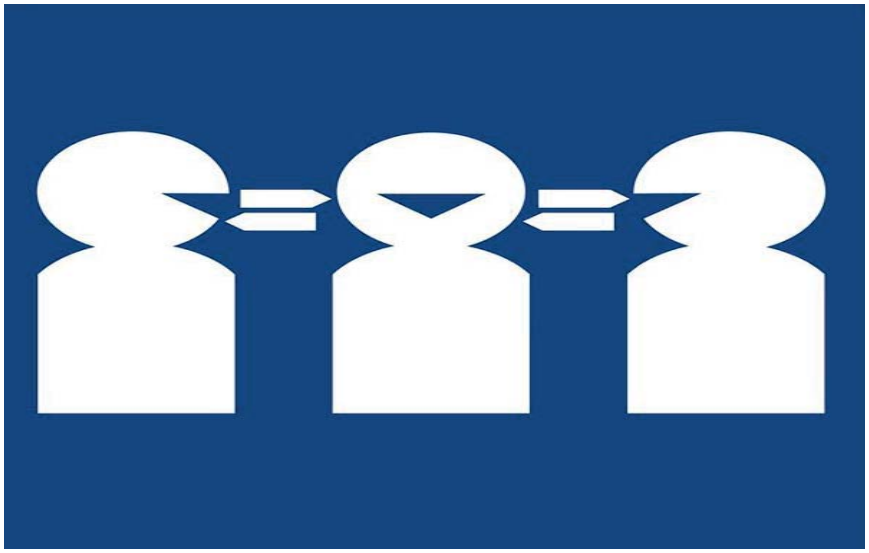
Dr. Towns is faculty psychiatrist at OHSU, where he works as the Medical Director at the Intercultural Psychiatric Program in the Department of Psychiatry. He received an undergraduate degree in History from Beloit College in Wisconsin, his medical degree from Des Moines University in Iowa, and completed his General Adult Psychiatry residency at OHSU in 2014. Since then, he has worked in a variety of settings, including in primary care / behavioral health integration, in Assertive Community Treatment teams, and in tele-psychiatry for the Oregon Department of Corrections. He now serves as a psychiatrist and the Medical Director at IPP, where he works with immigrants, refugees, and asylum-seekers from all over the world. He is also is the Director of the Torture Treatment Center of Oregon, which is embedded within IPP and is a federal grant program through the Office of Refugee Resettlement to support and provide holistic treatment to survivors of severe trauma and torture.

“Don’t tell the Doctor this but…”: Ethical Challenges in Medical Interpretation

Daniel Towns
Kinsman Bioethics Conference
April 12, 2019

Disclosures

- None.



Objectives

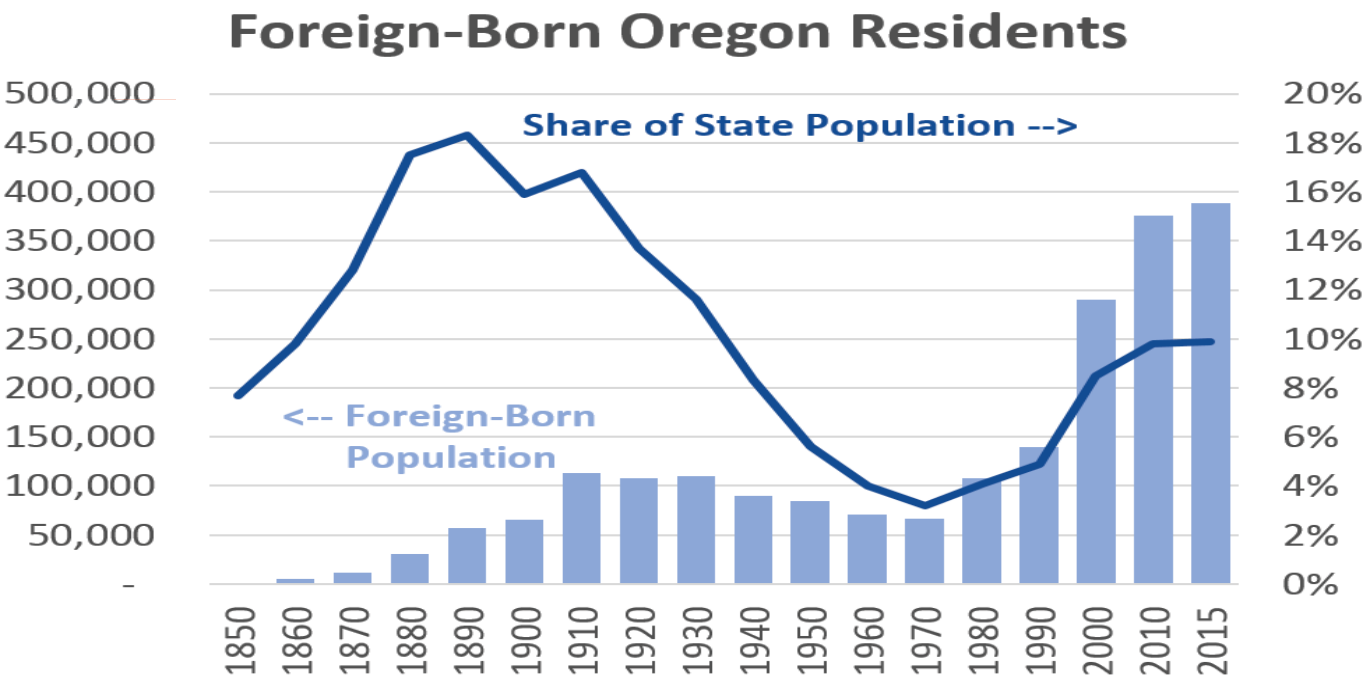
- Review current literature on the benefits of interpreters in health care settings for those with limited English proficiency.
- Discuss the different roles interpreters often assume in their work and the complications which may result for clients, family, and staff.
- Describe the general method of interpretation used at our program and the rationale behind it.

Background

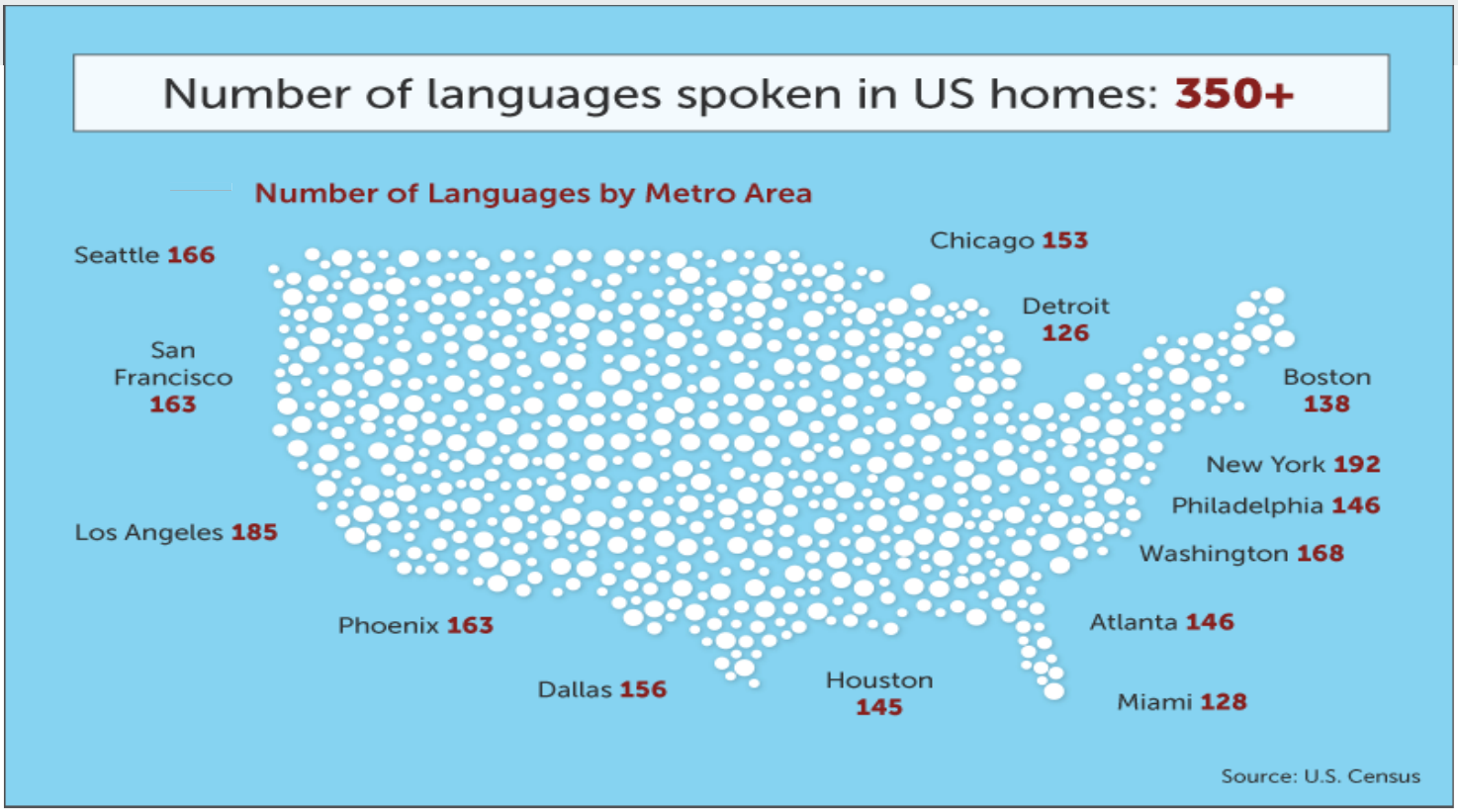
- 62 million people in the US indicate they speak a language other than English at home.
  - 25 million people say they speak English “less than very well.”
  - 4 million people are hearing impaired and require American Sign Language.
- Unclear as to how many interpreters are in the US.
  - US Bureau of Labor in 2016 indicated there were 68,000.
  - Other agencies have indicated that there are perhaps less than 2,000 interpreters certified for medical setting.

Background in Oregon

- In Oregon, roughly 10 % of Oregon residents are foreign-born.
  - Almost three-quarters (73.2 %) of immigrants reported speaking English “well” or “very well.”
  - Top countries of origin for immigrants were Mexico (37 percent of immigrants), China (6 percent), Vietnam (5.2 percent), India (4.1 percent), and Canada (3.6 percent).
- More than one-third of immigrants in Oregon are naturalized US citizens, while another third are undocumented immigrants.
- Nearly 90,000 US citizens in Oregon live with at least one family member who is undocumented.
- More than 10,000 Deferred Action for Childhood Arrivals (DACA) recipients live in Oregon.

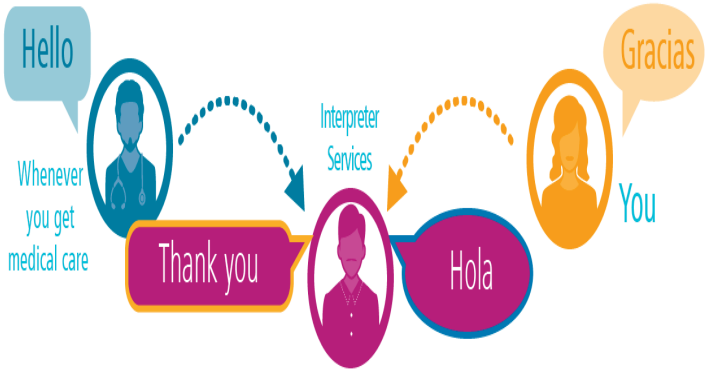


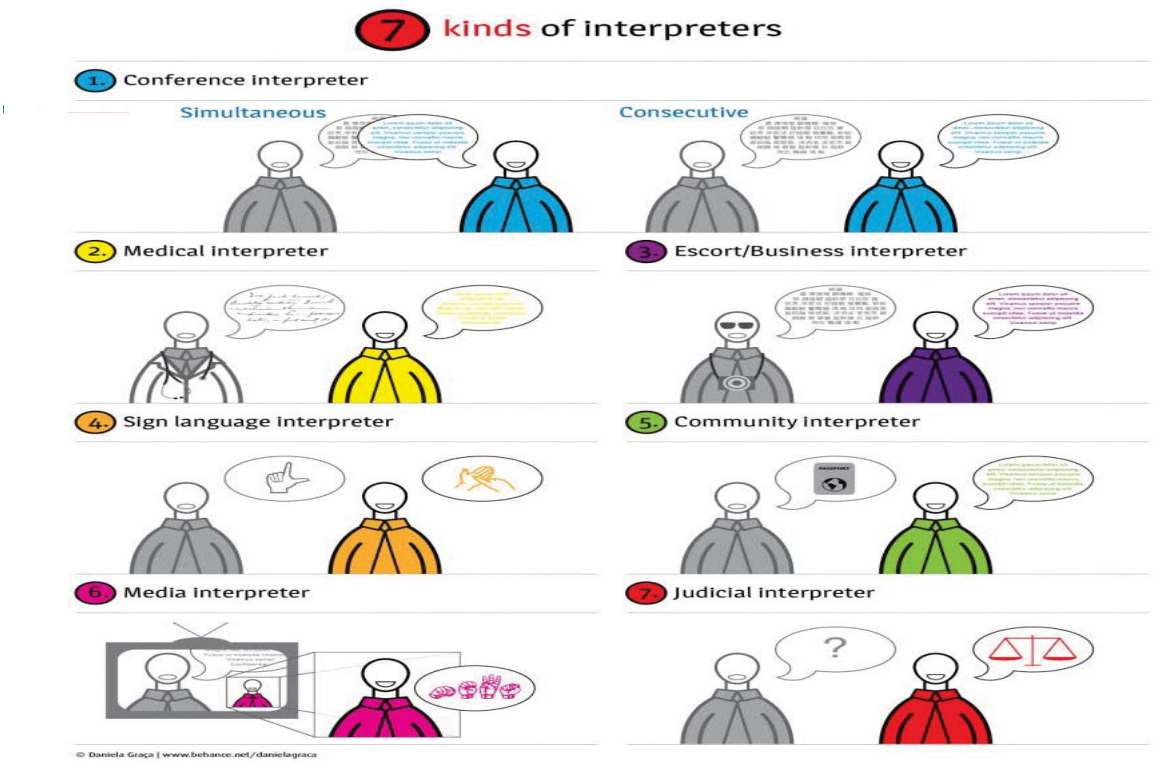
Source: U.S. Census Bureau, Portland State Population Research Center, Oregon Office of Economic Analysis



Languages spoken in Portland Metro Area

- https://multco.us/global/demographics
- In the Portland Metro Area, 19.6% of the population speaks a primary language other than English at home.
  - Around 120 languages spoken in total.
  - Spanish-speakers account for around 6% of total Portland area population.
  - Next most common are Russian, Vietnamese, Chinese, and Romanian.





Legislation around Interpretation

- Title VI of the Civil Rights Act of 1964 requires interpreter services for all patients with limited English proficiency in health care programs who are receiving federal financial assistance.
    - Language assistance access is a legal right.
    - Failure to provide interpretation when required is considered discriminatory.
- Office for Civil Rights of the DHS upholds the law.
- Particular state laws regarding language access vary greatly from state to state and are seemingly haphazard and inconsistent.
    - State laws are often focused on one situation or disease, rather than more general.

Funding of Interpretation

- The requirement to provide interpretation is essentially an unfunded mandate in much of the country.
  - States are not required to reimburse providers for the cost of language services. States may consider the cost of language services to be included in the regular rate of reimbursement for the underlying direct service.
  - 13 states and Washington DC provide some reimbursement for interpreter services. Oregon does not.
  - Many private (commercial) health insurances do not reimbursement providers for interpretation that is provided.
  - This is especially challenging for clinics/hospitals who serve high numbers of patients with Limited English Proficiency.

Reality regarding Interpretation

- Language barriers are a major contributor to health inequities and health care inequalities.
  - Language difficulties are often cited by people with LEP as a main reason for the problems with their health and with navigating the healthcare system.
- Still, many clinics and hospitals do not use interpreters when it is needed.
  - Family or bilingual staff are often used instead.
  - Cost and time involved with interpreters are often cited for main reasons for this.

Importance of Medical Interpreters

- Improved understanding of diagnosis/treatment and had fewer communication errors.
- Improved clinical outcomes.
- Improved patient satisfaction with health care provided.
- Equalize health care utilization.
- Reduced costs (ED room usage, hospital readmission rates, shorter hospital stays).
- Respect, acknowledgment, empowerment.

Varying roles of interpreters

- Cross Cultural Health Care Program proposes four roles for medical interpreters:
  - Conduit
  - Clarifier
  - Cultural broker
  - Advocate
- The conduit role is most commonly recommended by interpreting agencies and among health care providers - this is how interpreters are most often trained to work.
  - “Machine-like,” serving as a tool - communicating word for word, without discrimination or filtering.
  - Passive
  - Invisible
  - Simply as a voice - speaking in the first person.

The Interpreter's Challenge in Mental Health Settings

- It is natural for clients to expect more from the interpreter than simply a communication conduit.
- Most interpreters adopt different roles in different circumstances, depending on the setting, client, provider, their own background, comfort level and confidence, etc.
- Burnout, lack of support and opportunity for processing.
- Difficulty finding the right words.
- Matching emotions vs neutral stance.
- Being placed in uncomfortable situations (discussion of sensitive topics, being asked to interpret things they don't want to, etc).

The Interpreter's Challenge in Mental Health Settings

- In working with refugees and torture survivors in particular:
  - Vicarious trauma (or reactivation of traumatic experiences)
  - Survivor's guilt
  - Identification with client and their narrative
  - Feeling helpless/powerless
  - Feeling overwhelmed
  - Therapeutic distance - use of the first person.
  - When interpreter is of different tribe or ethnic group than client (and one that perpetrated the trauma/torture) - or vice versa.

General Ethical Challenges in Interpretation

IPP's model

- Started in late 1970s following end of Vietnam War and conflict in Cambodia produced refugees.
- Working with refugees, immigrants, and those seeking asylum from many countries.
- More than 1,000 active patients currently.
  - About 250 of whom are torture survivors.
- Model of clinical team with psychiatrist and culturally and linguistically matched counselor.
  - 7 mostly part-time psychiatrists
  - 14 counselors
  - 3 administrative staff
- Part of the OHSU Department of Psychiatry.

IPP's model

- The counselor serves both as the mental health therapist and, during client appointments with the doctor, as a case manager and interpreter.
- It is this counselor who accepts new referrals, processes registration paperwork, and performs the initial Mental Health Assessment.
    - The client's first experience of the counselor is not as an interpreter.
- Interpreting process evolves over time after gaining experience, trust with working with the doctor and eventually is typically much more as manager and cultural broker.
    - Often, significant filtering occurs.
    - Counselor is more active in sessions, makes their own therapeutic interventions as appropriate.
    - Everything the doctor says should be interpreted still.
- Supportive team approach.

Advice around working with Interpreters

- Do not use children, family members and untrained bilingual hospital employees as interpreters.
- Meet with the interpreter before an appointment and give the interpreter a brief background before the encounter.
- Allow for extra appointment time.
- Look and speak directly to the patient and family — not the interpreter.
- Use first person statements.
- Speak clearly and use short sentences.
- Avoid jargon, idioms and jokes.
- Refrain from saying anything that you don't wish to be interpreted during the encounter.

Perspective Taking Exercise

- Take the perspective of the patient, the interpreter, and the doctor in each of these situations - what are you thinking, how do you feel, etc?
    - “Don’t tell the doctor this but…” - during the appointment, the patient wishes to share something with only the interpreter.
    - Patient asks the interpreter for help with completing their citizenship application.
    - The doctor says something that if interpreted directly would be considered rude, offensive, inappropriate, etc.
    - While in the waiting room, the patient and interpreter are talking in their native language for ten minutes before the doctor comes to get them. What should be shared from their conversation with the doctor?
    - The doctor asks a question that the patient knows the interpreter already knows the answer to.
    - The interpreter knows that the patient is lying about a certain topic.
    - Non-English speaking patient shows up to the PCP appointment and is told “there is no interpreter available.”

Questions / Comments

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2019 Kinsman Bioethics Conference

Raising Voices:

The Ethics of Dialogue and Communication in Health Care

PLENARY SESSION	
Title	So Tired of Life: What Does Respect Require?
Speaker	Lynn A. Jansen, Ph.D., R.N.
Date	Friday, April 12, 2019
Time	1:00 – 1:55 PM
Location	Playwrights Hall

PLENARY SESSION OBJECTIVES

- Discuss characteristics of tired of life patients.
- Review trends in the treatment of tired of life patients.
- This Review ethical considerations bearing on the healthcare professional's role in caring for patients who are tired of life.

PLENARY SESSION SPEAKER

Lynn A. Jansen, Ph.D., R.N.

Dr. Jansen is the inaugural holder of the Madeline Brill Nelson Chair in Ethics Education in the Center for Ethics in Health Care at OHSU. After receiving her nursing degree and working as a registered nurse, she pursued academic studies at Columbia University, earning a doctorate in political science with a focus on political theory, and at the University of Chicago, MacLean Center as a postdoctoral fellow in medical ethics. Her work has appeared in the leading journals in the field including The Hastings Center Report, The Kennedy Institute of Ethics Journal, Bioethics and The Journal of Medicine and Philosophy. Dr. Jansen is the Principal Investigator on a five year RO1 Grant funded by the National Cancer Institute designed to study the impact of the optimistic bias on risk/benefit assessments by patient-subjects who enroll in early phase cancer trials. She was recently awarded a grant from the Greenwall Foundation to study the normative significance of the optimistic bias to informed consent. Her work on the optimistic bias has received national media attention and has been discussed in leading medical journals.

"So Tired of Life": What Does Respect Require?

Lynn A. Jansen PhD
Madeline Brill Nelson Chair in Ethics Education
Oregon Health & Science University

Lynn A. Jansen, Steven Wall, Franklin Miller. Drawing the line on physician-assisted death Journal of Medical Ethics Mar 2019, 45 (3) 190-197;

Conditional Question

- Suppose that PAD for patients who are terminally ill has been established as a legal practice in a given jurisdiction, what reasons (if any) are there to resist extending it to further classes of patients who are not terminally ill?

Neil S. Calman. "So Tired Of Life," HEALTH AFFAIRS VOL.23, NO. 3:MAY/JUNE 2004

A Doctor's Dilemma: Sarah

- "Dear Doctor, I hope you can help me. I am so tired. So very, very tired. I have lived a wonderful and full life, and now I am just no good. No good to myself and no good to anybody else. I have become a burden to everyone, and I have nothing left to live for. I hope you will help me. I just want to die"

Neil S. Calman. "So Tired Of Life," HEALTH AFFAIRS VOL. 23, NO. 3:MAY/JUNE 2004

Narrative Foreclosure (NF)

- The premature conviction that, even though one's life continues, in one's mind, one's life story has already ended.

Freeman, M. (2000). When the story's over: narrative foreclosure and the possibility of self-renewal. In M. Andrews, S. Slater, C. Squire, & A. Treacher (Eds.), Lines of narrative: Psychosocial perspectives (pp. 245–250). Toronto: Captus University Publications

Characteristics of Tired of Life/NF

- A sense of aching loneliness
- The experience of not mattering
- The perceived inability to express oneself
- Multidimensional feelings of tiredness
- A sense of aversion toward feared dependence and a concern about becoming a burden to others

van Wijngaarden E, Leget C, Goossensen A. Ready to give up on life: The lived experience of elderly people who feel life is completed and no longer worth living. Soc. Sci.Med. 2015 Aug;138:257-64.

A sense of aching loneliness

- "Deep inside you are very much alone. Totally, totally alone."
- "Deep heartfelt lonely feelings, regardless of whether there were others around."

van Wijngaarden E, Leget C, Goossensen A. Ready to give up on life: The lived experience of elderly people who feel life is completed and no longer worth living. Soc. Sci.Med. 2015 Aug;138:257-64.

The experience of not mattering

- A sense of being dispensable, redundant and not important to people or society.
- "At the moment, I strongly feel: my life is of no consequence anymore"

van Wijngaarden E, Leget C, Goossensen A. Ready to give up on life: The lived experience of elderly people who feel life is completed and no longer worth living. Soc. Sci.Med. 2015 Aug;138:257-64.

Inability to express oneself

- "If only I could express myself! I could give lectures, I could do lots of this, but I just sit here. Being unnecessary. Well, then it is easy to develop a desire for death."

van Wijngaarden E, Leget C, Goossensen A. Ready to give up on life: The lived experience of elderly people who feel life is completed and no longer worth living. Soc. Sci.Med. 2015 Aug;138:257-64.

Multidimensional feelings of tiredness

- "A complex and overwhelming fatigue often accompanied by a gloomy and despondent mood."

van Wijngaarden E, Leget C, Goossensen A. Ready to give up on life: The lived experience of elderly people who feel life is completed and no longer worth living. Soc. Sci.Med. 2015 Aug;138:257-64.

Policy and group centered paternalism

- Group centered paternalism seeks to devise policies that attend to the interests of all affected groups.
- Paternalism can be unjustified for an individual case, while being justified at the group level.

Lynn A. Jansen, Steven Wall, Franklin Miller. Drawing the line on physician-assisted death Journal of Medical Ethics Mar 2019, 45 (3) 190-197.

Two types of mistakes

- Mistake 1: when a patient who satisfies the autonomy and beneficence condition is denied the option of PAD
- Mistake 2: A patient is given the option of PAD when either or both the autonomy conditions is **not** satisfied

Lynn A. Jansen, Steven Wall, Franklin Miller. Drawing the line on physician-assisted death Journal of Medical Ethics Mar 2019, 45 (3) 190-197.

Justified group centered paternalism

- A concern with avoiding one type of mistake (that which occurs when patients are given an option that is not in their best interests or one that they cannot autonomously choose) justifies accepting or tolerating another kind of mistake (that which occurs when a patient is denied an option that she autonomously wants and is in her best interest)

Lynn A. Jansen, Steven Wall, Franklin Miller. Drawing the line on physician-assisted death Journal of Medical Ethics Mar 2019, 45 (3) 190-197.

Beyond autonomy and beneficence

- *WHAT DOES RESPECT REQUIRE?*

Responding to suffering

- Agent-narrative suffering
- Neuro-cognitive suffering

Conclusions…

- It is not enough to listen. One must also recognize the preconceptions that one brings to the listening. When we listen, we interpret; and when we interpret we make assumptions that help us understand the meaning of what is being said.

- It is important to listen to the voices of those who are tired of life not only to better understand their plight, but also to understand, and critically reflect on, one's own preconceptions about the aged and their value to the society in which they live.

2019 Kinsman Bioethics Conference

Raising Voices:

The Ethics of Dialogue and Communication in Health Care

SESSION E1	
Theme	Meeting the Patient Where They Are
Title	Street Medicine: Bringing Care to our Neighbors who are Living on the Streets
Speaker(s)	Dan Bissel, M.D. Drew Grabham, L.C.S.W. Lacey McCarley, R.N. Bill Toepper, M.D.
Date	Friday, April 12, 2019
Time	2:05 – 3:30 PM
Location	Directors

SESSION E1 OBJECTIVES

- Why Street Medicine is needed
- Talk about the three distinct groups we aim to serve
- Some of unique ethical /clinical challenges we see from providing care on the streets and how we address these

SESSION E1 SPEAKERS

Drew Grabham, LCSW

For the past 15+ years, Drew has worked as a social worker in the Emergency Department, in inpatient medical and inpatient psychiatric settings and in outpatient settings, I have been able to see for myself some of tragic system gaps that exist as well as celebrate some tremendous successes. He has a strong passion for working with people experiencing homelessness, by providing human centered, relationship based care that balances helping people change and advocating for system change. I have had the privilege to work for the past 6+ years as an Emergency Department Outreach Social Worker for OHSU. I get to work with people who have high ed utilization by providing intensive case management and outreach to them in the community and hospital settings. For the past year, Drew has worked alongside his fine colleagues to create and develop Portland Street Medicine.

Lacey McCarley, BSN

Lacey became interested in medical care for underserved populations while interning at Outside In Medical Clinic in Portland, OR. The internship transitioned into employment and Lacey stayed at Outside In for four years as a clinic administrator. Realizing that she wanted to provide more direct service to this population, she attended Linfield College and received her Bachelor of Science in Nursing in 2013. She has been working in Emergency Medicine for the past four years. She feels lucky to be included with a team of providers in developing Portland Street Medicine, a nonprofit that provides medical care and social services to houseless people where they are in our community.

Bill Toepper, MD

Dr. William Toepper was born and raised in the Chicago area. He attended med school University of Illinois at Chicago and completed residencies in pediatric and emergency medicine at the University of Chicago. He worked and taught at the Illinois Masonic Medical Center prior to relocating to the Portland area in 2009. From 2009 - 2017, he worked as ED physician at Legacy Salmon Creek.. After retiring, he spent summer of 2017 researching volunteer opportunities and discovered Street Medicine at the International Symposium in Allentown Pa. He then connected up with Dan Bissel, Lacey McCarley and Drew Grabham to form Portland Street Medicine.

PORTLAND STREET MEDICINE

Bringing Care To Our Neighbors Who Live On The Streets

Drew, Lacey, Dan and Bill

2019 Kinsman Conference

Disclosures

- We do not have any known conflict of interests or personal financial investments to disclose.

- We do want to disclose that we are really excited to be talking with you today about street medicine.

Our Goals for today:

To help each of you to have a greater understanding about:

- 1). Why Street Medicine is needed
- 2). The three distinct groups we are trying serve
- 3). Some of unique ethical /clinical challenges we see from providing care on the streets and how we address these

WHAT IS STREET MEDICINE?

- Providing care to our unsheltered neighbors
- "Rough Sleepers"
- Truly meeting people where they are at (both physically, but emotionally and psychologically)
- Basic care, not primary care
- Engagement / Relational Care
- Its about rebuilding trust in the system

WHY STREET MEDICINE?

- Point-in-time count over 4,000 people experiencing homelessness in Portland
- Fewer than 1,000 shelter beds available
- High burden of chronic illness
- Life expectancy 40-50 years old
- High cost of care within healthcare system, average 5 x higher than housed person

•10/2017 - 1st Community meeting
•2/1/2018 - Street Rounds begin
•5/2018 - Van Donated
•5/2018 - HRSA Free Clinic Status 5/25/2018
•8/2018 - Expansion to 2 shifts/week
•3/2019 - 501c3 Status
•3/2019 - 28 Credentialed providers

WHAT DO WE DO?

- Basic First Aid
- Medical Advice
- Basic interventions
- Resource Connection
- Collaboration
- Listen, Care, Relate
- What don't we do?
  - Robust Primary Care
  - Labs
  - Narcotics
  - Needle Exchange
  - Crisis Response

HOW DO WE DO IT?

- With Intention
- Trauma Informed
- We Listen to our Patients and to Each Other
- Consensus Decision Making
- Every team member has a voice
- It's okay to question and it's okay to disagree
- Orientation, Training, supervision and debriefs

PSM Core Beliefs

- Believe that people are the experts in their own lives
- Believe that people get to make their own decisions
- Believe there should no wrong doors
- Believe in harm reduction and being Strengths based
- People want to feel seen, heard and valued
- Believe in defining success 1 person at a time.

PSM Data

- For 2018, we served over 500.
- We provided over 110 Flu shots on the streets and in the Shelters
- In 2019, we have already had 400 interactions in 3 months.
- In 2019 – 54 comp and 84 follow up visits on established patients
- In 2019 - we have had a total of 162 brief encounters

Who we are trying to serve

- Individuals that are homeless (and their communities
- General Public / Community
- Healthcare Providers

Individuals who are experiencing homelessness

The Greater Community

- Both homeless community and other community
- Responding the the distress of the public
- Collaboration not duplication
- We are new to this and are learning as we go.

Provider Community

- Dealing with our own moral distress / injury
- Acknowledge and address
- Celebrate successes
- Honor the Story
- Trainings /Check ins / supervision / debriefings
- Next steps

PSM Ethical Issues

- Patient specific
- System failures
- Organization challenges
- Community Distress
- Professional health

Patient Case #1

- 60 yo female, with known vascular disease and self amputating toe. Significant History of Mental illness and recent psych hold at hospital. Been on streets for years. Looking for Black market Doctors to come and cut off her toe
- How do you proceed?

Patient Case #2

- 55 yo male, with hernia and weight loss. Homeless, Sleeping within 2 miles of PCP, but couldn't get there. Eventually diagnosed with advanced cancer and needing hospice
- What are you thinking about?

Ethical principles to consider with Street Medicine

- Patient / provider relationship
- Consent, communication and decision making
- Privacy, confidentiality and records
- Health of the community
- End of life Care
- Medical research
- Professional self regulation
- Inter-professional relationships
- Funding and Models of Care

Clinical Factors and Values to Consider

- Capacity
- MH vs addiction vs mistrust vs years of homelessness
- Patient and provider biases
- Risks and benefits

- Autonomy
- Beneficence
- Non Maleficence / Safety
- Justice

Outcomes of these Cases

That's All Folks

- Questions? / Reactions? / Reflections?
- **Thank You!**

PORTLAND STREET MEDICINE

- www.portlandstreetmedicine.org
- info@portlandstreetmedicine.org
- www.facebook.com/portlandstreetmedicine
- 503-501-1231

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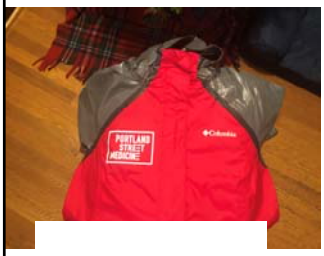

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2019 Kinsman Bioethics Conference

Raising Voices:

The Ethics of Dialogue and Communication in Health Care

SESSION E3	
Theme	Meeting the Patient Where They Are
Title	Vulnerable & Marginalized Patients: Now you See Them, Now you Don't. How to Truly See and Hear Your Patients So that They will Come to See You
Speaker(s)	Tera Roberts, D.N.P., F.N.P.-C.
Date	Friday, April 12, 2019
Time	2:05 – 3:30 PM
Location	Hansberry/Ferber

SESSION E3 OBJECTIVES

- Identify the under-represented and/or vulnerable populations and the way traditional health care structures limit their voices.
- Recognize the social determinants of health that limit the voice of the under-represented and/or vulnerable populations.
- Learn non- traditional communication strategies to improve health care advocacy and access.

SESSION E3 SPEAKER

Tera Roberts, D.N.P., F.N.P.-C.

Dr. Roberts attended Oregon Health & Science University for her undergraduate and graduate degrees in Nursing and was a trailblazer in the first Post Baccalaureate Doctor of Nursing Program offered at OHSU. Tera completed her doctoral clinical hours and research focusing on the barriers to care in rural communities and centered her work in Vernonia, Oregon and other rural communities in Columbia and Washington Counties.

Dr. Roberts has practiced in private practice, specialty care and have a long history of engagement with public health work in Columbia and Washington counties. Currently, she is partnered with Virginia Garcia Memorial Health Center as the on-site clinical provider at the Century School Based Health Center in Hillsboro Oregon and serves as the Associate Medical Director for SBHC's at Virgina Garcia. Her practice focuses on public health, reproductive/adolescent health and improving care in rural and underserved populations.

Tera currently resides in Vernonia, Oregon and has served on numerous wellness committees and health boards in that community over the past 23 years while raising a family of 9 children in the beautiful forest of the Pacific Northwest. The lived experience in this rural climate has allowed Tera to grow and question many of our current care practices and health care models.

Vulnerable & Marginalized Patients:

Now you see them...now you don't. How to truly see and hear your patients so that they will come to see you.

Dr. Tera Roberts, DNP, FNP-C

Disclosures

No conflicts of interest for the material contained in this presentation
&
No disclosures

Class Outline

Introduction to topics:

- Class Expectations
- Course Objectives
- Identifying Vulnerable Populations
- Setting the stage
- Communication- “How’s your Driving?”
- Striving for Cultural Competence
- Case Studies – small group/role play.
- Provider’s as part of the problem?
- “Burn out” vs “Moral Injury”
- Summary
- Citations

Class Expectations

- This is a safe and shared learning environment where the goal is to be reciprocal with our learning.
- For this class to be successful participants are encouraged to come prepared to share their personal experiences from their various professional and personal backgrounds-comments encouraged.
- This class will not take class time to cover books, articles or research on the topics discussed as those are referenced on the last slides of the power point.
- You may leave this class with more questions vs answers on the topics discussed-leave the class hungry to learn, search, seek more answers.
- This class will be interactive and participants may be asked to role play, participate in small group activities or read aloud in the class.

Course Objectives

- Identify the under represented/vulnerable populations and the way traditional health care structures limit their voices.
- Recognize the social determinants of health that limit the voice of the under represented/vulnerable populations.
- Learn non- traditional communication strategies to improve health care advocacy and access.

Who are the vulnerable and marginalized patients…

- Low in-come
- Persons of color
- Low literacy
- Low health literacy
- Mental Health Issues
- Developmentally Delayed
- Physically challenges
- Female
- Gender fluid/trans
- Rural
- Migrant Workers
- Children
- Teens
- English as second language/ not native language

Setting The Primary Care Stage (who's stage are you setting)

Western Medicine

- Scheduling an appointment
- Fees for showing up late or late cancelling a patient
- Insurance and billing for care
- Waiting room and exam rooms sterile, neutral tones, impersonal settings.
- Use of technology- EHR and MyChart.
- Telephonic interpretation
- Seeing someone in the "Care Home Model" at the clinic
- Appointment length 10-20 minutes

Cultural Considerations

- Walking in for care and waiting
- No fees for coming late and will be seen when they show up
- Barter and trade
- Use of colors, furniture, posters or marketing in line with cultures being served.
- Having tangible examples of medications, treatments, and including pictures on after visit summaries with instructions in their language at their literacy level.
- Seeing the same provider that they know and trust.
- Appointment length- longer due to cultural considerations-language, health literacy, mental illness, youth, etc.

Communication

- Consider that 80% of our communication is not what we say.
- Trust is a key component in making a connection in these populations and not easily regained once lost. How do we build trust in these populations?
- What does your body language and body positioning in the exam room say to the patient?
- What do your clothes say?
- What does the tone of your voice say?
- What does typing in the EHR during the office visit say to the patient?
- How does touch play a role in communication and does this improve trust?

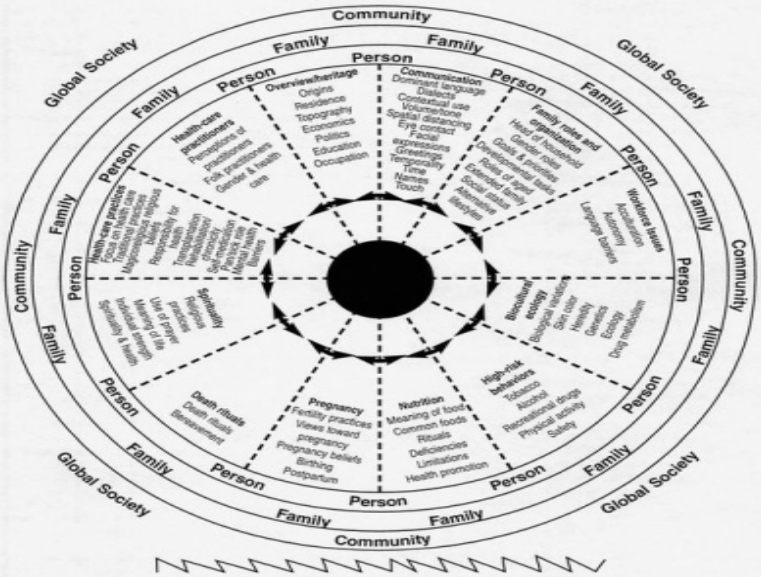
Cultural Competence

How do you gain cultural competence if you are not from the background of those you are serving? Can you gain competence?

Consider some topics that you may not have thought of as ***"cultures".***

- Guns-rural climates
- Depression, SI and Suicide
- Poverty
- Lack of formal education
- Sex Trafficking
- LGBTQ
- Religious or faith based/support groups
- Addictions
- Clubs and professions (agricultural, logging, fishing, etc.)

Figure 1 - The Purnell Model for Cultural Competence



“ One of the ethical and practical challenges in this environment is gaining a sufficient understanding to work within the culture of the patient and the community, with its strengths and weaknesses, in a way that does not communicate judgment of the values and the culture itself.” Nelson, W.(2009). ”

The way in which we use our communication skills will impart the following

Unconsciously incompetent to consciously incompetent

VS

Consciously competent to unconsciously competent

Case Studies

- Parent with 7 year old boy with ear pain.
- Twenty year old female with possible vaginal issues who is significantly developmentally delayed
- Parent with nine year old female with eye issue- family from Guatemala
- Forty- Five year old male heavy equipment operator on a logging crew in rural community in for high blood pressure.
- Sixteen year old teen in process of gender transition.
- Sixty year old Hispanic female with mobility issues in for follow-up on arthritis.
- Twenty-four year old male from rural community in for follow up on dysthymia and anxiety who has a gun and concealed carry permit.

How Do We As Providers and Gate Keepers of Health Become a Barrier to Access?

- What is meant by the term “burn out”
- What is “moral injury”
- How do our current health care models support continued "moral injury” to health care providers?
- Video- “It’s not Burnout, It’s Moral Injury” It's time to stop the victim shaming...and call it like it is.

https://www.youtube.com/watch?v=L_1PNZdHq6Q –by ZDoggMD- 6:20 minute video

Are we becoming part of the problem due to our current health care models??

Moral injury refers to an **injury** to an individual's **moral** conscience resulting from an act of perceived **moral** transgression which produces profound emotional shame. The concept of **moral injury** emphasizes the psychological, cultural, and spiritual aspects of trauma. Distinct from pathology, **moral injury** is a normal human response to an abnormal event

What is burnout in health care?
Burnout is common among **health care workers**. Characteristics of the health care environment, including time pressure, lack of control over work processes, role conflict, and poor relationships between groups and with leadership, combine with personal predisposing factors and the emotional intensity of clinical work to put clinicians at high risk.

Burnout, Professional. An excessive stress reaction to one's occupational or **professional** environment. It is manifested by feelings of emotional and physical exhaustion coupled with a sense of frustration and failure.

Techniques & Strategies to Improve Identifying vulnerable populations and to improve their voices in health care.

- Study the Purnell Model
- Simulation Lab participation
- Get involved in the culture where you practice, take time to get familiar with that cultures concerns, barriers, daily activities, heritage, etc.
- Identify the barriers in your agency/medical practice that create barriers-create moral injury to health care providers.
- Advocate at the local, state and federal levels for health care reform and development of health care models that are culturally competent.

Thank- you for your comments and sharing this time to consider how we as a group can make positive changes for our vulnerable patient populations.

Please contact me with any lingering questions or suggestions at troberts@vgmhc.org

Enjoy the Week-end!!

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2019 Kinsman Bioethics Conference

Raising Voices:

The Ethics of Dialogue and Communication in Health Care

SESSION E4	
Theme	Meeting the Patient Where They Are
Title	Listening for Non-Religious Belief Systems in Healthcare Ethics Consultation
Speaker(s)	Micki Varner, M.Div., B.C.C.
Date	Friday, April 12, 2019
Time	2:05 – 3:30 PM
Location	Playwrights Hall

SESSION E4 OBJECTIVES

- Define and discuss non-religious belief systems.
- Reflect on the influence of our own beliefs in healthcare ethics consults.
- Explore strategies for effectively recognizing and engaging a patient or family member's non-religious beliefs which inform their decision making.

SESSION E4 SPEAKER

Micki Varner, M.Div., B.C.C.

Micki Varner is the Manager of Spiritual Care for PeaceHealth's Oregon Network. She is a Board Certified Chaplain with the Association of Professional Chaplains and an ordained minister in the United Church of Christ. She received her BA in History and MA in Technical & Scientific Communication from James Madison University and her MDiv from Episcopal Divinity School. Micki's curiosity about the ways people find and express meaning in community through story and ritual informs her practice of ministry and her approach to healthcare ethics consultation.

Listening for Non-Religious Belief Systems in Healthcare Ethics Consultation

The Rev. Micki Varner, MA, MDiv, BCC
Manager of Spiritual Care
PeaceHealth Oregon Network

Objectives

- Define and discuss non-religious belief systems.
- Reflect on the influence of our own beliefs in healthcare ethics consults.
- Explore strategies for effectively recognizing and engaging a patient or family member's non-religious beliefs which inform their decision making.

Balcerowicz' Four Components of Religion

- Doctrine
- Religious practice (cult)
- Community
- Irrationality

Balcerowicz, Piotr. "Logic in religious and non-religious belief systems" Int J Philos Relig (2018) 84:113-129

Irrationality

- **Incomplete responsibility** (believers entrust responsibility for their fate to God)
- **Unquestionability of norms** (norms derived from religion can't be questioned)
- **Uncriticality** (critical thinking not applied to beliefs)
- **Essential unknowability** (*conscious* desire on the part of the believer to limit their knowledge of the world)

Balcerowicz concludes…

- Non-religious belief systems are those which can by modified by logic while religious belief systems are those which are not only unmodifiable but also defy logic.
- Non-religious belief system = math or science

What Is Spirituality?

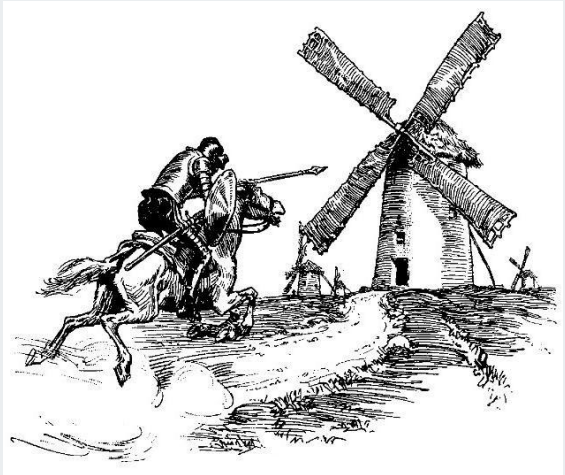
Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, and to the significant or sacred.

Consensus Conference to Improve the Quality of Spiritual Care as a Dimension of Palliative Care, February 2009

Working definition of non-religious belief systems

- Core belief derived from a significant life experience
- Limited to the individual or a family/friend group
- Irrationality
  - Uncriticality (critical thinking not applied to core belief)
  - Essential unknowability (facts do not impact the truth this belief)

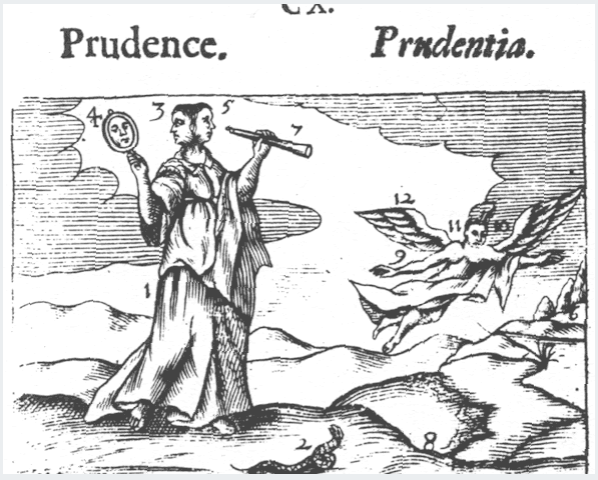
Knowable facts versus a belief system



Gardner's Theory of Multiple Intelligences

- Visual-Spacial Intelligence
- Linguistic-Verbal Intelligence
- Logical-Mathematical Intelligence
- Bodily-Kinesthetic Intelligence
- Musical Intelligence
- Interpersonal Intelligence
- Intrapersonal Intelligence
- Naturalistic Intelligence

What beliefs/biases am I bringing with me?



Strategies for working with non-religious beliefs

- Core belief derived from significant life experience
- Individual or small group of believers
- Irrationality
  - Uncriticality
  - Essential unknowability
- Listen to the person's experience, asking questions about meaning, identity, and life purpose
- Accept and respect that this belief is uniquely important to the person.
- These are not rational beliefs, rather these are emotional beliefs.

Skills for working with non-religious beliefs

- Listen to personal experience
- Accept and respect the unique importance of this belief
- Emotionally significant
- Open-ended questions about meaning, purpose, identity.
- Communicate your acceptance and respect through words and actions
- Listen for and respond to the emotional significance of this belief. Address emotions for what they are without responding to emotions with facts.

Case Studies