



Health Humanities
CONSORTIUM
#2023HHC

“Mobilizing Selves, Transforming Structures”

March 16-19, 2023

Health Education Campus, Cleveland, OH

Co-Hosted by:

Department of Bioethics, Case Western Reserve University School of Medicine
Program in Medical Humanities, Cleveland Clinic Lerner College of Medicine



SCHOOL OF MEDICINE

CASE WESTERN RESERVE
UNIVERSITY

Department of Bioethics



Cleveland Clinic

Lerner College of Medicine

of Case Western Reserve University

Conference Schedule At-A-Glance

Thursday, March 16, 2023

1:00-4:00 p.m. EDT

5:30 p.m. EDT

HAHPE Meeting

Reception in the Allen Memorial Library hosted by the Cleveland Clinic Lerner College of Medicine and the John P. Murphy Foundation. Participants will be able to tour the Dittrick Medical History Center.

7:00 p.m. EDT

Dr. Knock's 100th Birthday

Friday, March 17, 2023

8:30-9:00 a.m. EDT

9:00-9:30 a.m. EDT

9:30-10:00 a.m. EDT

10:00-11:15 a.m. EDT

11:15 a.m.-12:45 p.m. EDT

11:30 a.m.-12:30 p.m. EDT

12:45-2:00 p.m. EDT

2:00-2:30 p.m. EDT

2:30-3:45 p.m. EDT

3:45-4:15 p.m. EDT

4:15-5:30 p.m. EDT

Registration Open

Welcome Session

Break

Concurrent Sessions 1

Lunch Break (food available)

HHC Business Meeting

Concurrent Sessions 2

Break

Concurrent Sessions 3

Break

PLENARY LECTURE: David Fakunle

Saturday, March 18, 2023

9:00-10:15 a.m. EDT

10:15-10:45 a.m. EDT

10:45 a.m. -12:00 p.m. EDT

12:00-12:15 p.m. EDT

12:15-2:15 p.m. EDT

2:15 - 2:45 p.m. EDT

2:45-4:00 p.m. EDT

4:00 - 4:30 p.m. EDT

4:30-6:00 p.m. EDT

Concurrent Sessions 4

Break

Concurrent Sessions 5

Break/Lunch Available (can take into plenary session)

PLENARY WORKSHOP – Eli Clare

Break

Concurrent Sessions 6

Break/Light Reception

William Carlos Williams Poetry Award Ceremony

Sunday, March 19, 2023

9:00-10:15 a.m. EDT

10:15-10:45 a.m. EDT

10:45 a.m. -12:00 p.m. EDT

12:00 p.m. EDT

12:15-12:45 p.m. EDT

Concurrent Sessions 7

Break

Concurrent Sessions 8

Boxed Lunches Available (can take into closing session)

Closing Remarks

Thank you to our conference sponsors!



2023 Health Humanities Consortium Local Conference Planning Team

Eileen Anderson
Katherine Burke
Rita Dexter
Julia Knopes
Erin Lamb

2023 Health Humanities Consortium Conference Committee Members

Charise Alexander Adams
Eileen Anderson
Rachel Bracken
Katherine Burke
Rita Dexter
Julia Knopes

Ulrich Koch
Erin Lamb
Stephanie Larson
Tracy Leavelle
Sarah Roelle
Kym Weed

2023 Health Humanities Consortium Conference Tech Team Members

Trenley Anderson
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Mariah Lapinski
Cathy Li
Eli McCormick
Tim Nicholas

Nick Orgrinc
Lydia Pui
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Mahi Tomar
Julia Van Oordt
Deirdre Welch
Danielle Wilfand
Katie Xu

2022-2023 Health Humanities Consortium

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Thank you to our conference reviewers!

Kamna Balhara	Craig Klugman	Matthew Reznicek
Phillip Barrish	Julia Knopes	Cynthia Richards
Emily Beckman	Ulrich Koch	Paul R Solomon
Sarah Berry	Brooke Kowalke	Michael Tangeman
Rachel Bracken	Erin Lamb	Hope Torrents
Pamela Brett-MacLean	Susan Lamb	Megan Voeller
Amanda Caleb	Stephanie Larson	Rebecca Volpe
Gina Camodeca	Tracy Leavelle	Rosemary Weatherston
Youngjin Cho	Patricia Luck	Ryan Weber
Siobhan Conaty	Elizabeth Marhoffer	Kym Weed
Lorna Fitzsimmons	Marie McAllister	Tana Jean Welch
Martha Garcia	Ian McCoog	
Jacqueline Genovese	Juliet McMullin	
Lenny Grant	Madalina Meirosu	
Lindsey Grubbs	Woods Nash	
Nuria Ibáñez	Sharon Ostfeld-Johns	
Bushra Juhi Jani	Sheeba Kunjukrishnan Retnaba	

2023 Health Humanities Consortium Conference

“Mobilizing Selves, Transforming Structures”

Conference Schedule

*Events marked with an asterisk will not be offered in hybrid format

Thursday, March 16, 2023

*1:00-4:00 p.m. EDT	HAHPE Meeting
*5:30 p.m. EDT	Reception in the Allen Memorial Library hosted by the Cleveland Clinic Lerner College of Medicine and the John P. Murphy Foundation. Participants will be able to tour the Dittrick Medical History Center.
7:00 p.m. EDT	<i>Dr. Knock's</i> 100th Birthday

Friday, March 17, 2023

8:30-9:00 a.m. EDT	Registration Open
9:00-9:30 a.m. EDT	Welcome Session
9:30-10:00 a.m. EDT	Break
10:00-11:15 a.m. EDT	Concurrent Sessions 1

1A ROUNDTABLE: Developing Selves with State Intervention: How Embodied and Narrated Experience Can Lead the Way to Reform

Eileen Anderson, Elise Ellick, Case Western Reserve University School of Medicine

1B PANEL: Stress, Trauma, and Resilience in African-American Women's Narratives of Everyday Racism

James Phelan, Robyn Warhol, Simone Drake, Ohio State University
Lisa Zunshine, University of Kentucky

1C PAPER SESSION: Innovations in Medical and Dental Education

“Innovative Approaches to Dismantling Ableism through Medical Education”

Liz Bowen, The Hastings Center

Dorothy Tolchin, Harvard Medical School

Kerry Devlin, Johns Hopkins University

“The Art-Science of Close Listening: Music Lessons for Healthcare Personnel”

Timothy Nicholas, Case Western Reserve University School of Medicine

“The Root Cause: Creating a Safe Space to Discuss Racism in Dentistry”

Michelle Moncrieffe Foreman, University of Maryland

Eileen Harrington, University of Maryland Libraries

1D PAPER SESSION: Metaphor and Meaning

“Mutant Metaphors: Frankenstein in the Era of COVID-19”

Alexandre Djandji, Allison Coffelt, Narrative Medicine, Columbia University

“Cancer and Erasure of the Self as Metaphor in Romanian Interbellum Literature”

Madalina Meirosu, Swarthmore College

“The Stories We Tell: The Role of Narrative and Metaphor in Shaping Disability Within Ourselves and Society”

Danielle Wilfand, Case Western Reserve University School of Medicine

1E PAPER SESSION: Community Engagement for Health

“Root Cause: Establishment of a Monthly Health Fair to Empower the Local Community”

Elise Kao, Darby Billing, Alyssa Guo, Katelyn Haywood, Jennifer Grier, Jennifer Trilk, Jennifer Springhart, University of South Carolina School of Medicine Greenville

Jason Li, Greenville Technical College

Lauren Tyler, UT Southwestern Medical Center

Jacob Ritchie, University of Louisville/Norton Children’s Hospital

Lauren Fowler, Wake Forest School of Medicine

“The Health Humanities Are Health Care Infrastructure”

Lenny Grant, Syracuse University

“In the Analysis: Processes of Inclusion Through Anti-Oppressive Methodologies in Health Equity Research”

Juliet McMullin, University of California Irvine

Sherri Salgado, Riverside-San Bernardino Indian Health Inc.

Katheryn Rodriguez, UCR Center for Health Disparities Research

1F WORKSHOP: It Takes a Village: Creating Community to Transform Health and Healing

Mary Fridley, East Side Institute

11:15 a.m.-12:45 p.m. EDT

Lunch Break (food available)

11:30 a.m.-12:30 p.m. EDT

HHC Business Meeting

12:45-2:00 p.m. EDT

Concurrent Sessions 2

2A FLASH SESSION: Structure, Environment, and Inequity

“Science Journalism in a Pandemic: Resistance, Truth, and Trust”

Sriya Donthi, Case Western Reserve University School of Medicine

“Making a Right Turn: Collaborative Initiatives for Health Care Among Transgender Migrants, Refugees, and Asylum-Seekers in Sweden”

Debra Beight, Case Western Reserve University

“The Future of Medical Ethics: Addressing Inequities in Health AI”

Mahi Tomar, Case Western Reserve University

“The Role of Climate Change in Food Accessibility: A Global Way Forward”

Pooja Patel, Duquesne University

“Green Cities: Balancing Climate Action and Self-Determination of Historically Under-Resourced Communities”

Sophia Friedl, Case Western Reserve University School of Medicine

“Food Insecurity in Cuyahoga County: Evaluating the Efficiency of Policy Intervention on Health Outcomes”

Dieu Linh Nguyen, Case Western Reserve University

“Diseases of Despair & Horizons of Hope: Perceptions of Structural Drivers of Despair-related Illness by Members of Rural and Urban High-Prevalence Communities”

Daniel George, Penn State College of Medicine

2B PANEL DEAFMed: Deaf Education and Awareness For Medical Students

Natalie Perlov, Zachary Urdang, Irina Middleton, Julia Croce, Sidney Kimmel Medical College at Thomas Jefferson University

Arielle Spellun, Boston Children's Hospital

2C PAPER SESSION: Measuring Health Humanities

“A Baseline Survey of Health Humanities Baccalaureate and Graduate Programs”

Craig Klugman, DePaul University

Anna-leila Williams, Quinnipiac University

Sarah Berry, Connecticut College

Charise Alexander Adams, Creighton University

Gina Camodeca, D’Youville College

Tracy Leavelle, Creighton University

Erin Gentry Lamb, Case Western Reserve University

“Humanistic Sensitivity: A New Construct in the Search for Health Humanities Outcomes”

Rebecca Volpe, Katharine Dalke, Penn State College of Medicine

“Addressing the Gaps: Developing an Assessment and Program Evaluation Plan for Mixed Method Health Humanities Tool Used in an Interprofessional Nursing and Medical Undergraduate Education Setting”

Patricia Luck, University of Rochester School of Medicine and Dentistry

Caroline S. Nastro, University of Rochester School of Nursing

2D PAPER SESSION: Visual Art and Sound to Address Race and Inequality

“Paint Me as I Am: Overcoming Inequality through the Visual Discourse of Healthcare Workers”

Diana-Andreea Novaceanu, University of Bucharest

“Black Skin, White Lights: The Double Bind of Photographing Dark Skin in a White Society”

Katie Xu, Case Western Reserve University School of Medicine

“Sound Health, Sonic Cosmologies: Decolonizing the Biomedical in the Work of Guadalupe Maravilla and Milford Graves”

Megan Voeller, Thomas Jefferson University

2E PAPER SESSION: Digital Health Humanities Innovations

“Everyday Medicine: Mapping People and Plant Relations in Contemporary Minneapolis”

Macey Flood, Boston University/University of Minnesota

Emily Beck, Wangenstein Historical Library

“Supporting Recovery from Opioid Addiction through Autobiographical Game Design: Preliminary Findings”

Sandra Danilovic, Kenny Chee, Wilfrid Laurier University

“A Missing Link: Empowering Youth to Take Charge of their Healthcare”

Sara Bharwani, University of Nebraska-Lincoln

Alex (Trout) Hamilton, Jacqueline Huscroft D'Angelo, Oregon Research Institute

2F WORKSHOP: Palliative Care as a Model to Help Decision-Makers Mitigate the Health Effects of Climate Change

Daniel Mahoney, Baylor College of Medicine

2:00-2:30 p.m. EDT

Break

2:30-3:45 p.m. EDT

Concurrent Sessions 3

3A FLASH SESSION: Disability/Ableism and Aging/Ageism

“From Erasure to Affirmation: Transforming Medicine to Affirm Disability Identity Development”

Devika Nandwana, Case Western Reserve University School of Medicine

Perna Mamileti, Independent Scholar

“Reimagining the Foundations of Guardianship for Adults with Disabilities”

Prudence Riva, Case Western Reserve University

“Power of Horror: Dementia Care and Social Justice in Ariyoshi Sawako’s *Twilight Years* (1972)”

Yingzhi Lu, University of Illinois at Urbana Champaign

“Making Peace with Aging: Deconstructing the War Metaphor in Anti-Aging Rhetoric”

Grayson Holt, Case Western Reserve University

“Medical Ageism Faced by Young Adults and Children: How Young-Onset Rheumatoid Arthritis is Overlooked as a Potential Diagnosis in Youth”

Deirdre Welch, Case Western Reserve University

“Draw YOUR Story: An Art and Storytelling Program for Older Adults”

Sujal Manohar, Baylor College of Medicine

Oluwapelumi Oloyede, University of Houston College of Medicine

“Effects of Narrative Storytelling on Continuing Care Retirement Community (CCRC) Older Adults”

Catherine Bryant, Jason Burnett, University of Texas Health Science Center at Houston

Renee J. Flores, Mary E. Kollmer Horton, McGovern Center for Humanities and Ethics, University of Texas Health Science Center at Houston

3B PANEL: Writing Beyond What We Witness

Amy Haddad, Creighton University
Jay Baruch, Alpert Medical School, Brown University
Stacy R. Nigliazzo, Baylor College of Medicine
Rachel Kowalsky, Weill Cornell Medicine

3C PANEL: “The God Trick of Seeing Everything from Nowhere”: Evidence-Based Medicine in Contemporary Healthcare

Anita Slominska, St. Mary's Hospital Research Centre
Ailish Burns, Brown University
Ryan Hart, Independent Scholar

3D PAPER SESSION: Health Care Workers

“Masking Affects: The Cruel Optimism of the Discourse on Healthcare Worker Distress During the COVID-19 Pandemic”

Maryam Golafshani, University of Toronto Faculty of Medicine

“Reckoning and Revisiting: Ambiguous Loss in the Healer's Burden”

Kimia Heydari, Columbia University

“The Mindful Art Pause: Leveraging Individual Experience of a Brief Multi-Media Recording to Improve Clinical Team Outcomes and Wellbeing”

Patricia Luck, Susan Dodge-Peters Daiss, University of Rochester School of Medicine and Dentistry

Gaelen McCormick, Eastman School of Music at the University of Rochester

3E PAPER SESSION: Political-Economic Structures and Public Health

“Will the Circular Economy Take the Health Care Sector Beyond Social Injustice?”

Lorna Fitzsimmons, California State University Dominguez Hills

“American Dementia: Applying a Structural Analysis to our Deranged Societal Approach to Alzheimer's”

Daniel George, Penn State College of Medicine

Peter Whitehouse, Case Western Reserve University

“Redlining: Addressing Residential Segregation's Persisting Symptoms in Clinical Care”

Fareeda Farhan Naduvil Valappil, Case Western Reserve University

3F WORKSHOP: Gestures of Care - Exploring Creative Movement Exercise to Reflect On and Cultivate Caring Consciousness in Care Interaction

Michael Koon Boon Tan, Noemie Soula, Sheffield Hallam University

3:45-4:15 p.m. EDT

Break

4:15-5:30 p.m. EDT

PLENARY LECTURE

“The Lion's Side: The Utilization of Storytelling for Transformation in Arts, Culture & Health”

David Olawuyi Fakunle, Ph.D.

Assistant Professor of Public Health, Morgan State University School of Community Health & Policy; Adjunct Assistant Professor, University of Florida Center for Arts in Medicine; Associate Faculty in the Mental Health Department, Johns Hopkins Bloomberg School of Public Health

Evening

On Own

Optional “Art of Seeing” Event at the Cleveland Museum of Art

Saturday, March 18, 2023

9:00-10:15 a.m. EDT

Concurrent Sessions 4

4A FLASH SESSION: Representation and the Arts

“Mortality as Depicted in Medical TV Shows Compared with Reality”

Kushagra Kumar, Justin Ceasar, Robert P. Olympia, Penn State College of Medicine

“Ethics Without Ethicists: Exploring the Absence and Narrative Potential of Professional Ethicists as Characters in Medical Film and Television”

Stephanie Larson, Independent Scholar

“Using (Marginalized) Memoir to Teach Social Determinants of Health”

Robin McCrary, Syracuse University

“Traditional Dance Health Narratives and the Aseemkala Initiative: Using Diverse Storytelling for Equity in Medical Education”

Shilpa Darivemula, University of North Carolina

Isha Parupudi, Columbia University

Shreya Srivastava, Albany Medical College

Monica Shah, St. John’s University

“Body in a Built World: A Poetry Reading”

Anna Leahy, Chapman University

“Coloring Inside the Lines: A Critique of the Diversity in Medical Diagrams”

Anna Cryan, Case Western Reserve University

“Artists with Ocular Disease: Perspectives on Vision, Artistry, and Disability”

Mallory Bowers, Sidney Kimmel Medical College

4B PANEL: Narrating Trauma, Narrating Identity: Forming the Physician-Self in the Anatomy Lab

Margie Hodges Shaw, Christopher J. Mooney, Natercia Rodrigues, Erik Larsen, University of Rochester School of Medicine and Dentistry

4C PANEL: Mobilizing Health Humanities to Address Health Disparities

Kirsten Gardner, Şerife Tekin, Bianca Pulido, Melissa Wallace, Sophia Dove, Shamshad Khan, Kimberly Kline, Eric Shattuck, University of Texas at San Antonio

4D PAPER SESSION: Rethorizing Key Terms: Fear, Regret, Pain

“Structures of Fearing: Or, How We Learned to Stop Worrying and Love Disease”

Emily Waples, Hiram College

“A Measure of Regret: Historicizing Decisional Regret in the Ethics of Surgical Decision-Making”

Jacob Moses, University of Texas Medical Branch at Galveston

“False Promises of (Non)Universal Languages: Theorizing Pain and Social Justice through the Arts”

Ryan Weber, Geisinger Commonwealth School of Medicine

4E PAPER SESSION: Reconceptualizing Autism

“Visualizing Autism: How Films and TV Programs Shape Our Views”

Kristine Mulhorn, David Flood, Drexel University

“The Differences Within: Autism, the Media, and Self-Advocacy in India”

Shubha Ranganathan, Indian Institute of Technology Hyderabad

“Turning Theory to Practice: Intersectionality and Decolonizing Autism”

Samantha Chipman, Loyola University Chicago

4F ROUNDTABLE Translational Medical Humanities

Kirsten Ostherr, Rice University

Marta Arnaldi, University of Oxford & University of Oslo

Eivind Engebretsen, John Ødemark, University of Oslo

Charles Forsdick, University of Liverpool

***4G WORKSHOP: Behind the Mask: Art as a Third Object for Important Conversations about Race and Bias**

Mark Stephens, Penn State College of Medicine

10:15-10:45 a.m. EDT

Break

10:45 a.m. -12:00 p.m. EDT

Concurrent Sessions 5

5A ROUNDTABLE: The Meanings of Dementia: How Cultural Narratives Shape Experience, Expectations, and Social Change

Nancy Berlinger, Liz Bowen, Mercer Gary, The Hastings Center

Kate de Medeiros, Miami University

Darlingtona Esiaka, Rutgers University

Erin Gentry Lamb, Case Western Reserve University School of Medicine

Candidus Nwakasi, Providence College

Deborah Rose, Duke University Medical Center

5B Panel: Caring In and Through Literature: Literary, Pedagogical, and Social Systems of Care

Brooke Kowalke, Matthew Reznicek, Creighton University
Ingrid Berg, University of Missouri and Creighton University

5C PAPER SESSION: Social Media for Social Change

“#NarcansavesLives: Digital Assembly and the Social Construction of a Public Health Intervention”

Allison Schlosser, Roma Subramanian, University of Nebraska Omaha
Kelli Boling, Ciera Kirkpatrick, Patrick Habecker, Valerie Jones, University of Nebraska Lincoln

Jessica Hample, University of Nebraska Kearney

“#TransTikTok: Filling the Void of Medical and Social Support for the Trans Community”

Trenley Anderson, Case Western Reserve University School of Medicine

“Abortion Storytelling: #ShoutYourAbortion and Resisting Oppressive Narratives”

Kate Lafferty-Danner, Geisinger Commonwealth School of Medicine

5D PAPER SESSION: Addressing and Assessing Health Equity in Pre-Health and Medical Education

“Health Humanities Education and Students’ Health Equity Choices in Career Path: A Qualitative Outcomes Study”

Kiana Fields, University of Louisville

Sarah Berry, Connecticut College

“Student Perceptions: Assessing Impact and Informing Development of a Medical Humanities and Health Equity Curriculum”

Elizabeth Torrez, Schuyler L. Gaillard, Marcela Campoli, Lakshmi Krishnan,
Georgetown University School of Medicine

“Developing an Asian American and Pacific Islander (AAPI) Health Curriculum for Medical Students in the COVID-19 Era”

Isabela Bumanlag, Megan Jiao, McGovern Medical School, The University of Texas Health Science Center at Houston

5E PAPER SESSION: Pragmatic Solidarity for Health Equity

“Towards an Ethic of Accompaniment in Surgery”

C. Phifer Nicholson Jr., Monica Bodd, Duke University School of Medicine/Duke Divinity School

Ellery Sarosi, Michigan Medical School/Duke Divinity School

Martha Carlough, UNC Gillings School of Public Health/Duke Divinity School

“Envisioning Pragmatic Solidarity in Health Care Through the Lens of Ollas Comunes in Peru”

Michael Gilbert, Duke University

“Designing Health Justice: COVID-19, ‘Racial’ Disparities, Sociogenomics, and Beyond”

Rosalynn Vega, The University of Texas Rio Grande Valley

5F WORKSHOP: Deconstructing Systems: An Art-Based Approach to Inequities in Health

Corinne Zimmermann, Corinne Zimmermann Consultancy
Kamna Balhara, Johns Hopkins University School of Medicine

12:00-12:15 p.m. EDT

Break/Lunch Available (can take into plenary session)

12:15-2:15 p.m. EDT

PLENARY WORKSHOP

“Transforming Structure, Dreaming Futures: Yearning Toward Justice”

Eli Clare

Writer, Activist, Educator, and Speaker

2:15 - 2:45 p.m. EDT

Break

2:45-4:00 p.m. EDT

Concurrent Sessions 6

6A FLASH SESSION: Education

“Use of Narrative Medicine as an Education Tool at Different Levels of Medical Education”

Shwetha Bindhu, Case Western Reserve University School of Medicine

“Developing Collaborative Competencies in Interprofessional Trainees through a Visual Arts-based Observation Activity”

Nicholas R. Mercado, University of Rochester School of Medicine and Dentistry

Aleena Paul, New York Medical College School of Medicine

Lauren Block, Gabrielle Goldberg, Donald and Barbara Zucker School of Medicine at Hofstra/Northwell

Barbara DeVoe, Hofstra Northwell School of Nursing and Physician Assistant Studies

Nancy Richner, Independent Art Museum Educator

“Local Impact of a Global Pandemic: Health Inequities & COVID-19”

Yujia Song, Tina Reid, Salisbury University

“How to Integrate Arts and Humanities Resources into Existing Medical Curricula”

Shannon Fang, Case Western Reserve University School of Medicine

“Diversifying Diversity Curriculum”

Nathaniel Davis, Case Western Reserve University School of Medicine

“Empowering Trainees to Confront Structural Ableism in Medicine: A Curricular Approach”

Prerna Mamileti, Independent Scholar

Devika Nandwana, Case Western Reserve University School of Medicine

“Exploring Challenges in Health Humanities Through Medical Readers’ Theater”

Cheryl Dellasega, Lisa Erdman, Roberta Chardulo Dias de Andrade, Daniel

George, Kayla Krause, Penn State College of Medicine,

John Messmer, Penn State Health

6B PANEL: The Power of Health Narratives to Illuminate Social Structures and Lived Experiences

Kristine Muñoz, Janet Weaver, University of Iowa

Daena Goldsmith, Lewis & Clark College

Brian Park, Elaine Waller Uchison, Pam Pierce, Elizabeth Lahti, Oregon Health & Science University

Janet Weaver, University of Iowa Libraries

6C PANEL: Equity, Diversity, and Inclusion in Healthcare Education: A Longitudinal Health Humanities Approach

Sarah L. Berry, Connecticut College

Charlene K. Green, University of California, Davis and Los Rio Community College District

Kamna S. Balhara, Johns Hopkins University School of Medicine

Elianna Sanchez, New York Institute of Technology College of Osteopathic Medicine

6D PAPER SESSION: Care, Story, Identity, and Social Change

“Exploring Caring Through Story: The Meaning(s) of Relationships Between “Essential Caregivers” and People Living with Dementia in Long-Term Care”

Melanie Lalani, University of Toronto

“LGBTQ Aging: Pandemic Narratives through Poetry”

Al Ogawa, Stephanie Clark, University of Rochester School of Medicine and Dentistry

“Metagnosis: How Retrospective Revelations Empower Individuals to Mobilize and Transform Structures of Health and Identity”

Danielle Spencer, Columbia University

6E PAPER SESSION: Psychiatry and Politics

“Politics in and of the Clinic: Public Psychiatry and the Anglophone Crisis in Central Africa”

Elizabeth Durham, University of Michigan

“Beyond Mental Health: Psychotherapy as a Moral and Political Technology”

Ulrich Koch, George Washington University

“Inpatient Psychiatric Unit Design: A New Role for the Medical Humanities”

Grayson Holt, Case Western Reserve University

Jeffrey Zabinski, Columbia University Irving Medical Center

6F WORKSHOP: Parallel Play: How Humanistic Science Labs Brings Faculty Together to Increase Teaching Satisfaction, Improve Student Outcomes, and Disrupt Healthcare Education (In a Good Way)

Jeremiah Davie, Joshua Gooch, Gina Camodeca, D’Youville University

Briana Jegier, Baptist Health Sciences University and D’Youville University

4:00 - 4:30 p.m. EDT

Break/Light Reception

4:30-6:00 p.m. EDT

William Carlos Williams Poetry Award Ceremony

Sponsored by the Northeast Ohio University of Medicine (NEOMED)

Featuring readings by student winners and Amy Haddad, PhD, MSN, MFA, FAAN

Evening

Dinner on Own

Sunday, March 19, 2023

9:00-10:15 a.m. EDT

Concurrent Sessions 7

7A FLASH SESSION: Clinicians, Patients, and Identity

“Race and Medicine in the Physician Memoir: Stories and Silences”

Marie E. McAllister, University of Mary Washington

“Sexism in Medicine: Autistic Women's Lived Experiences with an Adulthood Diagnosis”

Elizabeth Mathews, Case Western Reserve University

“More Than A Clinician, More Than A Patient: Humanizing the Hospital Experience with Tell Me More”

Bryana Belin, Ishi Aron, Shyam Bhagat, Taranjeet Kalra Ahuja, Alice Fornari,
Donald & Barbara Zucker School of Medicine at Hofstra/Northwell

“Agency Through Homeopathy in the German Romantic Era: Connecting Patients’ Stories to Today’s Allopathy”

Claire Staresinic, Case Western Reserve University School of Medicine

“A Humanistic Inquiry of Chronic Pain Management: (Re)Examining the Quadruple Aims through a Feminist Relational Lens for Enhanced Provider Well-Being”

Vinita Agarwal, Alison Sutton-Ryan, Salisbury University

“Disembodied Data-fiction: Consequences of Virtual Grief on the Future of Telehealth”

Katie Xu, Case Western Reserve University School of Medicine

“Shaping Pediatric ECMO Decisions through Multidisciplinary Perspectives”

Julie M. Aultman, Adiaratou Ba, Northeast Ohio Medical University

Patricia Raimer, Daniel Grossoehme, Ryan Nofziger, Sarah Friebert, Akron
Children's Hospital

“Structural Issues, Policy Changes, and Living Without Dignity in Nursing Homes during COVID-19”

Millie Sun, Case Western Reserve University

7B PANEL: Transforming Disability-Focused Health Professions Education: Mobilizing Insight from the Intersection of Disability Studies and the Health Humanities

Kenneth Richman, Massachusetts College of Pharmacy and Health Sciences

M. Ariel Cascio, Shay Dawson, Neli Ragina, Central Michigan University College of
Medicine

Rachel Conrad Bracken, Rebecca Fischbein, Northeast Ohio Medical University

Rebecca Garden, SUNY Upstate Medical University

7C PAPER SESSION: Self-Care and Peer Care

“The Politics of Self-Care in Women’s Chronic Illness Narratives”

Jess Libow, Haverford College

“Undergraduates Under Stress: Discursive Boundary Work and Rhetorical Care of the Self”

Kimberly Emmons, Case Western Reserve University

“Boundaries, Equity, and Lived Experience in Peer Mental Health Support”

Maia Delegal, Case Western Reserve University Department of Bioethics

7D PAPER SESSION: New Perspectives on Health History

“Ethiopian Healing Scrolls as Graphic Visualizations of Illness Narratives”

Xiaoli Pan, Case Western Reserve University

“The Feminization of Frontal Lobotomies: A Critical Analysis of the Role of Gender and Queerness in the Lobotomy Era”

Missy Tepe, Loyola University Chicago

“Exploring the Interdependence of Disability, Spirituality, and Community at Lourdes Sanctuary”

Liz Hutter, University of Dayton

7E PAPER SESSION: Envisioning Clinical Interventions

“Primary Care Needs Neurodiversity: Implications of the Double Empathy Problem in Autism Spectrum Disorder (ASD)”

Alyssa Harbaugh, Case Western Reserve University School of Medicine

"Sitting With Grief: Towards an Infrastructure of Intimacy on the Oncology Unit"

Doria Charlson, Northeastern University

“Biomedicine’s Languid Approach to Gender-Affirming Care Advancements”

Daniel Hamilton, Case Western Reserve University

7F WORKSHOP: Why Aren't I Making Art? The Problem with Artists in Medical Education

Katherine Burke, Cleveland Clinic Lerner College of Medicine

Gretchen Case, University of Utah School of Medicine

10:15-10:45 a.m. EDT

Break

10:45 a.m. -12:00 p.m. EDT

Concurrent Sessions 8

8A ROUNDTABLE: (Dis)abled Minds: Lived Experience and Institutional Harm

Julia Knopes, Kristi Ninnemann, Case Western Reserve University

Ariel Cascio, Central Michigan University College of Medicine

Neşe Devenot, University of Cincinnati

Austin Wiley Duncan, University of Arizona College of Medicine

Laura Guidry-Grimes, Cleveland Clinic

8B PANEL: Poetry of Equity: Transformations From Within Healthcare and Medical Education Systems

Yvette Perry, Elizabeth Pringle, Zina Mercil, Jenny Heglan, The Good Listening Project

8C PAPER SESSION: Critiquing Representations

“Unassisted Surgery in Fact and Fiction”

Pedro Ponce, St. Lawrence University

“The Vagina: An Anatomy of Misunderstanding”

Alexis Doyle, Carmen Thong, Stanford University

“Pathologized Desires”

Ira Halpern, Northeastern University

8D PAPER SESSION: Turning to Texts to Understand, Critique, and Heal

“*Wuthering Heights* and Medical Noncompliance: Considerations for Empathetic Engagement”

Crystal Veronie, The University of Southern Mississippi

“Pedagogical Reflection: Mirrors, Cadavers, and the Surgical Instruments of Whiteness”

Heather Glenny, University of Chicago

“Attending to Wounds: Contemporary Narratives of Trauma and Healing in AfroBoricua Literature”

Roberta Hurtado, SUNY Oswego

8E PAPER SESSION: Interrogating the Terms of Research

“Trauma Informed Abortion Research: Transforming Structures Shaping Debates”

Elizabeth Lanphier, Cincinnati Children's Hospital Medical Center

“‘Control, Control, Control, Where’s Your Control?’ Drug Trials and the White Man’s Burden from Arrowsmith to AIDS”

Phillip Barrish, University of Texas at Austin

“The Changing Identity of ‘Refugee’: A Structural Problem in Healthcare and Research”

Julie Aultman, Northeast Ohio Medical University

8F WORKSHOP: The Joy of Dementia: Creating a New Performance of Life (and Dementia)

Mary Fridley, East Side Institute

12:00 p.m. EDT

Boxed Lunches Available (can take into closing session)

12:15-12:45 p.m. EDT

Closing Remarks

PRESENTATION ABSTRACTS

Concurrent Sessions 1 – Friday, March 17, 10:00-11:15 a.m. EDT

1A ROUNDTABLE: Developing Selves With State Intervention: How Embodied and Narrated Experience Can Lead the Way to Reform

Eileen Anderson, Elise Ellick, Case Western Reserve University School of Medicine

A large minority of young people in the United States end up interacting with the legal system in some way. Whether it is through a contested divorce, foster placement, juvenile justice, legal status, or medical need, the state is in the position of making significant - and sometimes life and death - decisions for our youth every day. The dramatic variation in the system to be able to handle young people's hardest moments creates a range of outcomes from productive to traumatizing. This roundtable examines the experiences of vulnerable children and adolescents who have a court-ordered guardian weighing in on their situation to understand the impact of state-backed decisions on intimate matters impacting human development. In turn, the lessons from close examination of these youths' experiences provide clues and even roadmaps to reforms in policy and practice.

This roundtable will present data and cases about guardianship from research and practice in different contexts where child well-being matters centrally. In particular, examples from family law, foster care, and hospital care will be presented. Issues such as mental health, LGBTQI+ health, and decision-making capacity will be explored. Particular attention will be given to how the institutions involved structure subjectivity, and how subjective experiences and narratives provide insight in how to improve structural barriers through the gatekeeping role of the guardian. Best practices and tools for guardians will be presented. The roundtable format encourages discussion among researchers, guardians and other practitioners, and families who have concerns and ideas about young people's well-being in a system unprepared to handle the many types of diversity it encounters every day.

1B PANEL: Stress, Trauma, and Resilience in African-American Women's Narratives of Everyday Racism

James Phelan, Robyn Warhol, Simone Drake, Ohio State University

Lisa Zunshine, University of Kentucky

In this panel, four narrative theorists analyze a corpus of sixteen oral narratives told by eight African American women from central Indiana in Autumn 2021 about their experiences with racism. The eight women each told two stories in response to a prompt that asked them to tell one story in which they encountered racism and managed to successfully deal with it and a second story in which they were unable to overcome it. Collectively the women's stories provide:

1. Powerful testimony about the ways African American women experience racism as an inescapable part of their lives--and sometimes as a force that radically changes their lives.
2. Experience-based demonstrations of how pervasive systemic racism is and how it relies on power differentials that are baked into institutions such as schools, law enforcement, businesses, and the health care system.
3. Extensive evidence of the prevalence of white people's implicit and explicit biases in their everyday interactions with African American women.
4. Countless signs of the stress and trauma that accompany and follow from experiences of racism.
5. Considerable evidence of the women's resilience as well as their unending need for it, as they continue to feel the negative effects of experiences that occurred many years ago.

The four papers in this panel expand upon these findings by drawing on different but complementary branches of scholarship to analyze the narratives: work on African American storytelling, on narrative as rhetoric, on feminist narratology, and cognitive cultural narratology. The titles provide mini-abstracts that highlight particularly salient elements of the women's narratives:

“Testifyin’ and Signifyin’: Black Women’s Narratives on Navigating Structural Racism in Central Indiana”

“Structures of Everyday Racism in the Stories of Eight African American Women”

“Misinterpreting the Body Language of African American Women Storytellers”

“Rhetorical Listening: Character, Progression, and Fictionality in African American Women’s Stories of Everyday Racism”

As the papers unpack the complex skill involved in the women's handling of so many elements of their narratives, they also identify the effects this handling generates in listeners, and the larger thematic significance of those effects. The papers conclude with reflections on the value of the women's storytelling: how they are sometimes cathartic for the women; how they highlight the importance of listening—and the possibility of misunderstanding; and how, if they and others like them were widely disseminated, they would be a force to counteract the structural racism they so vividly expose.

1C PAPER SESSION: Innovations in Medical and Dental Education

“Innovative Approaches to Dismantling Ableism through Medical Education”

Liz Bowen, The Hastings Center

Dorothy Tolchin, Harvard Medical School

Kerry Devlin, Johns Hopkins University

Disability advocates have been drawing attention to issues of ableism in the healthcare system for decades, from biases in genetic counseling to the discriminatory effects of quality-adjusted life years. Recent years have exacerbated the urgency of these problems as pandemic-related crisis standards of care threatened to deprioritize disabled lives, and new research shows that 82% of physicians believe disabled people have diminished quality of life

and 68% feel at risk of lawsuits for violating the Americans with Disabilities Act (Iezzoni et al. 2021, Iezzoni et al. 2022). Despite increased societal awareness around issues of ableism, many health care professionals report receiving little to no training on the ableist biases and structural inequities that produce health disparities for disabled people (Seidel and Crowe 2017; Stillman et al. 2021). This presentation will provide an overview of the current landscape of disability education in medical education, based on a review of published and unpublished articles, reports, and curricula, as well as on conversations with educators and disability advocates from medical schools across the United States. It will identify the benefits and limitations of common approaches to teaching about disability and ableism in the health care context, and then give examples of innovative approaches that go beyond the status quo to foster deeper development of the knowledge, attitudes, skills, and practices needed to provide equitable care for patients with disabilities. The presentation will also discuss common barriers to curriculum development in this area and suggestions for how they might be overcome.

“The Art-Science of Close Listening: Music Lessons for Healthcare Personnel”
Timothy Nicholas, Case Western Reserve University School of Medicine

Although patients identify listening skills as defining features of “good” clinicians, professionals across healthcare disciplines continue to identify practitioner listening deficits in clinical practice. While these listening deficits have been attributed to various individual and systemic factors, research nevertheless correlates clinician listening skills and patient-perceived clinician empathy with increased patient enablement, greater patient and clinician satisfaction, lower healthcare costs, less litigation, and even superior clinical outcomes. Given the evidence-based value of clinical listening skills, demonstrated need for greater clinical listening skills training, and the absence of formalized musical arts-based strategies for educating clinical close listening skills, I thus present a novel healthcare education innovation, entitled: “Musical-Clinical Close Listening Strategies for Healthcare Personnel.” Harmonizing my multi-professional experiences in music, education, and healthcare with a chorus of music educator, music practitioner, healthcare educator, and healthcare practitioner perspectives, I articulate how salient, overlapping listening strategies, such as silent listening and reflective listening, are used by healthcare and music practitioners alike. Moreover, considering music’s ubiquity and idiosyncratic properties alongside the need for both clinicians and musicians to demonstrate their co-constructivist listening skills in real-time, I distinguish the practice and educational value of musical-clinical close listening skills from other approaches used to foster clinical listening skills, such as close reading and close looking clinical pedagogies. Ultimately, I argue that orchestrating close listening music lessons for healthcare personnel not only advances healthcare equity by reaching broader learner audiences and amplifying musical arts interprofessional voices, but might also expand healthcare justice through improved clinical experiences and outcomes.

“The Root Cause: Creating a Safe Space to Discuss Racism in Dentistry”
Michelle Moncrieffe Foreman, University of Maryland
Eileen Harrington, University of Maryland Libraries

Oral healthcare outcomes for racial and ethnic minorities present a stark divide between populations who can access regular dental care, and communities struggling to receive basic and sometimes life-saving treatment. Public libraries have a history of providing access to high quality health information and connecting people to healthcare. Through narrative inquiry and health education, this project aims to demonstrate the effectiveness of utilizing public libraries as alternative, neutral, and safe spaces for bringing together underserved communities, dental and dental hygiene, pre-medicine, and journalism students. Through these interactions, they can together build holistic and accurate narratives that reveal a fuller account of the dental care experience of racial and ethnic minorities and trainee clinicians charged with providing equitable care.

This project employs four different interrelated approaches to achieve this goal:

- Health fairs conducted at public libraries to share information about oral health care and accessing dental services
- Focus groups with prospective dental patients from underserved racial and ethnic minorities
- Narrative dentistry workshops for trainees to reflect on their experiences in working with diverse communities and respond to the summary of patient experiences;
- Generate education modules to incorporate into trainings and curricula

This trans-disciplinary project brings together academics and clinicians in English, journalism, dentistry, and librarianship, employing narrative inquiry and reflective practice to understand the social and structural barriers to the provision of equitable care in dentistry. This presentation will provide an overview of the project and preliminary data collected.

1D PAPER SESSION: Metaphor and Meaning

“Mutant Metaphors: Frankenstein in the Era of COVID-19”

Alexandre Djandji, Allison Coffelt, Narrative Medicine, Columbia University

Since its debut, Mary Shelley’s *Frankenstein* has, fittingly, assumed a life of its own. In today’s cultural landscape, the mere mention of “mutant” evokes the language of Othering, including Frankenstenian metaphors, such as those used to describe the omicron variant of SARS-CoV-2. When scientists referred to omicron as a Frankenstein variant and news outlets propagated this naming, they demonstrated the inherent mutability of the myth—a myth that is crucial in biomedicine and public health. In this article, the authors examine the shifting nature of Frankenstein metaphors through the lens of what Priscilla Wald calls “outbreak narratives.” The authors consider mutant narratives in the context of the United States’ COVID-19 policies, and point to the ready instatement of travel bans as evidence of how such a potent myth is used to create and sell public policy. This analysis demonstrates how these policies, at once personal and political, are evidence of how “mutant is other” has become an epistemological means for responding to pandemic. In response, the authors apply Donna Haraway’s concept of “boundary breakdowns” to reimagine relationships with mutancy. They examine how deconstructing the idea of “mutant is other” in contemporary virus narratives may offer ways to

reconfigure our relationships of self and other, reorder our ways of knowing, and move beyond the hegemonic and nativist policies of the present.

“Cancer and Erasure of The Self as Metaphor in Romanian Interbellum Literature”
Madalina Meirosu, Swarthmore College

This presentation utilizes the field of the Medical Humanities in order to open new perspectives on Hortensia Papadat-Bengescu’s work and to deepen our appreciation of this unique writer’s contribution to Romanian and world literature. Owing to her personal training and experience as a nurse during the first World War, Papadat-Bengescu was well-positioned to describe spaces of illness and healing, offering nuanced portrayals of medical providers and other aspects of Romanian medical care during the interbellum period. Eschewing romanticization, her unflinching eye favored a realistic depiction of the failures and limitations of medical professionals and healing places. Using frameworks provided by the Medical Humanities, as well as Gender Studies and Disability Studies, this presentation analyzes the metaphorical use of illness in the novel *The Hidden Way* (1932) so as to show the subtle ways in which a character’s encounter with, and feeble fight against, uterine cancer becomes synonymous with the loss of her position in her household. The very representation of uterine cancer in this interbellum novel is a unique achievement in Romanian Literature, and Papadat-Bengescu describes in painstaking detail the various stages of the disease, while also dramatizing the gender expectations that prevent Lenora, the main character, from seeking help or disclosing her suffering before it is too late. Such a portrayal of societal constraints that deter patients from disclosing symptoms, as well as the carefully presented power relationships at the micro, meso and macro levels, are a treasure trove in the field of narrative medicine and narrative bioethics.

“The Stories We Tell: The Role of Narrative and Metaphor in Shaping Disability Within Ourselves and Society”
Danielle Wilfand, Case Western Reserve University School of Medicine

Metaphor and narrative are integral parts of not only how we describe illness but how we experience it. One of the most pervasive narratives within the medical model is the martial metaphor of illness which utilizes militaristic language, likening the experience of living with illness to war within one’s body and medicine as a war on disease. Martial metaphors are frequently used within advocacy organizations for people affected by illness and disability, including in efforts to raise funds for disease-specific research as well as in survivorship support groups. While these movements seek to empower people affected by illness, the utilization of martial metaphors serves to reinforce and propagate an ableist narrative surrounding disability, namely that comparing illness to a battle that can be won or lost, with winning or losing hinging on the innate characteristics of the individual, is not truly an empowering narrative for disabled people. In my presentation, I will discuss how metaphors of illness have shaped my own relationship with disability as well as the perception of my disability by others. I will focus my analysis on examining the militaristic metaphor of disease through the lens of the cultural model of disability to discuss how these metaphors can be deconstructed and reconstructed to

reclaim the narrative of chronic illness and disability. I argue that constructing non-martial narratives surrounding disability in support service spaces can improve individuals' own relationships with disability as well as improve the stigmatization of disability more broadly in society.

1E PAPER SESSION: Community Engagement for Health

“Root Cause: Establishment of a Monthly Health Fair to Empower the Local Community”

Elise Kao, Darby Billing, Alyssa Guo, Katelyn Haywood, Jennifer Grier, Jennifer Trilk, Jennifer Springhart, University of South Carolina School of Medicine
Greenville

Jason Li, Greenville Technical College

Lauren Tyler, UT Southwestern Medical Center

Jacob Ritchie, University of Louisville/Norton Children's Hospital

Lauren Fowler, Wake Forest School of Medicine

Root Cause is a monthly health and public services initiative started by a medical school that works with 35+ community partners (community organizations that provide health education/resources) to address the root causes of disease by increasing healthcare access, promoting healthy lifestyles, and reducing health disparities. A Needs Assessment identified the Dunean community, composed of 30% African Americans where many have poor healthcare access, with the greatest needs in the areas of mental health (17.4% of residents diagnosed with depression), affordable housing (753 people identified as homeless during 2019's point in time count), obesity/access to healthier food (14% reported food insecurity), and healthcare inaccessibility (12% of residents are uninsured). At Root Cause, medical students and community partners have monthly rotating booths, such as healthy cooking demonstrations and promotion of free insurance signups for eligible residents, with goals of alleviating the aforementioned disparities. Since Root Cause's establishment in 2019, we have successfully secured \$262,926 from internal and external grant fundings to facilitate 11 monthly health fairs that resulted in 2,707 unique interactions among community partners/members/medical students to improve health and wellbeing.

The purpose of this presentation is to introduce the concept of utilizing medical student-led health fairs for students to develop multicultural and diverse perspectives of challenges in local communities and actively improve community health outcomes. This presentation will highlight health fairs' role in developing bi-directional relationships with community members to understand needs from their perspective. Our goal is to inspire and mobilize community shareholders in developing trust with community members to collectively combat health disparities. With tense community relationships in the setting of a failing healthcare system, we hope to inspire those in academic medicine to leverage the power of connecting the community with itself, a new pedagogical approach to both educate and learn from communities to create collective action and achieve justice in health.

“The Health Humanities Are Health Care Infrastructure”

Lenny Grant, Syracuse University

Media coverage of COVID-19 raised Americans' awareness of the vulnerable state of their communities' medical resources. Beyond surveillance data on dashboards, health care workers' op-eds detailed the psychological effects of providing care in an inadequate health care infrastructure. In Onondaga County, NY, this presentation's setting, nurses and social workers left their positions in hospitals, further weakening local infrastructure. Hospitals have since developed ambulance "turn away" protocols for times when staffing is too low to accept emergency patients.

Taking workforce retention as an exigence, I ask, "What can we in the Health Humanities collectively do to support our local health care infrastructures?" In response, I introduce the Community-Engaged Health Humanities (CEHH), which synthesizes and extends existing research agendas in the field (including creative public health, public health humanities, and translational humanities) into a service-oriented paradigm that cares for the health care workers who care for our communities. Unlike other public-facing health humanities initiatives, CEHH explicitly focuses on applying the arts and humanities to the well-being of health care workers, who are the backbone of local health care infrastructure.

After theorizing CEHH as the entanglement of bioethics (subsidiarity), policy (community health care justice), and community development (Asset Based Health Inquiry), I describe the Resilience Writing Project (RWP). RWP originated as an expressive writing workshop series for social workers and nurses at a public hospital and has grown into a community-wide training program for health care workers across the county. I conclude with suggestions for others to engage their local health care infrastructures.

"In the Analysis: Processes of Inclusion Through Anti-Oppressive Methodologies in Health Equity Research"

Juliet McMullin, University of California Irvine

Sherri Salgado, Riverside-San Bernardino Indian Health Inc.

Katheryn Rodriguez, UCR Center for Health Disparities Research

Community engaged research's institutionalization in federal calls for funding has made it a method of choice particularly for projects focusing on health disparities. Of primary concern is the inclusion of community members in all levels of research, translation of research findings to communities and individuals, and creation of research that is more meaningful and robust for the communities it is meant to serve. And yet, the process of analyzing data is a key phase of research where communities are intentionally and systematically excluded from the production of knowledge. This exclusion is based on having sufficient training in data analysis, completing ethics and Institutional Review Board trainings, and a host of degrees that validate one as being eligible to produce knowledge. Drawing on experiences of gathering data to develop a grounded historical trauma curriculum with Native American community members and health care professionals, we describe how we sought to decolonize the analysis phase of research. Recounting the research proposal plans, subsequent missteps, pauses, and revisions to the plan as they happen, we demonstrate the oppressive, epistemicidal agendas that analysis deploys and describe anti-oppressive practices that foster more inclusive analytical frameworks.

1F WORKSHOP: It Takes a Village: Creating Community to Transform Health and Healing

Gwen Lowenheim, East Side Institute

“It Takes a Village: Creating Community to Transform Health and Healing” introduces a relational practice of health and healing - the “Health Team” - that is social, collaborative and performance based. The Health Team model is a self-organized grouping of the patient, friends, family and professionals that as a unit navigates the complex, often contradictory, sources of information, recommendations and experiences of illness in 21st century America. It is a challenge to the individual bias of current health practices.

The Health Team, originally organized in response to complex medical (and life) issues such as cancer or heart disease, meets regularly and, under the direction of the patient, takes ownership of every aspect of the illness that includes pain, disability, emotionality and medical decision-making. The chapter presents the model, provides examples of the practice, samples of dialogue, and an analysis of what has been learned over 30 years of using health teams - several dozen of which have been formed in that time - in the service of creating a new performance of health.

While the health team concept was originally created by the late Dr. Susan Massad, a primary care physician, and Barbara Silverman, a practicing clinical social worker, the practice has its roots in the consumer-driven health movements of the 1960s and 1970s, is inspired by the many grassroots efforts to reform health care and doctor-patient communication, and is one of several relational health practices--patient-centered care, collaborative care, and socio-cultural-biological - that is challenging the individual bias of current health practices. We feel the practice has the potential for helping many others who are grappling with complex and/or chronic medical issues - all exacerbated by the Covid pandemic - that are part of living in 21st century America.

Workshop participants will learn more about health teams, their history, the social therapeutic approach used to create them, and what we have learned to be the benefits and challenges of this collaborative process. Participants will also hear from those who have benefitted from them, including people living with cancer, dementia and other illnesses, as well as from medical professionals who have worked with patients and teams. The workshop will also include examples of conversational dialogues from some of the teams and give participants the opportunity to create their own.

Concurrent Sessions 2 – Friday, March 17, 12:45-2:00 p.m. EDT

2A FLASH SESSION: Structure, Environment, and Inequity

“Science Journalism in a Pandemic: Resistance, Truth, and Trust”

Sriya Donthi, Case Western Reserve University School of Medicine

Christopher Haufe, Case Western Reserve University

In March of 2020, it was not uncommon to open your newsfeed to two articles discussing a COVID-19 study in dramatically different ways. While both reported the statistics,

one claimed that virulence and cases were declining and the other urged for masking and vaccination. In the pandemic and post-pandemic world, science journalists navigate misinformation, politicization, and a resistance to science. I argue that there are two incompatibilities that perpetuate a cyclical resistance to science on the part of society. These incompatibilities challenge the structure and actions of scientific journalism to coexist with the needs and actions of a trusting democratic society. The first is between (1) the expected roles of science journalism and (2) the structure of science in a democratic society. The second is between (3) the structure of science journalism and (4) the necessary conditions that shape trust. Science journalism has an obligation to report the truth independently, proportionally, and engagingly (storytelling balanced with consumer selection). However, science contains many versions of the scientific truth, is value-laden, and is too vast to be inherently proportional in its subparts. Moreover, fostering trust requires consistency in reporting, free-debate, and value-neutrality. These needs of trust conflict with the natures of science and scientific progress (characterized by oscillation and narrowing to an eventual truth). Identifying and understanding these fundamental discrepancies is the first step in developing necessary changes in science journalism practices/education and reframing the role of science journalism to lower societal resistance to science.

“Making a Right Turn: Collaborative Initiatives for Health Care Among Transgender Migrants, Refugees, and Asylum-Seekers in Sweden”

Debra Beight, Case Western Reserve University

Migrant, refugee, and asylum-seeking populations experience inequalities in navigating health care systems. Transgender populations face similar challenges in health care. In Sweden, for those sitting at the intersection of trans-migrant, refugee, asylum status, the expanded far-right regime recently elected to Parliament may present more challenges in accessing care.

Since 1972 Sweden has been a leader on the global stage for transgender recognition to improve legal status, healthcare, and overall quality of life. Since 2015 Sweden has strived to also be a leader in acceptance and integration for diverse migrant, refugee, and asylum-seeking populations, specifically in the aftermath of the Syrian refugee crisis.

The far-right political shift that has increased since 2015 demonstrates a shift in attitudes towards non-Swedish born citizens, primarily driven by xenophobic rhetoric from the Social Democrat party. This party established in the 1990s from the neo-Nazi movement, directs a misguided focus on migrant and refugee crime and threats to Swedish ways of life. Social Democrats consistently exhibit strong opposition to LGBTQ rights in general and specifically against trans rights. In 2013, they were the only party to vote against a law to abolish forced sterilizations for trans individuals.

This paper seeks to explore initiatives for engagement within the changing political structure. Transgender and refugee health and service organizations, typically separate entities, have the potential to enact collective action plans to challenge the misconceptions of migrant/refugee-transgender experiences and improve their social standing.

By exploring the manner in which these disparate groups can mobilize and build relationships between individuals, communities, and the political structures of Sweden, I seek to investigate the following: How can coping capacities be developed and employed to meet

immediate health needs for these populations; what adaptive capacities from past experiences can be utilized and applied to present and future health concerns; what is the potential for transformative capacities for both individual and societal health improvements?

“The Future of Medical Ethics: Addressing Inequities in Health AI”

Mahi Tomar, Case Western Reserve University

Medical AI has pioneered a new frontier in healthcare, as these algorithms can be taught medical practices, such as the diagnosis and treatment of basic ailments, and cheaply deployed in communities where access to healthcare is restricted due to various socioeconomic factors. However, these well-intentioned algorithms often perpetuate existing inequities in the healthcare system, such as racism, due to a lack of ethical considerations. This is why I am proposing the creation of ethical standards for medical AI. One example we can look to for guidance is the development of the kidney allocation algorithm by UNOS. This system is constantly evolving as committees continue debating its details, making changes to minimize unfair bias. While this system has its flaws, such as its bureaucratic inefficiency in its decision-making process, we can draw from this, the AMA’s existing medical code of ethics, and other existing AI codes of ethics to form one for the medical community that can be adhered to when designing an algorithm that will be used in the medical field. This code will demand transparency and accountability in terms of the development of the algorithm, as well as ensure that steps are taken in order to minimize biases that may arise from the data, such as those based on race or sex. Medical AI is a complex and fast-growing field that promises to change the face of healthcare. It is vital that we take steps to prevent the inequity that has taken root in the medical system from infecting this new field.

“The Role of Climate Change in Food Accessibility: A Global Way Forward”

Pooja Patel, Duquesne University

Climate change is a growing global concern. The United Nations recognizes the need to “take urgent action to combat climate change and its impacts” as stated in Goal 13 of their Sustainable Development Goals (sdgs.un.org). Likewise, the World Health Organization, identifies climate change as one of the greatest challenges that humanity is confronted with, impacting social and environmental determinants of health ([who.int](https://www.who.int)). Climate change negatively impacts every stage in the food production lifecycle thus making it a vital health issue, consequently leading to food scarcity, undernutrition, and other harmful effects of human health and well-being.

Climate change impacts the availability and accessibility of food. For instance, increasing temperatures and natural disasters create disruptions in the food production lifecycle which then create food scarcity as well as increased food prices ([usda.gov](https://www.usda.gov)). In this flash presentation, I explore the opportunity to reduce impacts of climate change by developing a health policy at the global level.

I will also discuss a global strategy to combat climate change and food insecurity by investigating the role of global health entities in climate change efforts. The global health policy proposed will outline practical, ethical methods that can be undertaken to create sustainable

changes. Furthermore, the ethical concerns of the proposed global health policy will be analyzed, and possible solutions will be evaluated. The development of a global health policy that addresses climate change is indispensable for social as well as environmental justice.

“Green Cities: Balancing Climate Action and Self-Determination of Historically Under-Resourced Communities”

Sophia Friedl, Case Western Reserve University School of Medicine

We face the existential threat of climate change, accompanied by rising sea levels, expanded droughts, increased flooding, and intensified wildfires. To prevent these severe weather events and limit loss of life and property, changes in infrastructure, energy consumption, and land use must take place on a massive scale. As the nation and the world implement climate mitigation and adaptation measures, many of the most under-resourced communities will be most impacted due not only to the fact that these communities on average will be disproportionately harmed by the impacts of climate change but also because politicians and policymakers may see these communities as more easily displaced. In the United States specifically, a long history of redlining, discriminatory zoning ordinances, and lack of investment have combined to systematically disenfranchise poor communities, especially communities of color. There is limited evidence to this point showing that future investment in climate resilient infrastructure will change this trend. In this paper, I explore a brief history of discriminatory land-use practices in the United States, current climate mitigation proposals in select communities, how these proposals exacerbate existing inequalities, and how the health of communities of color will be impacted. I also outline some potential solutions to incorporate communities in adapting to a climate-uncertain future. As the effects of climate change begin to manifest, the health and physical safety of under-resourced communities has the potential to deteriorate drastically. Establishing a framework for protecting the self-determination, safety, and health of under-resourced communities as the climate disaster worsens is critical.

“Food Insecurity in Cuyahoga County: Evaluating the Efficiency of Policy Intervention on Health Outcomes”

Dieu Linh Nguyen, Case Western Reserve University

Research has shown a strong correlation between lower food security status and higher risks of chronic health conditions. Food insecurity reflects limited access to adequate, nutritious food and is a public health concern given its high prevalence and negative consequences. In this flash presentation, I will describe the causes and consequences of food insecurity in Cleveland’s Cuyahoga County in order to argue for the importance of federal intervention to improve food security and health. I will first analyze the cause of the substantially higher rate of food insecurity in Cuyahoga, exploring how price volatility disproportionately affects minority communities and how food deserts perpetuate the problem of lack of access to food. Given that high price volatility depreciates income and purchasing power, racial minority and low-income groups are more sensitive to price changes due to structural and systemic inequities, such as wealth gaps, poverty, and racialized access to food. Low-income families tend to navigate toward the most accessible and least expensive food, which is high in calories but low in

essential nutrients. Such poor diets increase the risk of chronic conditions, such as obesity and cardiovascular disease. Food insecurity, therefore, is associated with higher healthcare usage and expenditures. I will then argue for the importance of policies, including price control and social protection measures, to alleviate food insecurity and thereby reduce the need for medical care. High rates of food insecurity in Cuyahoga express the immediate urgency to explore the root cause to combat hunger and promote health.

“Diseases of Despair & Horizons of Hope: Perceptions of Structural Drivers of Despair-related Illness by Members of Rural and Urban High-Prevalence Communities”
Daniel George, Penn State College of Medicine

Diseases of despair (DoD), i.e., mortality/morbidity from suicidality, drug abuse, and alcoholism, were first characterized in 2015 as increasing in rural White working-class populations in midlife with low educational attainment and associated with long-term economic decline. More recently, excess mortality has been associated with working-class citizens across racial, gender, age, and geographic boundaries, and these despair-related illnesses have contributed to an unprecedented drop in US life expectancy. While epidemiological research has established the scope and scale of the problem, no known qualitative studies have engaged residents of rural and urban locales with high prevalence of DoD to learn their perspectives.

I will draw upon mixed methods research recently conducted in DoD “hot-spots” in Central Pennsylvania in which our research team has explored perceptions of structural causes of despair-related illness and potential intervention strategies among racially-diverse community members in high-prevalence neighborhoods. So too will I present narratives of people in active recovery from addiction who spoke to the causes of their despair and the means by which they found resilience to addiction. Overall, participants in rural and urban areas consistently identify structural factors at the heart of despair-related illness, including financial distress, lack of infrastructure or social services, deteriorating sense of community, and family fragmentation. These insights help inform an understanding that political-economy is driving the crisis (rather than cultural- or individual-level factors) while establishing horizons of hope through community-level coordination and state investments in social services and infrastructure.

2B PANEL DEAFMed: Deaf Education and Awareness for Medical Students

Natalie Perlov, Zachary Urdang, Irina Middleton, Julia Croce, Sidney Kimmel Medical College at Thomas Jefferson University
Arielle Spellun, Boston Children's Hospital

Background: Hearing loss is one of the most common childhood disabilities; an estimated 5/1,000 children have some form of hearing loss. 90% of these children are born to hearing parents who rely on medical professionals for guidance regarding language-based interventions and access; these decisions can have a significant impact on children’s cognitive and social development. Furthermore, nearly 15% of American adults have some degree of hearing difficulty, with 50% of seniors reporting disabling hearing loss. Therefore, it is important

to have healthcare professionals who understand hearing differences to accommodate patients in all phases of life.

Despite the prevalence of hearing loss, there are many barriers to communication for Deaf and Hard of Hearing (DHH) individuals, leading to poorer health outcomes. Many advocates have underscored the need for cultural sensitivity and communication training across healthcare professions, especially for DHH individuals. However, there are currently few medical school curricula that directly address the healthcare inequities this population faces.

Methods: The DEAFMed lecture series contains five 2-hour long lectures on a broad range of topics in Deaf culture and healthcare that runs through the fall of 2022. Each lecture is taught by experts in Deaf culture and American Sign Language (ASL). Health professions students are eligible to participate in the study and will receive one humanities credit for each lecture attended. Data is collected through pre- and post-test surveys at each session to assess changes in baseline beliefs and knowledge about Deaf culture. Surveys are anonymized and included a mixture of multiple-choice questions assessing demographics as well as Likert-scale questions. Data are analyzed using paired t-tests.

Primary endpoints include students' and clinicians' awareness of Deaf culture and comfort in bridging communication barriers. We hypothesize that students who participate in this pilot program will develop a heightened awareness of Deaf culture and ASL that can allow them to bridge communication gaps with the DHH population.

Results: Data collection is ongoing. After the first session, 26 students participated in the survey. Data show significant changes in students' perceptions of the Deaf, including comfort communicating with Deaf patients ($p < 0.0001$), knowledge of differences between ASL and English ($p = 0.03$), communication barriers for Deaf patients ($p = 0.008$), and knowledge of Deaf culture ($p = 0.0004$). On average, students rated their enjoyment of the session 8.8/10.

Conclusions: These data suggest that this type of curriculum may be effective in changing healthcare trainees' and clinicians' perceptions surrounding DHH patients. These results emphasize the importance of this type of medical education and other interventions to improve the quality of care of these populations.

2C PAPER SESSION: Measuring Health Humanities

"A Baseline Survey of Health Humanities Baccalaureate and Graduate Programs"

Craig Klugman, DePaul University

Anna-leila Williams, Quinnipiac University

Sarah Berry, Connecticut College

Charise Alexander Adams, Creighton University

Gina Camodeca, D'Youville College

Tracy Leavelle, Creighton University

Erin Gentry Lamb, Case Western Reserve University

Over two decades, the number of U.S. health humanities baccalaureate and graduate programs has increased annually. Presently, there are 150 degree (major, minor, masters, doctorate) and certificate programs in the U.S. Previous surveys marked total programs as a metric for growth, but none have looked at the infrastructure and support undergirding

programs. Spring 2021, the Health Humanities Consortium conducted a national survey of new and established health humanities programs (N=131) to assess the state of the field. With a 57.3% response rate, we learned that twice as many programs use the nomenclature “medical” instead of “health” humanities; while 28.6% use the medical/health humanities CIP code. Most programs have a director though barely half are compensated, and fewer than one-third of programs have additional paid faculty or staff. 28.2% reported dedicated funding usually tied to a budget line, grant, or endowment. Most academic programs require an introductory course and a capstone; few require student research or internships. Overall, a median of 9.5 students complete each program annually. The survey also inquired about what resources programs need to gain institutional support and establish institutional capital. Most programs expressed a need for additional faculty, funding, and tools to recruit students. 80.9% reported interest in some form of national standards or accreditation. The authors discuss implications of the findings within the context of higher education and social needs. The authors also investigate the potential repercussions of an academic field that is largely resourced by individual passion rather than institutional support, and propose mitigation tactics.

“Humanistic Sensitivity: A New Construct in the Search for Health Humanities Outcomes”

Rebecca Volpe, Katharine Dalke, Penn State College of Medicine

The outcomes of health humanities training for medical students that have been discussed and examined in the peer-reviewed literature include but are not limited to: empathy, respect, compassion, humanism, altruism, identity, excellence, integrity, visual thinking skills, professional identity formation, and well-being. These outcomes are inconsistent and oriented to dyadic relationships and intrapersonal reflection, which leads to difficulties in assessment of curricula and programs, especially those emphasizing structural competence.

In this presentation, we share a higher-level pedagogical outcome that is dispositional, concrete, and measurable: humanistic sensitivity. Humanistic sensitivity is a way of being that involves: 1) noticing that there is a humanities issue; 2) adapting strategies and behaviors to the humanities issue; 3) reflecting on the effectiveness of the strategies and behaviors and 4) reorienting and reflecting to develop new approaches for one’s future practice, including barriers and facilitators within society and the culture of medicine.

As an umbrella concept, humanistic sensitivity can be adapted to a wide range of dyadic and structural health humanities problems. In this presentation, we will illustrate humanistic sensitivity in depth by applying it to a clinical manifestation of structural inequity, describe our first efforts at cultivating humanistic sensitivity in a cohort of 150 medical students during a required pre-clerkship humanities course, and share a first effort at what evaluation of this concept might entail.

“Addressing the Gaps: Developing an Assessment and Program Evaluation Plan for Mixed Method Health Humanities Tool Used in an Interprofessional Nursing and Medical Undergraduate Education Setting”

Patricia Luck, University of Rochester School of Medicine and Dentistry
Caroline Nestro, University of Rochester School of Nursing

This presentation will describe a novel interprofessional education program with medical and nursing students using a mixed medium health humanities tool to develop close looking, close reading, and reflection practice skills, as well as foster interprofessional attitudinal change.

This project is multi-faceted. Not only are we curious if this small mixed medium health humanities reflection tool can capture change in learner self-reflective skills over time but also in its potential to foster interdisciplinary and interprofessional engagement around a shared experience. Our long-term project goals are to develop methods to evaluate individual learner reflective skills development with the use of this tool, interprofessional attitudinal change, and the program itself.

We will report initial results from the first assignment administered to both medical and nursing students, as well as the interprofessional focus group. This will include:

- Learners beginning to engage with each other as nursing and medical students and through discussion of the assignment the unique challenges of their professional work.
- Allowing for the opportunity to discuss their reactions and perspectives to patient encounters, both the similarities and differences.
- Providing a process to examine current interdisciplinary and interprofessional encounters they witness and how they would like future professional relationships to be as teammates in providing patient care.
- Learnings from the students as to their satisfaction with this activity, what was useful and what was not, and why.

Both presenters took part in the inaugural AAMC FRAHME Program Evaluation Course and will highlight some learnings from this.

2D PAPER SESSION: Visual Art and Sound to Address Race and Inequality

“Paint Me as I Am: Overcoming Inequality through the Visual Discourse of Healthcare Workers”

Diana-Andreea Novaceanu, University of Bucharest

This paper addresses the ways in which current structural inequalities of healthcare are reflected in works of visual arts. By focusing on the creations of health professionals, I argue that the joining of a medical and artistic gaze offers not only palpable reminders of institutional injustice but a path to move forward. Furthermore, I assert that the study of such works provides the chance to engage in an open dialogue regarding oppression, discrimination and stigma within the labour force of the medical establishment.

A series of case-studies will highlight the ways in which artworks challenge conventional medical representation narratives. The project “Women of Color on the Front lines”, initiated by Sarah E. Rowan (MD) during the COVID-19 pandemic recruited artists (some of them also working as physicians) to depict BIPOC healthcare providers, otherwise underrepresented on public media. Nurse-artist Andrea Gall challenges the white, male-centric representation of surgeons that persists in medical schools. Her series of portraits reflects the growing diversity of the field, offering students passing the halls a visual reminder of surgeons that share their gender or ethnic background. Finally, artist Sue Greeff (South Africa) delves into both the racial and sexual

objectification of nurses (herself having worked as one at a previous time). The series “Stick it” is based on a personal archive of photographs that are painted and overprocessed yet still maintain a clinical quality. The discussion will conclude with an assessment of how such artistic discourse may be best contextualized within the health humanities, as to fully achieve its potential and achieve structural change.

“Black Skin, White Lights: The Double Bind of Photographing Dark Skin in a White Society”

Katie Xu, Case Western Reserve University School of Medicine

Medical reference materials overwhelmingly depict disease presentations on fair skin, overlooking their significant variable presentations on darker skin tones. While there exists a movement to increase images of dark skin in medical texts, skin of color remains underrepresented in photography instruction. Image rendering, white balancing, and camera film itself are historically tailored to depict White skin. The natural instinct of an untrained photographer shooting with default camera settings is to flood a dark-skinned subject with light in order to make their skin look more White. This not only reflects pervasive colonialist attitudes rooted in the structural practices of the arts that assume a White standard, but also flattens the color and contrast of dark skin, undermining diagnostic accuracy.

I draw from Frantz Fanon’s racial theory on the displaced identity of colonized people to understand the experience of dark skin being caught in a double bind. To shine white light on dark skin is to reduce racial complexity to a White standard, sacrificing the color and texture of the skin. On the other hand, to avoid overexposure is to remain authentic to one’s racial identity and present dark skin that is rarely depicted in formative training. Both ways, patients with dark skin are at a disadvantage when it comes to accurate diagnosis. In this paper, I will illustrate the dialectical quandary of having dark skin in a White society, and I will present some art and photography techniques tailored to capturing dark skin that preserves its racial, textural, and diagnostic integrity.

“Sound Health, Sonic Cosmologies: Decolonizing the Biomedical in the Work of Guadalupe Maravilla and Milford Graves”

Megan Voeller, Thomas Jefferson University

This presentation focuses on two artists—Guadalupe Maravilla (b. 1976 in San Salvador, lives and works in Brooklyn) and Milford Graves (b. 1941-d. 2021, Queens, New York)—whose artmaking has worked to imagine new medicines. In response to life-changing experiences of illness, both Maravilla and Graves developed complex intermedia practices that bridge sculpture, installation, performance, community practice and, most importantly, sound as a mechanism of healing, repair, and change. For more than 20 years, Graves studied the quality and variation of human heart sounds in conjunction with his practice as a pioneering free jazz percussionist. He visualized his findings and research process in animations and sculptural installations and developed experimental therapies to correct heart rhythm irregularities, using himself as a research subject. Following his recovery from colon cancer, Maravilla developed a

practice as a self-described healer, facilitating sound baths and other forms of mutual aid with groups of undocumented immigrants to the U.S., as well as with public audiences in art museums. This presentation brings together the work of Graves and Maravilla as efforts to decolonize medicine and trouble the implicit whiteness of its institutions, knowledge paradigms and assumptions about relationships between body, mind and society. I place particular emphasis on the artists' public dialogues and collaborations with physicians and scientists. These physician-artist exchanges are key to understanding how and why the artists' work should be understood as having direct relevance to medicine, rather than as functioning in a primarily symbolic and metaphorical realm.

2E PAPER SESSION: Digital Health Humanities Innovations

“Everyday Medicine: Mapping People and Plant Relations in Contemporary Minneapolis”
Macey Flood, Boston University/University of Minnesota
Emily Beck, Wangensteen Historical Library

In this paper, we explore the ways in which digital humanities can illuminate and amplify the diversity, complexity, and historical contingency of human-plant relationship in the Great Lakes region of the Midwest US, particularly around St. Paul and Minneapolis, MN. History of medicine and health humanities have traditionally focused on allopathic medicine. As historians and educators, our long-term work has been to include alternative practices, particularly herbal medicine, in the types of history we teach, write, and curate. Such public-facing and publicly-engaged work is one way in which academic historians and other health humanists can direct academic research for the diverse publics that we serve.

We will focus on a community-based oral history project in Minneapolis and St. Paul, home to a large number of western herbalists with vibrant practices and educational structures. Alongside 60+ oral histories, this project has included the development of a digital archive and an online exhibit using ArcGIS StoryMaps containing stories about everyday use of plants for health. The archive and the StoryMap it supports creates an herbal memoir of a place, one that is in form and interpretation both more complex than traditional narratives and more readily accessible to a broader public. Our digital map melds geography with stories and images, encouraging viewers to locate multiple narratives depending on time and themes. This medium helps clarify the structural forces, from the development of the park system to the effects of redlining, that in turn have shaped the practices and prevalence of plant practitioners today.

“Supporting Recovery from Opioid Addiction through Autobiographical Game Design: Preliminary Findings”
Sandra Danilovic, Kenny Chee, Wilfrid Laurier University

The opioid epidemic is a persistent public health problem across Canada. Opioid-related deaths have almost doubled during the COVID-19 pandemic which has exacerbated this crisis by creating access barriers to social services for people using drugs (Gomes et al. 2021, 3). Focusing on the community of Brantford, Ontario, which has the second highest rate of opioid poisoning in Canada (Canadian Institute for Health Information 2018, 22), our arts-based, participatory

study invited adults recovering from opioid addiction to express their life stories through digital game design during a two-day game jam (game making workshop). We present preliminary findings from two game jams, including participant semi-structured interviews, sketches, and digital games. Thirteen jammers between the ages of 18 and 49 harnessed digital game design to support their recovery and fight addiction stigmas. First, jammers stepped out of their 12-step programs, methadone clinics, and other medicalized venues managing their opioid addiction to a space of computational creativity and self-empowerment. Secondly, jammers harnessed metaphor to fictionalize their experiences, conveying their perspectives on navigating the healthcare system, living in poverty, and grappling with addiction through world building. Notably, they rendered their life stories as a decision-making process—a dynamic mode of interactive storytelling. These game making practices foster a sense of achievement, restoring agency and dignity to individuals in addiction recovery. Ultimately, life storytelling through digital games has the potential to build empathy with the public and challenge preconceived ideas about addiction while giving insight to policymakers addressing structural outcomes related to the opioid crisis.

“A Missing Link: Empowering Youth to Take Charge of their Healthcare”

Sara Bharwani, University of Nebraska-Lincoln

Alex (Trout) Hamilton, Jacqueline Huscroft D'Angelo, Oregon Research Institute

Navigating the US healthcare system is a complicated and onerous task, placing responsibility on individuals to trudge their way through a labyrinth of information and tasks. By addressing health literacy, which is the ability to locate, understand, and use health-related information and services to make informed decisions for oneself and others (Centers for Disease Control and Prevention, 2022), individuals can mobilize themselves to tackle their healthcare needs. Addressing individual health literacy is likely to lead to increased medical care quality, decreased costs, and reduced levels of healthcare disparities (Nutbeam & Lloyd, 2021).

While all individuals would benefit from increased levels of health literacy, our focus is on adolescents transitioning to adulthood. This developmental stage is a critical period to advance health literacy strategies as youth typically move to independent living during this time. Further, addressing health literacy has far-reaching effects, as it positively impacts social, emotional, physical, and financial well-being across the lifespan (Nutbeam & Lloyd, 2021).

To address this challenge, we developed HealthyU, a comprehensive web-based curriculum to improve health literacy outcomes. This pedagogical strategy, conceptualized, developed, implemented, and iteratively refined by a diverse cadre of experts, is a promising product which has been tested in feasibility and pilot studies as well as a randomized controlled trial. In this presentation, I will discuss the importance of health literacy, the collaborative development process, and future conceptualizations. We seek to expand HealthyU's reach so that youth have a better chance at leading fulfilling and healthy lives.

2F WORKSHOP: Palliative Care as a Model to Help Decision-Makers Mitigate the Health Effects of Climate Change

Daniel Mahoney, Baylor College of Medicine

Earth has a serious illness: climate change. Climate change will contribute to increased suffering and death for humans and other species over the coming decades. The people who contribute to climate change the least (those living in low- and middle-income countries as well as future generations, including our children) will bear the heaviest costs to health and quality of life. Palliative care provides a model for individuals facing serious illness to evaluate their goals, values, priorities, and decisions. It also provides strategies to mitigate distressing symptoms and quality of life changes in the face of serious illness.

This workshop will walk the audience through a brief palliative care consult for Earth, with the audience serving as surrogate decision makers. The presenter will describe a model for complex decision-making used at the bedside with families of children with serious illness. Participants will be asked to identify not only their own values and goals but those of the various systems and structures that also have a stake in climate change, paying particular attention to areas of overlapping interests. The presenter will use this model to help the audience identify individualized goal-concordant strategies to implement decisions and actions to mitigate the effects of climate change. The presenter will also support the audience through this decision-making process by naming some of the complex emotions that accompany difficult decisions in the context of an unjust serious illness.

Concurrent Sessions 3 – Friday, March 17, 2:30-3:45 p.m. EDT

3A FLASH SESSION: Disability/Ableism and Aging/Ageism

“From Erasure to Affirmation: Transforming Medicine to Affirm Disability Identity Development”

Devika Nandwana, Case Western Reserve University School of Medicine
Prerna Mamileti, Independent Scholar

Research has shown that a strong sense of self and healthy identity development are essential components of a healthy psyche, particularly when an individual is forced to contend with discrimination. The current standard of care in medicine is to validate sexual orientation, gender identity, and race as fundamental aspects of one’s identity. Yet the medical model of disability sees disability as a characteristic to be “fixed” rather than another dimension of identity to be nurtured, highlighting structural ableism within healthcare. In this project, we argue that ableism is inherent in the medical model of disability through curative and paternalistic treatment approaches that lead to an erasure of disability identities and experiences. In an effort to combat structural ableism in medicine, we put forth an analytical argument for a disability-affirming model of medicine that puts disability identity development at the forefront of care. Given that medicine is one of the structures that disabled individuals have the most extensive, intimate interactions with, we believe that healthcare professionals have the potential to strongly influence their patients’ disability identities in a way that can redefine medicine’s long-standing relationship with the disability community.

“Reimagining the Foundations of Guardianship for Adults with Disabilities”

Prudence Riva, Case Western Reserve University

In the United States, guardianship systems for adults with disabilities are built on assumptions rooted primarily in the medical model of disability. When facilitating guardianships, our legal and social service systems rely on a set of guiding questions that reflect a tragic failure to imagine how our society can support and integrate those with disabilities. In this paper, I critique these problematic assumptions which are characteristic of guardianship proceedings and then propose a new set of guiding questions for fostering more socially-just disability support. This altered approach to guardianship at a structural level trickles down to a new conception of what the interpersonal relationship between a guardian and their ward should look like. This new ideal emphasizes appreciating, supplementing, and nurturing a disabled individual's abilities, rather than supplanting their legal rights. Integrating this rationale with an exploration of the concepts of autonomy and decision-making capacity, I outline three essential facets of this ideal guardianship: (1) it is actively anti-oppressive and therefore must be trauma-informed, (2) it is to be used as an accessibility device rather than a means of social control, and (3) it is a dynamic relationship sensitive to changes in needs and abilities over time. This critique of the assumptions at the heart of the guardianship system can provide the basis for major reforms in guardianship policy – or perhaps even a complete dismantling of the system as we know it.

“Power of Horror: Dementia Care and Social Justice in Ariyoshi Sawako’s *Twilight Years* (1972)”

Yingzhi Lu, University of Illinois at Urbana Champaign

Topping the rank of aging countries, Japan's aging population is both an achievement and a challenge to its modernization of medicine. This dominant political perception of the aged, however, often overlooks the individual experience of aging and their female caregivers who are excluded from the welfare state's biopolitics of healthy aging. Looking back to Japan's critical transitional period to a welfare state, this paper looks at Ariyoshi Sawako's *Twilight Years* (1972) to examine the embodied structural ignorance of disability, aging, and female caregivers in Japan. Narrated from the perspective of a female caregiver to her demented father-in-law, this novel exposes the hypocrisy not only of the political welfare institutions, but also the social and moral structures imposed on the new women, or career women. Although the novel is outdated for its stereotypical depiction of the demented patient as a loss and even a non-human being, this paper looks at the interpersonal relationship between the caregiver and the patient instead. My paper argues that the lack of authentic intersubjective communications between the caregiver and the patient represents the underlying disconnection between the individual conditions and the moral, political, and social institutions at the height of Japanese economic growth. It is through the despair and fear of disconnection that the novel succeeded in provoking social movements to reform the political and moral institutions to establish more meaningful connections with the abject individual families.

“Making Peace with Aging: Deconstructing the War Metaphor in Anti-Aging Rhetoric”

Grayson Holt, Case Western Reserve University

War metaphors encouraging one to “fight aging!” are a staple of anti-aging science and consumer culture as well as popular culture more broadly. War metaphors have been studied extensively in healthcare in the context of cancer and recently COVID-19. In this flash presentation, we argue that, when applied to aging, the benefits of the war metaphor are lost and its detriments are exacerbated. Two benefits of the war metaphor are commonly cited: its ability to drive attention to a problem, and the hope it engenders through an empowering survivor rhetoric. In the context of aging, neither is applicable: all people are aware of aging, and all people are mortal. Previous research has identified a plethora of problematic consequences. One cluster focuses on the experiential component including a loss of compassion for those who are defeated, reinforcement of fear, a loss of opportunity to define one’s own experience, and a focus on conquering the unconquerable. The other cluster concerns society’s response to its purported enemy, focusing efforts on biology and intervention. Anti-aging war metaphors worsen these effects, reinforcing anxiety resulting from aging’s coupling with death and the common desire for control. Finally, we argue that this metaphor will contribute to measurable deleterious outcomes. Research has demonstrated that expectations for aging affect later-life health outcomes and life expectancies. Additionally, patients viewing their illness as an enemy has been linked to higher levels of depression, anxiety, and pain. Therefore, the time has come to make peace with aging and discard the military metaphor.

“Medical Ageism Faced by Young Adults and Children: How Young-Onset Rheumatoid Arthritis is Overlooked as a Potential Diagnosis in Youth”

Deirdre Welch, Case Western Reserve University

It is well-known that ageism amplifies healthcare disparities in geriatric contexts, but the systemic ageism against children/young adults is largely denied. Popular institutional definitions of ageism describe the term as discrimination strictly against mature parties. However, younger people are not immune to this form of inequity. “Youth” is, socially and professionally, synonymous with the idea of “health” and wellbeing. This bias inevitably bleeds into the healthcare system and has the effect of leading healthcare providers to dismiss complaints in younger patients. Throughout this study, I will perform a qualitative analysis of interviews which will explore the experiences of chronically ill young adults aged 18-25 diagnosed with young-onset rheumatoid arthritis in their childhood (under 18). The number of young adults ages 18-34 diagnosed with rheumatoid arthritis (RA) is about .008%, while there are no known statistics on the number of minors diagnosed. While rare, it is not impossible for a child or young adult to be diagnosed with RA; the unwritten expectation that younger people cannot have RA leads to postponed diagnosis and treatment. I will argue that ageism against young adults/children is prominent in the American healthcare system and significantly impacts the resources available to younger people with health conditions, specifically RA. The reduced quality of care and deferred diagnosis experienced by young adults with RA results in prolonged physical suffering and discomfort.

“Draw YOUR Story: An Art and Storytelling Program for Older Adults”

Sujal Manohar, Baylor College of Medicine
Oluwapelumi Oloyede, University of Houston College of Medicine

The COVID-19 pandemic has limited senior care facility activities, exacerbating loneliness and social isolation. We describe a creative intervention for addressing these challenges and fostering intergenerational connections between students and older adults.

“Draw YOUR Story” is an art and storytelling program at a senior care community addressing loneliness and social isolation among older adults. Supported by the Albert Schweitzer Fellowship, this program has three goals: (1) to reduce loneliness among older adults; (2) to foster intergenerational relationships between older adults and medical student volunteers; (3) to utilize art and storytelling activities as an avenue for building these connections.

Each session has a unique theme and begins with open-ended questions to spark conversation. While sharing stories, participants create a small drawing or painting on a 5” x 5” cardstock square. The artwork, which can take an abstract or literal form, is inspired by their story or that of another participant. At the end of the program, we will create a collaborative art project with the drawings from each session. This exhibition will be displayed at the senior community and a medical institution.

We aim to evaluate this program as a potential model for other organizations looking to engage with older adults. It is also a valuable activity for medical students to gain comfort interacting with older adults outside of clinical settings. Through a quality improvement project, we will better understand this program’s impact on older adults’ loneliness and isolation as well as medical students’ empathy and perceptions of older adults.

“Effects of Narrative Storytelling on Continuing Care Retirement Community (CCRC) Older Adults”

Catherine Bryant, Jason Burnett, University of Texas Health Science Center at Houston

Renee J. Flores, Mary E. Kollmer Horton, McGovern Center for Humanities and Ethics, University of Texas Health Science Center at Houston

Older adults living in continuing care retirement communities (CCRC) experience unique circumstances such as relocation into assisted living, loss of social networks, decreased mobility, widowhood, and retirement from employment that impact their physical and emotional well-being. This project adopts the principles of narrative medicine to use storytelling as an intervention in CCRC older adult care. It provides health profession students with a unique opportunity to understand aging. Engaging in storytelling exercises is an enjoyable community-building exercise with potential benefits for residents' cognition, loneliness, depression, and mental health.

Residents of a CCRC were recruited to meet weekly for a one-hour group narrative activity. Residents recounted stories of their lives, followed by discussion and questions. Audio of the exchanges was recorded. This project reached 41 residents over ten weeks. Baseline and quantitative assessment tools were used to identify measurable changes.

Narrative storytelling is an engaging exercise that can be utilized as an enjoyable and beneficial intervention in CCRC older adult care. Transcripts of the shared stories reveal moments of individual reflection, cognitive stimulation, interpersonal connections, cultural appreciation, spiritual awareness, memory recall, and dynamic learning. In addition, incorporating clinical student volunteers provides invaluable training for the next generation of healthcare providers who will better understand aging, improve their communication and service to older patients, and appreciate the patient as a person within their life story.

3B PANEL: Writing Beyond What We Witness

Amy Haddad, Creighton University

Jay Baruch, Alpert Medical School, Brown University

Stacy R. Nigliazzo, Memorial Hermann Hospital

Rachel Kowalsky, Weill Cornell Medicine

For creative writers who are also health care professionals, rendering authenticity in their writing is complicated especially when the subject matter they write about is often drawn from their clinical experiences. The panelists, who are poets, essayists, and fiction writers, will consider the ways their work gives voice to nurses, physicians, and patients as well as the ethical/professional elements involved in their choice of content, characters, and setting. They will address the role of imagination, structure, poetic form, inspiration, and the different ways they process experiences through writing. They will reflect on how their writing process may, or may not, inform their clinical work or experiences as patients. They will also discuss how their perspectives shift due to context such as practice setting, disciplinary background, and personal illness experiences. The panel will read examples of their work and examine how an observation or experience makes it to the page in the form of an essay, poem or short story and others linger in creative purgatory for years.

3C PANEL: “The God Trick of Seeing Everything from Nowhere”: Evidence-Based Medicine in Contemporary Healthcare

Anita Slominska, St. Mary's Hospital Research Centre

Ailish Burns, Brown University

Ryan Hart, Independent Scholar

In 1988, Donna Haraway proposed the seminal concept of “situated knowledge,” which posits that all knowledge and perception is embodied and located and conditioned by geographically and historically specific circumstances. The idea that all knowledge is partial and situated contrasts with the doctrine of disembodied scientific objectivity that lays claim to “unrestricted vision,” a totalizing and single vision that amounts to what Haraway calls “the god trick of seeing everything from nowhere” [1].

“Seeing everything from nowhere” is an apt description of evidence-based medicine (EBM), which privileges scientific and statistical generalizations and “objective” and algorithmic decision-making in contemporary healthcare. It disavows the particularity and variability of individual patients with its “gold standard” of aggregated research data (“everything”) that is stripped of all contextual and “situated” circumstances (“from nowhere”).

In EBM, statistics, systems of measurement and ranking override human judgment and interpretation, as well as clinical and patient experience. Claims of adhering to the highest-standards of research evidence preclude sustained critical inquiry into location, embodiment and partial perspectives; instead EBM is aligned with what historians Lorraine Daston and Peter Galison call “mechanical objectivity.” According to Daston and Galison, the origins of “objective knowledge” in the mid-19thC were linked to seeing subjectivity in a negative (or even dangerous) way. The ideal of “objectivity” was “noninterventionist” and involved the deliberate censoring of the personal and “squelching the subjectivity of interpretation” [2].

EBM, as a paragon of “mechanical objectivity,” is an important mediating factor in the relationship between individuals and healthcare systems. While EBM is meant to increase transparency and accountability in medicine, it leads to the use of opaque models that are not explained, or even unexplainable, to health-care users. This panel explores the grip of evidence-based medicine/“mechanical objectivity” in healthcare practices and policies and the tensions it creates between individual lived experience and institutional priorities.

Two of the panelists will examine specific cases of the use of algorithms in healthcare rationing and medical decision-making. One presenter will present their paper, “Working within the algocracy: subjective understandings of disability in Medicaid functional assessments.” This paper examines how Wisconsin Medicaid employees use algorithms to assess the functional eligibility of long-term care applicants. In Wisconsin, algorithms guide Medicaid workers through functional assessments, helping them quantify the “level” of disability of an applicant and determine whether this warrants state-funded long-term care. Through interviews and observations, they explore how workers’ own understandings of health and disability shape their use and interpretation of these algorithms.

The second presenter (who will also serve as the panel moderator) will examine the use of algorithms in allocation policy for liver transplantation and efforts to eliminate “subjective criteria” in the prioritization of transplant candidates. The current allocation system ranks patients according to a standardized definition of medical urgency, with a narrow focus on measuring mortality endpoints. This paper examines how an “evidence-based” approach circumvents complexity (by reducing it to what is quantifiable) and ignores many aspects of illness-as-lived from the patient’s perspective.

The third presenter will draw on the work of Gabriel Marcel and Karl Jaspers to explore the incompatibilities of lived experience and objectifications from a philosophical perspective. His paper will propose ways that philosophical insights on lived experience as being situated in the world can be used to create more productive relations between the experiences of individuals and the objectifications of medical practice in the EBM paradigm.

3D PAPER SESSION: Health Care Workers

“Masking Affects: The Cruel Optimism of the Discourse on Healthcare Worker Distress During the COVID-19 Pandemic”

Maryam Golafshani, University of Toronto Faculty of Medicine

Healthcare worker (HCW) distress throughout the COVID-19 pandemic manifests as a vast range of affects from grief and fear to anger and betrayal. And the discourse around this distress is constructed through a vast range of sources from academic literature and institutional policies to media articles and tweets. Drawing upon Sara Ahmed and Lauren Berlant's affect theories, I will explore how this discourse of distress elides certain affects in favor of others and, more specifically, argue that this discourse masks anger and betrayal as "intolerable" affective responses to distress.

Whereas affects like grief, fear, anxiety, and burnout focus on the individual's mental state, affects like anger and betrayal are outwardly directed towards an other, most often institutions like governments or hospitals. Whereas the latter affects demand systems-level responses to HCW distress (e.g., paid sick days, reasonable work hours, mask and vaccine mandates), a discourse of distress that foregrounds the former affects and masks the latter can justify the implementation of solely individual-level responses to HCW distress (e.g., wellness resources and psychotherapy).

Ultimately, we will see how at the heart of this discourse is a relation of cruel optimism à la Lauren Berlant. There is an optimistic attachment to and desire for a well, "un-distressed," even heroic HCW. But this optimism is cruel because the focus on individual-level interventions for HCW distress at the exclusion of systems-level transformation always already compromises the conditions of possibility for achieving that desired object.

"Reckoning and Revisiting: Ambiguous Loss in *The Healer's Burden*"

Kimia Heydari, Columbia University

The Healer's Burden is an anthology of clinicians' meditations on grief. Healthcare providers are in a uniquely challenging position when it comes to grief, since they see a large number of patients suffer and die, often without being able to process the depth of their feelings adequately. My close reading of three key pieces of this collection in view of Pauline Boss' theory of "ambiguous loss" offers up an opportunity to highlight uncertainties surrounding loss and to ultimately appreciate the particularity of individual narratives and fill gaps in existing psychological theories of grief.

During this literary analysis project, I connected with psychiatrists, bereavement scholars, and clinician-writers whose work I closely parsed with my tools as a literary critic. Part of this effort sought to clarify the relationship between clinicians' reflection on their emotional experiences and their effectiveness as medical providers. From interviews with ICU doctors, I learnt that clinicians who avoid reflecting on their grief might risk over-treating their subsequent patients. As one of my interviewees said, "some of my colleagues in the ICU fell into misguided patterns of care."

My analysis carves out space for the small-scale, granular, and internal evocations of grief, affording a series of snapshots of healthcare workers' psychological digestion of the experience of loss. In this way, I argue that healthcare workers' experience of professional grief engenders ambiguous boundaries and continuously enmeshes them in ambiguous losses.

"The Mindful Art Pause: Leveraging Individual Experience of a Brief Multi-Media Recording to Improve Clinical Team Outcomes and Wellbeing"

Patricia Luck, Susan Dodge-Peters Daiss, University of Rochester School of
Medicine and Dentistry
Gaelen McCormick, Eastman School of Music at the University of Rochester

The *Mindful Art Pause* (MAP) project was created during the early months of the pandemic when clinical shifts were experiencing unprecedented patient loads and deaths from a disease not yet fully understood. Healthcare teams faced reduced staffing levels from illness and pandemic fatigue. The need to support both the individual healthcare worker and the clinical teams was apparent. The challenge was finding time to address these needs.

Acknowledging both the urgency of the need and the limitations of time, the MAP team created a series of three-minute multi-media digital recordings which combine the visual arts, music, and poetry within an eight-week mindfulness-based practice framework. The *MAP* was developed by three university and medical school faculty members collaborating across institutional units and disciplinary departments. This paper presentation will briefly explore the history of the *Mindful Art Pause*, the development of the project, and discuss future research potential. The main focus of the presentation will reveal the experiential learnings of attendees as we piloted this program with a variety of clinical teams.

The *MAP* program has focused to date on program development, evolving each subsequent version to respond to participants' reactions and recommendations. Addressed in our paper will be our explicit engagement next with research initiatives: 1) to understand how the *MAP* experience impacts stressors specific to clinical settings; 2) to focus *MAP* content to reflect DEI concerns faced by individuals and clinical teams, and ultimately community health.

3E PAPER SESSION: Political-Economic Structures and Public Health

“Will the Circular Economy Take the Health Care Sector Beyond Social Injustice?”
Lorna Fitzsimmons, California State University Dominguez Hills

Health Care Without Harm (HCWH) estimates that the health care industry is responsible for 4.4% of global net emissions. If it were a country, the health care sector would be the fifth largest emitter on Earth, according to HCWH. To align health care with sustainable development initiatives, the concept of the circular economy (CE) has been championed against the prevailing linear model of produce-use-dispose: the circular model is touted as one that “looks beyond the current take-make-waste model and aims to create a new economy that operates in a continually evolving cycle.” Its reduce-reuse-recycle framework has been described as “balancing the ecological boundaries of the planet with the social boundaries of humanity.” The World Health Organization (WHO) links the circular economy to the green economy as defined by the United Nations Environmental Program—an economy “that results in improved human well-being and social equity, while significantly reducing environmental risks and ecological scarcities.” Yet, complaints about the marginalization of social equity in contemporary CE discourse grow. According to American anthropologist Brienne Berry, we need to understand the multidimensionality of the concept of social justice if the term is to be more than a buzzword in CE conversations. Taking a cross-cultural approach to the issue, this

presentation discusses some recent examples of CE discourse addressing the healthcare sector in Brazil, India, the United Kingdom, and Europe.

“American Dementia: Applying a Structural Analysis to our Deranged Societal Approach to Alzheimer’s”

Daniel George, Penn State College of Medicine

Peter Whitehouse, Case Western Reserve University

For decades, researchers have chased a pharmaceutical cure for memory loss. But despite the fact that no disease-modifying biotech treatments have emerged, recent research suggests that dementia rates have actually declined in the United States, Canada, and Western Europe over the last decade. Studies have strongly linked these falling rates to structural shifts in mid-twentieth century Western democracies that—in reducing inequality, providing widespread access to education and healthcare, reducing smoking, and de-leading gasoline—have influenced social determinants of brain health across the lifespan of generations currently in their graying years.

In contrast to the social democratic reforms of the mid-20th century that ushered in these brain health benefits, the neoliberal order of the last several decades has—in dramatically reordering political-economy and worsening population and environmental health—begun reversing these gains. Moreover, current societal approaches to dementia remain profoundly limited by molecular-reductionist thinking and market-based, individualized/consumerist approaches to cure and prevention. Even advocacy organizations like the national Alzheimer’s Association minimize public health and public policy as levers for change, instead embracing an unrealistic biomedical focus on finding a single cure. In this session, we will apply a structural analysis to brain aging, giving an overview of the abovementioned studies linking reduced dementia rates with mid-20th century political-economy, and examining the “demented” nature of current culturally-dominant approaches. As a case study, we will focus on the disastrous 2021 FDA approval of the Alzheimer’s drug Aduhelm as especially emblematic of the misplaced priorities of the neoliberal era.

“Redlining: Addressing Residential Segregation’s Persisting Symptoms in Clinical Care”

Fareeda Farhan Naduvil Valappil, Case Western Reserve University

The National Housing Act introduced a discriminatory policy in 1934 that denied mortgages to low-income neighborhoods primarily inhabited by racial and ethnic minorities. Coined as “redlining”, this discriminatory denial of loans was outlawed in the Fair Housing Act of 1968, yet remains an issue today. Unfortunately, residential segregation continues to ravage low-income Black and Hispanic communities: they suffer higher rates of poverty, lack of access to education, homelessness, and even hotter neighborhoods particularly susceptible to heatwaves, leading to worse health outcomes. Indeed, redlined neighborhoods experience lower life expectancy, worse effects regarding COVID-19, and poorer mental health, all relevant yet often uncontextualized factors in healthcare.

In this paper, I argue how physician care must effectively consider social determinants to care for patients victimized by historical redlining. Novel programs such as Health Beyond the

Hospital in New Jersey that integrate social determinants into the clinical approach are analyzed for possible contributions to addressing redlined community healthcare. Furthermore, considerations on the inequality of hospital assets and healthcare for green versus red zones are explored to contextualize the greater effect of redlining and its implications on future healthcare policy. Additionally, although discussions on physician involvement in policy primarily center around those directly related to healthcare, I will examine physician responsibility in other policy areas that may affect health indirectly, like those addressing redlining and other forms of systemic inequality. Addressing and incorporating redlining's historical and current effects in patient care is imperative to removing the lingering lines of structural racism in clinical care.

3F WORKSHOP: Gestures of Care - Exploring Creative Movement Exercise to Reflect On and Cultivate Caring Consciousness in Care Interaction

Michael Koon Boon Tan, Noemie Soula, Sheffield Hallam University

We hope this workshop will contribute to the conference interest to reflect on the effects of perspectives and action on health and wellbeing outcomes and to explore ways to promote the manner we interact, socially, professionally and structurally.

Care encounters and exchanges, as we know, is a complex process involving verbal and nonverbal communication. Although a substantial portion of our communication is nonverbal - the percentage of nonverbal communication is four times that of verbal communication; only 20% is being conveyed with the use of words while our actions and gestures make up the remaining 80% (Hull, 2016), nonverbal communication in care interaction, often risks slipping or getting relegated to the periphery of one's attention in the hectic, and sometimes stressful caregiving routine. For some, the limited opportunities to explore and develop nonverbal communication skills, may result in a lack of 'know-how', awareness, and confidence when encountering another person. This inevitably may have less than desired consequence on the experience of care.

The workshop attends to this gap by providing participants a space to reflect on and explore the nonverbal elements in care interaction. Informed by concepts of noetics (intentionality) and transpersonal caring (consciousness & connectedness), we hope the creative movement activities will support individuals to foster their perceptivity and capacity to communicate care nonverbally. The creative movement exercises will be involved with some partner work and occasional (optional) light touching.

In asking What is the place of listening in care exchange? What does it mean to listen? Do we only listen with our ears (What else might be involved)? Can our body listen?, the workshop explores together with the participants the nonverbal modality and nuances in caring using creative movement activities. In doing so, we are keen to draw attention to the value and importance of intentionality, embodied listening and attunement in care encounters and exchanges. In addition to an experiential session, participants can look forward to reflecting on and reviewing their values and aspirations for caregiving and exchange with others their nonverbal caring experiences.

In view of time, the format of the workshop will be a truncated version comprising of the following segments:

- Welcome and Introduction (10 mins): Share with attendees the overall structure of the full workshop,
- Experiential session (50 mins): Conduct some of the keys activities and highlight key touch points in those activities which aims to engage attendees to reflect and accentuate caring consciousness.
- Discussion and feedback (15 mins): We are interested to learn about the attendees' opinion and experience of the workshop to enable us evaluate the relevance of the activities and inform further work in this subject which we wish to share with a wider group of participants.

Concurrent Sessions 4 – Saturday, March 18, 9:00-10:15 a.m. EDT

4A FLASH SESSION: Representation and the Arts

“Mortality as Depicted in Medical TV Shows Compared with Reality”

Kushagra Kumar, Justin Ceasar, Robert P. Olympia, Penn State College of Medicine

Medical TV shows have the potential to distort viewer perception of reality regarding healthcare, and viewership is linked with perceiving reality in the context of what is being portrayed. Previous studies have demonstrated how television depiction of medical scenarios can lead to the formation of false perceptions about medical care, and other studies have found discrepancies in portrayal of healthcare topics when compared to real data. The objective of this study was to analyze the depiction of mortality in popular medical TV dramas as compared to real-world data. We conducted a prospective, observational study of 8 medical TV dramas. Two researchers independently viewed the first three, middle three, and last three episodes of the first season for each drama. Data abstracted included patient demographics, category of death, and specific cause of death. Comparisons with real-world data were determined utilizing the CDC WONDER database. In the depiction of mortality, the most common demographics were adult, male, and white, and depicted in an ED. The most common categories of death were natural and accident, and the most common specific causes of death were motor vehicle crash, infection/sepsis, and cardiac death. When comparing medical TV and real-world data, discrepancies were found in all demographics except for age-young adult, age-elderly, and medical setting-inpatient floor. Additionally, the percent of patients depicted as dying in an inpatient and ED setting were higher than real-world data. Viewers of these television shows may develop skewed perceptions of mortality that could reduce their trust in medical care they would receive.

“Ethics Without Ethicists: Exploring the Absence and Narrative Potential of Professional Ethicists as Characters in Medical Film and Television”

Stephanie Larson, Independent Scholar

Health humanities scholarship is rich with studies of film and television that revolves around medicine. One particularly generative path of research has explored the way ethical

issues are portrayed in medical dramas. Often, medical dramas depict a range of biomedical ethics issues yet often rely on plots that resolve the issues in unethical ways. In recent years, some bioethicists have called for media to more accurately portray ethical issues given that for many viewers, medical dramas may be their first encounter with certain biomedical issues. Others have argued that accuracy might come at the expense of the very draw for many viewers: compelling characters, tension, and dramatic plot.

Often missing from the discussion of ethics in film and television is the portrayal of professional ethicists. Despite the increasing professionalization of clinical ethics through postdoctoral fellowships, societies, and accreditation, the fictional hospitals in medical dramas seem to exist in a universe where bioethics consultants do not exist. This paper will accomplish two goals. The first is to present an exploratory study of clinical ethics as a profession on the large and small screen. The second goal of this paper is to consider the narrative potential of clinical ethicists as characters in medical dramas. Specifically, I will consider whether such characters can be built into medical plot lines to help more accurately portray biomedical issues without sacrificing compelling plots.

“Using (Marginalized) Memoir to Teach Social Determinants of Health”

Robin McCrary, Syracuse University

Exploring narratives of illness from minoritized/marginalized authors, in particular through autobiography and/or memoir, can address numerous questions around the disproportionate accounts of illness and health experiences. Through work from authors such as Theresa Blankmeyer Burke, Porochista Khakpour, Audre Lorde, and more, students in health humanities and writing studies courses alike can learn to more clearly interrogate the inequitable structures contributing to SDH/social determinants of health—defined here by the World Health Organization as “the conditions in which people are born, grow, live, work, and age, including the health system” (National Academy of Sciences, Engineering, and Medicine). Examining the stories within such works can offer health humanities and writing studies educators ways to explore potential public health interventions via an awareness of authors’ experiences of illness, healing, and disability in both clinical encounters and built environments.

Including but not limited to the authors listed above, this paper presentation explores pedagogical methods and materials used in the presenter’s courses toward exploring SDH in particular for minoritized/marginalized persons—ultimately moving toward a creative needs assessment for populations for whom structural and social inequities are a likely part of their illness and health experiences. Especially for educators who may be involved in practices of creative public health and/or narrative medicine, this paper presentation aims to reflect on seminar and workshop pedagogies that may allow educators to examine and interrogate relationships between social biases, built environments, and experiences of illness and health harbored by people with minoritized and marginalized statuses.

“Traditional Dance Health Narratives and the Aseemkala Initiative: Using Diverse Storytelling for Equity in Medical Education”

Shilpa Darivemula, University of North Carolina

Isha Parupudi, Columbia University

Shreya Srivastava, Albany Medical College
Monica Shah, St. John's University

Medical education in the United States often struggles to incorporate authentic cultural responsiveness, equity, bias, and other humanities focused curriculum into clinical education (Sharma, 2018). Narrative medicine, a form of storytelling that communicates ideas on health with cultural and personal nuance, may serve as an educational tool that can be used in medical training (Charon, 2001). One variation on narrative medicine, narrative dance medicine, uses traditional dance to convey stories on health and may be especially effective in generating cultural conversations that challenge preconceived biases on culture and society. This is because many cultures have traditional dance forms through which stories are performed within diverse, cultural contexts. To investigate whether narrative dance medicine can generate thoughts on culture, society, and equity among medical students, we conducted a narrative dance medicine series at a single academic institution. Medical students were sent videos of traditional dance performances that expressed health-related concepts followed by a survey. Although we plan several iterations of this series, to date, among the 15 respondents thus far, 66.7% of agreed that narrative medicine was helpful for doctor-patient relationships, and 86.7% agreed that narrative medicine was helpful for reflection. 93.3% of respondents agreed that dance narratives would be effective tools for educating healthcare trainees on healthcare equity, social determinants of health, and cultural competency. Open-ended responses indicated that the performances inspired deep reflection on cultural nuances with patient interactions. These results suggest that narrative dance medicine should be further investigated as a promising tool for enhancing culturally responsive training in medical education.

“Body in a Built World: A Poetry Reading”

Anna Leahy, Chapman University

This creative presentation will include poems that explore the body in a built world, with both physical and social structures as context for disability and illness. The poem “Accommodation is a precious mettle,” for instance, offers the composite character Ada, whose name is also acronym; during the pandemic, Ada is asked to transform and then un-transform, to rebalance abilities and limitations in an ongoing attempt to negotiate policies intended to match an individual body with workplace and social structures. Based on a ritualistic visit to the dentist, “Method of Articulation” documents what happens when good hygiene unexpectedly fails in the face of inflammation; the poem also considers the role of the physical mouth in language and habitual action. “Raised by a Wolf” uses a mirror effect to emphasize the repetition and evolution of ongoing symptoms; it questions whether prevailing systems of time are appropriate structures for understanding chronic conditions. The poems themselves are built structures—couplets that parse and pace information down the page, enjambed lines that interrupt and propel forward, etc. Poetic form becomes inseparable from the poem’s content, just as the physical body cannot be separated from who we are. While some of the other poems in the larger manuscript-in-progress have been published, the poems to be included in this presentation are unpublished. This reading is intended to be in conversation with other artists,

designers, writers, and literary scholars working with representations of the (impaired? ill?) body in a built world.

“Coloring Inside the Lines: A Critique of the Diversity in Medical Diagrams”

Anna Cryan, Case Western Reserve University

Medical diagrams provide a crucial intersection between health and the humanities. However, anatomy textbooks and posters rarely use a variety of skin tones and body types in their depictions. In this presentation, I argue that holding the white, fit, able-bodied male as the standard in medical illustrations directly narrows our ideas on what can be seen as “healthy” and skews our views of what is a “normal” body. While many scholars have already addressed the importance of including depictions of peoples of many races and ethnicities in medical diagrams, I will discuss the necessity of illustrating folks of all gender identities, especially outside of matters relating to reproductive health, as many assigned female at birth people are only shown in reference to their reproductive anatomy. Lastly, I will break down how only showing fit and able-bodied individuals contributes to the rampant fatphobia in health fields. The lack of diverse representation in healthcare diagrams contributes to a knowledge deficit in medical and nursing students and affects their ability to diagnose and treat patients, which in turn leads to detrimental health outcomes. Additionally, the homogeneity of anatomical illustrations can influence how patients understand and feel about their health.

“Artists with Ocular Disease: Perspectives on Vision, Artistry, and Disability”

Mallory Bowers, Sidney Kimmel Medical College

Evidence for the impact of visual impairment on the artistry of Claude Monet, Edgar Degas, and other deceased artists of renown is limited to medical records, letters, and other primary sources. The aim of this project was to interview contemporary artists with visual impairment to better understand if and how visual changes related to ocular trauma or disease impacted their artistic process and body of work. A secondary aim is to interrogate assumptions about visual disability by the author, a medical student, and whether interviews confirmed or disconfirmed these assumptions. After obtaining consent, semi-structured surveys were administered to participants identified via snowball sampling through the Pennsylvania Academy of Fine Arts. Four artists and one accessibility consultant were interviewed. The artists who were interviewed have minimal vision and work with three-dimensional art, including stone sculpture, ceramics, and textiles, as well as acrylic and watercolor paints. Participants related the importance of tactile information, as well as different “types” of touch, as a means of creating and consuming art. One participant, who experienced progressive visual decline in middle age, described the importance of prior artistic training and memory in continuing to create watercolor paintings with diminished visual feedback. These accounts suggest that visual impairment impacts the process, medium and, subsequently, final artistic product. Participant interviews broadened the author’s view of visual disability, particularly their understanding of assistive technology and capacity for adaptation with increased impairment. The author’s limited experience with disability mirrored participants’ description of healthcare professionals as uninformed regarding vision impairment.

4B PANEL: Narrating Trauma, Narrating Identity: Forming the Physician-Self in the Anatomy Lab

Margie Hodges Shaw, Christopher J. Mooney, Natercia Rodrigues, Erik Larsen, University of Rochester School of Medicine and Dentistry

For many students, medical education begins with the challenging task of human dissection. In the anatomy lab, students become intimately aware of our complex physical structures by cutting, disassembling, and touching deceased bodies. They carry this invaluable knowledge with them and apply it throughout their careers, but many also carry traumatic experiences from their work in the lab. The cadaver is both an educational tool and the remains of a person; trauma often results when students struggle to separate one identity from the other—when they experience their efforts as violence rather than education. Students confronted with trauma begin to make meaning from their experiences as best they can, often developing narratives about their roles as healers and their relationships with patients and peers that shape their perspectives in perpetuity.

Based on a multi-year research project in a Department of Health Humanities and Bioethics, this panel will explore what student narratives teach us about responses to trauma in the lab and in medical education more generally. The panel's discussion will focus on transcriptions derived from original interviews conducted with several first-year medical students at our University. This research suggests that students respond to challenging and often traumatic experiences in the lab by developing common patterns of narrative response. For example, many tell stories that position their narrators as heroically suffering for the greater good, or as engaged in pathological behavior. Drawing on Arthur Frank's illness-narrative typologies, the panel will investigate how medical students, like their patients, confront trauma by reimagining the self in its relationship to suffering and medicine.

Informed by this work, the panel will discuss the systemic failure of medical schools to adequately support medical students as they experience trauma, and how this omission can lead to harmful consequences that may endure well beyond the first year of training. Finally, the panel will explore what interventions, particularly those developed in health humanities programs, might help students recognize the stories they tell about trauma and their implications.

The panel will consist of faculty representing different disciplinary perspectives from the Department of Health Humanities and Bioethics.

4C PANEL: Mobilizing Health Humanities to Address Health Disparities

Kirsten Gardner, Şerife Tekin, Bianca Pulido, Melissa Wallace, Sophia Dove, Shamshad Khan, Kimberly Kline, Eric Shattuck, University of Texas at San Antonio

Our panel showcases interdisciplinary pedagogical strategies aimed at communicating with students and society at large about the intimate interplay between structural racism, health disparities, and healthcare systems. It brings together faculty from History, Philosophy, Modern Languages and Literatures, Communication, and Public Health, at the University of Texas at San Antonio (UTSA), and draws on research conducted in collaboration with UTSA

students pertaining to community-engaged and community-centered research focused on health disparities in vulnerable communities in South-central Texas and the borderlands.

Kirsten Gardner (History) uses the example of a History of Medicine class she taught at UTSA, in which students grappled with the City Council's 2020 declaration of racism as a public health crisis. She demonstrates how learning strategies that insist on the inclusion of local studies within the History of Medicine helped students gain agency and voice to embed their experiential histories within larger context of the 20th-21st century medicine. Şerife Tekin and Bianca Pulido (Philosophy) illustrate how feminist epistemology and pedagogy can inform decision making in contexts of mental health care by engaging with patients' lived experiences and testimony, using examples of student work in the Medical Humanities Seminar. They argue that participatory and collaborative approaches in psychiatric care can undo the epistemic injustices faced by clinical patients.

Panelists then discuss the importance of engaging and communicating with key stakeholders and the general public about the intimate and intersecting layers of connection that exist between structures, individuals, communities and illness/health. Melissa Wallace (Modern Languages and Literature) focuses on the role of institutional racism in mental health challenges faced by detained immigrants, ranging from Post-Traumatic Stress Disorder to depression and generalized anxiety, as well as exacerbation of these problems without language-assisted access to mental health services. She turns a critical eye toward the broken promises of current language access legislation and institutional policies, despite the general agreement that interpreter services enable patients to talk about problems and feelings and are integral in providing mental healthcare for refugees and migrants. Sophia Dove, Shamshad Khan, and Kimberly Kline (Communication) draw on an extensive document analysis and key informant interviews to share findings pertaining to COVID-19's impact on the lives of local communities in South-central Texas. They evaluate the promises and challenges that exist in the communicative interface between health researchers/practitioners, policy makers, and community organizations, and suggest pathways to building a sustainable communication infrastructure that strategically mobilizes collective action to address health disparities in the face of future pandemics. Finally, Eric Shattuck (Public Health) calls for increased attention to the ways in which immune function – including its behavioral aspects – are responsive to social contexts at multiple levels. Engaging with research that demonstrates how the quantity and quality of social connections can affect immune responses, he considers the effects of structural factors – a society's economic, political, and environmental landscape – on exposure to pathogens and subsequent immune responses. He calls for communicating with the public a holistic understanding of the effects of social contexts on health.

4D PAPER SESSION: Retheorizing Key Terms: Fear, Regret, Pain

“Structures of Fearing: Or, How We Learned to Stop Worrying and Love Disease”
Emily Waples, Hiram College

Many health decisions are motivated, in full or in part, by fear. For instance, over the past decade, researchers have noted that an escalating number of early-stage breast cancer patients are opting for contralateral prophylactic mastectomy, citing fear of recurrence as a

primary factor influencing this treatment decision. During the COVID-19 pandemic, fear has occupied a prominent place in the practices and discourses of public health, from pathos-based appeals to admonishments of fearmongering media to the repudiation of mitigation efforts as a defiant refusal to “live in fear.” In conversation with theorizations of socially and historically-situated affective frameworks from Raymond Williams and others, this paper examines fear as a “structure of feeling” that shapes individual risk assessment and concomitant health decision-making in contemporary biomedical culture. Ultimately, it also issues a provocation: a defense of fear—even or especially so-called “unfounded” fear—as a legitimate rather than pathological affect. In so doing, it calls for a considered examination of the extent to which dismissal of fear as justification for individual health decisions is based in a misogynistic devaluation of “feminine”-coded emotion and associated history of medical paternalism. By seeking to recuperate fear from the clutches of statistical risk assessment as an admissible basis for health decision-making, I aim to argue not that we “should” live in fear, but rather to show how we do live in fear—or rather, riffing on Williams, in “structures of fearing” that inform our relationships to our own bodies and the bodies of others.

“A Measure of Regret: Historicizing Decisional Regret in the Ethics of Surgical Decision-Making”

Jacob Moses, University of Texas Medical Branch at Galveston

This paper engages the conference theme of “Mobilizing Selves, Transforming Structures” to consider what Raymond Williams called “structures of feeling.” The paper analyzes the role of affect in medical decision-making. Its primary object of analysis is “decisional regret,” a technical measure health researchers employ to evaluate outcomes in uncertain and complex domains of clinical practice, particularly in surgery. The paper utilizes historical methods and evidence from the history of surgery to examine how decisional regret entered into medical discourse in the latter half of the twentieth century. This is a history that has direct relevance to interpretive and ethical questions in contemporary health contexts. When a practitioner, patient, or caregiver expresses regret about a course of medical care, should this quantified datum call into doubt the soundness of the decision-making process that produced a regrettable result? Should the presence (or absence) of regret be used to scrutinize (or affirm) the ethical appropriateness of a type of medical intervention? The paper argues that regret first gained traction as a consumerist proxy for assessing medical decisions amid an expanded array of biomedical technologies. Regret was also a discursive space for formulating normative claims in several morally charged areas of clinical practice. Considering how decisional regret has been conceived and quantified reveals how the history of medical decision-making has been co-produced with an image of medical decision-making freighted with notions of gender, race, class, and ability that open new lines of inquiry for the health humanities.

“False Promises of (Non)Universal Languages: Theorizing Pain and Social Justice through the Arts”

Ryan Weber, Geisinger Commonwealth School of Medicine

Henry Wadsworth Longfellow is one of countless figures to describe music as the “universal language of mankind.” The same term has also been used to conceptualize mechanisms of pain, especially by adherents of the biomedical model of illness. Although these domains appear distant on the surface, underlying the history of music and the history of pain is a common quest to uncover the universal. Whether it comes to the description, measurement, and treatment of pain or the attempts to give expression to suffering through the arts, methodological dead ends underscore these shared attempts to flatten out difference. Such false promises are compounded by the fact that pain is not just a biomedical problem, but also a social justice issue. Indeed, as Joanna Bourke has demonstrated in her study *The Story of Pain* (2014), “pain is undemocratic.”

Therefore, in this paper, I will demonstrate how the circulation of pain narratives in music and medicine has privileged a particular form of agency while denying voice to others. By applying a four-part analysis of labeling, grouping, evaluating, and containing/controlling, I will theorize how reductionist approaches have led to the proliferation of dangerous hierarchies. I will also demonstrate how a particularized, pervasive aesthetics of the body popularized through certain social structures has only obfuscated our understanding of pain as both an experience and an event. The scope entails a diachronic analysis of case studies from Nordic countries beginning with composers Percy Grainger and Jón Leifs and extending to contemporary clinical approaches.

4E PAPER SESSION: Reconceptualizing Autism

“Visualizing Autism: How Films and TV Programs Shape Our Views”

Kristine Mulhorn, David Flood, Drexel University

When *Rain Man* appeared in theaters in 1988, few people were aware of autism. This film quickly changed that. Aided by the star power of Dustin Hoffman and up-and-coming Tom Cruise, the film entrenched the idea of autism as savant syndrome. As Noel Murray indicates in “More Than *Rain Man*: Autism Portrayals on Screen” (2016), although film and TV began including a broader range of autistic characters, the *Rain Man* view predominated for the next three decades here and abroad.

Examples include *The Good Doctor*, featuring an autistic savant physician with extraordinary diagnostic ability but lacking in social skills for treating patients and interacting with others. Internationally, the Korean series *Extraordinary Attorney Woo* likewise has a socially awkward young autistic savant, the female lawyer Woo, portrayed with a lightly comic touch rather than the harsh, confrontational tone often found in such portrayals. Tellingly, it became one of the more popular Korean programs. Now, many autism portrayals do not involve savants. For example, *As We See It*, based on an Israeli series, presents three characters across the autism spectrum. Moreover, following an increasing trend, all three roles are played by those with autism.

Join our discussion of autism visualizations here and abroad as we explore their role in three central areas: forming the general audience’s view of autism; expressing the struggle of those with autism as they try to determine how they might be perceived; and importantly, shaping the views of those in healthcare who may interact with them.

“The Differences Within: Autism, the Media, and Self-Advocacy in India”
Shubha Ranganathan, Indian Institute of Technology Hyderabad

The last few years have seen a discernible explosion of media content on autism, including documentaries, short animation films, Netflix series, to name a few. With the increased consumption of such media content, both autistic and non-autistic individuals are considering what it means to be neurodivergent. In India, the terms ‘neurodiversity’ and ‘neurodivergence’ have seen much greater circulation in mainstream media, whether in the context of multinational organizations acknowledging the potential of neurodiverse talent, or of hospitality establishments engaging in aggressive recruitment of persons with disabilities, or of mental health services celebrating neurodiversity. Returning to autism, media depictions have increasingly had to deal with the thorny issue of representation, that is, the question of whether autism depictions are accurate representations of lived experiences. In this context, what do autistic individuals in India, some of whom identify as self-advocates, feel about media depictions of autism? Given that the autism self-advocacy movement in India is just picking up momentum, with autistics actively speaking out against descriptions of autism by non-autistics, this paper delves into the perspectives and lived experiences of autistic self-advocates with regard to media representations of autism in particular, as well as their experiences around advocacy in general. Drawing on ongoing interviews with autistic self-advocates in different parts of the country, the paper reflects on the changes in the discursive terrain of autism in India. The paper concludes with reflections on the implications of these findings for pedagogy in the health humanities and disability studies.

“Turning Theory to Practice: Intersectionality and Decolonizing Autism”
Samantha Chipman, Loyola University Chicago

Autism activists have long since written and voiced their experiences as people of color and/or gender minorities with Autism. It is time for the writings of Autism advocates and bloggers to be critically examined as critical theory, and for scholarly writings about Autism, gender, and decoloniality to be held in conversation with these less conventional forms of theorizing. Autism has been conceptualized in between the power hierarchies of medical norms and the voices of those in the Autism community. In this talk, I will argue that Autism should be conceptualized and addressed along intersectional axes of race, gender, and disability. I will examine the testimonies of a small sample of bloggers with Autism, and connect their writings to decolonial theory and proposed practices to decolonize Autism. This presentation will describe a few overlapping forms of structural inequities experienced by those with Autism. Then, I will propose and critically examine ways to decolonize Autism as a method for institutional and structural change. Hopefully, this talk will incite further discussion and debate about ways to decolonize Autism while also recognizing the theoretical and structural complexities of defining “Autism” and “decoloniality” in society.

4F ROUNDTABLE Translational Medical Humanities
Kirsten Ostherr, Rice University

Marta Arnaldi, University of Oxford & University of Oslo
Eivind Engebretsen, John Ødemark, University of Oslo
Charles Forsdick, University of Liverpool

The participants in this roundtable have been engaged over several years in research, writing, and digital projects that explore the concept of “translation” as a critical and generative conceptual framing for future directions in medical and health humanities. Through diverse methodologies and focus areas, the work of this group collectively argues that the concept of translation is a powerful yet underestimated instrument for relating to alterity in different forms and epistemological contexts. Moreover, as a key trope in both the life sciences and the humanities, this group proposes that translation is an ideal site for exploring, challenging, and developing notions and experiences of health and disease beyond prejudicial and normative notions of identity, language, gender, sex, race, nationality, and ability. As the participants in this roundtable have argued in recent publications, the translational lens – one that is concerned with diversity by definition – can help us focus upon, and ideally expand, areas of perspectival change in the health and medical humanities as we endeavor to explore the (non-) physical locations, societal implications, and cultural constructions of health and disease in both human and non-human bodies. This approach is likely to significantly impact our understanding of notions of ecology and sustainability as it will allow us to analyze health and disease against the backdrop of human and non-human societies.

Taking this broad perspective as our starting point, this roundtable will explore the meanings and new methods opened up by the concept of translational medical or health humanities. We will consider translation in its many forms: from bench to bedside, across languages, cultures, and nations, across diverse forms of mediated narration, across perspectives and positions of power or powerlessness, across human and more-than-human species, across the individual and the planetary, across academic and community-based sites of knowledge creation, across biospheres. Building on the translational ethos that has long characterized work that bridges from the humanities and the arts into medicine, public health, and life sciences, this roundtable will discuss the ways that the idea of translation can open up new forms of intervention for researchers, teachers, and practitioners in the health humanities.

4G WORKSHOP: Behind the Mask: Art as a Third Object for Important Conversations about Race and Bias

Mark Stephens, Penn State College of Medicine

Participants will engage in an interactive arts-based activity whereby they create a mask (materials provided) representing their individual identity (and/or) experiences with race, racism, bias and systemic injustice. 10 minutes will be allocated to an introduction describing the use of mask making in the context of identity and identity formation (particularly in the context of medical education). 45 minutes will then be devoted to the mask-making exercise itself. Participants will be given a blank paper mache mask with necessary supplies (brushes, paints, glue, craft material) to create an artistic object (the mask) that represents core elements of identity that they express to the world (outside of the mask) and/or keep to themselves (the inside of the mask). Participants will be encouraged to particularly consider elements of race,

ethnicity, gender and/or sexual orientation when creating their masks. The final 15 minutes will be devoted to small group discussions whereby participants use the mask itself as a 'third object' to facilitate conversations about personal experiences with racism, sexism, institutional and personal bias. The overall purpose of the workshop is to introduce mask making as both product (the mask) and process (the creation of the mask) that can be used to explore individual identity and group identity while simultaneously opening safe space for difficult conversations. Using the mask as an artistic 'third object' allows participants to share experiences through the mask itself. This concept will be more fully explained and developed during the workshop so that participants can take both their product (the masks they create) and the process (mask-making) back to their home institutions to apply in multiple settings. Here at Penn State, we have used mask making to explore professional identity formation in medical students over time. We are also using mask making to open conversations about microaggressions, racial bias and upstander training in the context of diversity, equity and belonging.

Concurrent Sessions 5 – Saturday, Mar. 18, 10:45 a.m.-12:00 p.m. EDT

5A ROUNDTABLE: The Meanings of Dementia: How Cultural Narratives Shape Experience, Expectations, and Social Change

Nancy Berlinger, Liz Bowen, Mercer Gary, The Hastings Center

Kate de Medeiros, Miami University

Darlingtona Esiaka, Rutgers University

Erin Gentry Lamb, Case Western Reserve University School of Medicine

Candidus Nwakasi, Providence College

Deborah Rose, Duke University Medical Center

This Roundtable session will explore the interdisciplinary study of cultural narratives about dementia. Though the health humanities often attend to personal narratives or narrative representations of dementia, the study of cultural narratives – the shared ideas and values that circulate within a society, a population, a health care profession, or public policy – is distinct. Understanding how cultural narratives serve as facilitators or barriers to justice-focused social change is increasingly recognized as part of equity-based research and practice. This session will explore how scholars and practitioners can work across disciplines to better understand cultural narratives about dementia, and how diverse communities affected by dementia may produce cultural narratives that counter or are influenced by dominant narratives.

This Roundtable is informed by an ongoing health humanities research collaboration among scholars based in age studies, bioethics, care ethics, disability studies, social gerontology, social work research, and other fields, including socially engaged initiatives for people living with dementia and for dementia caregivers. It is also informed by related empirical projects that concern narratives shared within professional cultures, such as those of clinicians responsible for the care of patients with dementia or health disparities researchers studying dementia in communities with higher incidence of this disease.

The eight panelists (seven discussants plus a presider) encompass significant diversity of age/career stage, race/ethnicity, and fields engaged in dementia research. They include four early-career scholars (disability studies, psychology/social gerontology, care ethics, neurology); one mid-career scholar (social gerontology), and three senior scholars (bioethics, health humanities [presider], social gerontology). Three participants are Black and have research interests focused on Black American and West African communities.

Our format encourages thoughtful, highly engaged discussion among panelists and attendees. After introductions that include summaries of the research collaborations and empirical studies described above, panelists will initiate discussion of selected scholarly or professional questions of broad interest to health humanities scholars and practitioners. Sample potential questions include:

- If one goal of critical humanities scholarship is to change how dementia is perceived by repairing flawed cultural narratives, how do we avoid minimizing or romanticizing the undeniably difficult experiences of living with dementia or providing dementia care?
- What narratives about experiences of living with dementia or of dementia caregiving are embedded in research agendas, including research focused on high-incidence populations or in regions beyond the Global North? How do research narratives shape experiences and expectations of people affected by dementia?
- How far can “cultural” comparisons stretch across socioeconomic differences, including how much a society invests in dementia care or expects families to pay for, manage, or provide?
- How should socially engaged dementia research or publicly engaged scholarship involve persons facing dementia (i.e., living with dementia or having elevated risk) in efforts to reframe, repair, or otherwise change public narratives about dementia?
- How can health humanities scholars and practitioners collaborate with social science researchers to foster and share innovative approaches to empirical research on experiences of individuals living with dementia or of dementia caregiving, including practices of networking and collaboration with on-the-ground social change efforts?

5B Panel: Caring In and Through Literature: Literary, Pedagogical, and Social Systems of Care

Brooke Kowalke, Matthew Reznicek, Creighton University

Ingrid Berg, University of Missouri and Creighton University

Introducing their *Care Ethics in the Age of Precarity*, Maurice Hamington and Michael Flower suggest that “care can be characterized as responsive inquiry, empathy, and action. Care is always a response to the particularity of someone’s circumstance that requires concrete knowledge of their situation, entailing imaginative connection and actions on behalf of their flourishing and growth” (p. 6). Applying the questions of care and care ethics to literary analysis, this panel explores the power of imaginative connection to the stories of individuals vulnerable within various systems and institutions. We argue that a literary analysis influenced by care ethics provides an important approach to understanding the medical questions within the texts and an important pedagogical technique to help students use literary narratives to re/imagine a better healthcare future. Approaching narratives from diverse historical moments and socio-cultural positions, we argue this care-based form of literary analysis reveals the ways in which care can challenge, undermine, and reframe social systems that depend upon racism, compulsory

heteronormativity and able-bodiedness, and neurotypicality. Recognizing the experience of care as central to selfhood, this approach demonstrates the necessity of care ethics to understanding selfhood beyond the text—especially within professionalized health care.

The individual papers on the panel demonstrate that we can make these transformative connections by reading a number of genres, including memoir, poetry, and fiction from the nineteenth century to the twenty-first. Speaker 1, focusing on Terese Marie Mailhot's *Heart Berries* and Stephanie Foo's *What My Bones Know*, will examine the potential of the illness memoir genre to draw attention to areas of healthcare that need an institutional overhaul. These memoirs provide opportunities for health care workers to reflect on how best to meet the needs of minority women burdened by the legacy of abuse and invisibility. Speaker 2 discusses how Molly McCully Brown's poetry collection, *The Virginia State Colony for Epileptics and Feeble-minded*, invites readers to create a caring relationship with the storytellers, to make an imaginative connection with them by deciphering metaphors and filling in gaps between the lines, and then to be challenged to take action on behalf of the speakers' metaphoric descendants who may still find themselves vulnerable to ableist perceptions and practices today. Tracing these concerns well beyond the twenty-first century, Speaker 3 argues that in Walter Scott's *The Black Dwarf* (1817), the disabled person is crucial to achieving the personal union of marriage and, moreover, is essential to quelling the Jacobite threat that undermines the stability of the political Union. The representation of health, illness, and disability refines our conceptions of citizenship and belonging, as well as our understanding of health and ability, in the early years of nineteenth-century Britain. Together, these papers suggest that reading through the lens of an ethics of care—and teaching others to do the same—allows us to find points of hope, to use connections within stories to spur readers to advocate and enact change on both individual and systemic levels.

5C PAPER SESSION: Social Media for Social Change

“#NarcanSavesLives: Digital Assembly and the Social Construction of a Public Health Intervention”

Allison Schlosser, Roma Subramanian, University of Nebraska Omaha
Kelli Boling, Ciera Kirkpatrick, Patrick Habecker, Valerie Jones, University of Nebraska Lincoln
Jessica Hample, University of Nebraska Kearney

Opioid-related overdose death continues to be a public health crisis in the U.S., reaching a new peak in 2021 with more than 100,000 people dying of drug overdose; 75% of these deaths involved an opioid. Naloxone, often distributed in the form of Narcan® nasal spray, is a medication that can be easily administered to prevent opioid overdose death. Yet this potentially lifesaving tool has generated controversy as it challenges the longstanding moral value of abstinence from drug use in the U.S. Thus, critics have framed Narcan as a “moral hazard” that encourages drug use. Social media platforms such as Twitter and TikTok have become key sites for such debates. These are digital social spaces in which individuals enact identities, build communities, and bond over shared experiences. They are also spaces in which dominant narratives and structural inequalities may be reproduced and/or challenged.

Interactions in these spaces contribute to the social construction of “addiction” and related interventions, including Narcan. Yet little research explores these dynamics. This presentation draws on semi-structured, open-ended interviews with 20 social media influencers who frequently post using the #narcansaveslives and/or #naloxonesaveslives hashtags. Drawing on interview narratives, we examine how individuals and communities assemble online to construct the meaning of Narcan and explore how their narratives reinforce and/or challenge stigmas associated with drug addiction. We also explore how structural inequalities and dominant narratives about Narcan are represented, reproduced, and resisted in online interactions, and consider the implications of these findings for future overdose prevention efforts.

“#TransTikTok: Filling the Void of Medical and Social Support for the Trans Community”
Trenley Anderson, Case Western Reserve University School of Medicine

There is increasing awareness that transgender people face healthcare inequities, health disparities, and structural discrimination that infiltrates healthcare spaces. While efforts to mitigate these issues have recently increased, discrimination and gaps in care remain. These injustices interweave with a history of anti-trans stigma, pathologization of gender variance, and insufficient education within the medical community—all leading to a mistrust of healthcare structures by trans individuals, left without ordinary avenues of care, information, and support. I argue that the trans community has navigated these structural holes by mobilizing to create a virtual community that helps to fill the void of support generally provided by healthcare, education, and social systems. Drawing from transgender studies, digital ethnography, sociological literature on patient groups, and my own experience as a member of the trans community, I present Trans TikTok as a communal model of wellbeing and health advocacy that brings to light the intersections between transgender medicine, trans culture, and queer social groups. Through a content survey and analysis of videos, I show that TikTok—with its hashtags, algorithms, accessibility, and universal reach—serves as a welcoming and effective platform for social support, storytelling, and information sharing. Trans TikTok reveals to those interested in social justice and healthcare equity several needs of the trans community that are unmet by the structures we have in place—thereby presenting priorities for change.

“Abortion Storytelling: #ShoutYourAbortion and Resisting Oppressive Narratives”
Kate Lafferty-Danner, Geisinger Commonwealth School of Medicine

Abortion storytelling can act as a powerful tool to resist and push against harmful legislation. The first public abortion storytelling event was the Redstockings Speak-Out in 1969, where women shared their stories of getting abortions to highlight the importance of legal and safe abortions. Over 50 years later, in 2015, as attacks to defund Planned Parenthood increased and harmful abortion legislation was consistently passed through, a new abortion movement was born. The #ShoutYourAbortion movement began online as a way to highlight the individual voices of those who have abortions.

This presentation will explore how abortion storytelling can resist the identities imposed on individuals by their oppressors. By crafting their own stories, individuals who have had

abortions can “reidentify” themselves in ways that are respectful and counteract more negative associations with abortion. By using social media, primarily Twitter, #ShoutYourAbortion attempts to destigmatize and normalize abortion in American culture, working to combat the negative associations related to abortion and those who have them. The sharing of individual abortion narratives provides unique perspectives on the abortion debate, especially when shared publicly on social media sites, and can perhaps aid in eliminating some abortion stigma within American culture.

5D PAPER SESSION: Addressing and Assessing Health Equity in Pre-Health and Medical Education

“Health Humanities Education and Students’ Health Equity Choices in Career Path: A Qualitative Outcomes Study”

Kiana Fields, University of Louisville

Sarah Berry, Connecticut College

Recently, bodies like AAMC have called for health equity education in medical training. Simultaneously, the effectiveness of structural competency training at the baccalaureate level has been demonstrated (Metzl et al. 2018). Yet there are few studies of health equity pedagogy in health humanities education, and none, to our knowledge, measuring the impact of baccalaureate health humanities training on health equity proficiency on post-baccalaureate healthcare work or professional training. We conducted a qualitative study to assess outcomes of early exposure to medical and health humanities (MHH) training in a pre-health clinical internship focused on health disparities in regional communities. We hypothesized that pre-health MHH education in a baccalaureate clinical internship program increases involvement with health equity work (including choice of further education, leadership roles, community building, and career plans) after participants complete the program. Through purposive sampling, we used one on one interviews with former participants to collect data. Specifically, we aimed to identify what impact the program had on participants’ knowledge of critical concepts (e.g., disparities and social determinants such as race, region, and rural contexts); value-based decisions regarding subsequent medical education or career pathway; self-efficacy; and post-program likelihood to address inequities in health/care. Our study shows positive outcomes for participants in each area, suggesting that baccalaureate MHH training increases investment and confidence in continuing equity work in medical school and healthcare jobs. Moving forward, we hope to expand this study through collaboration with other programs to collect more outcomes data and to broaden this intervention.

“Student Perceptions: Assessing Impact and Informing Development of a Medical Humanities and Health Equity Curriculum”

Elizabeth Torrez, Schuyler L. Gaillard, Marcela Campoli, Lakshmi Krishnan,

Georgetown University School of Medicine

Medical humanities encompass a wide range of topics, from medical ethics to the history of medicine and contextualizing modern-day health inequities. As awareness of

structural problems in healthcare increases, so does the public's motivation to recognize and change structural inequalities. Medical humanities courses offer the opportunity to increase awareness and understanding of systemic challenges in medicine and introduce more students to the field. Georgetown University has recently launched an intercampus Medical Humanities Initiative, with curricula for undergraduate and healthcare professional graduate students; however, evidence-based practices to guide intentional improvement and expansion are necessary. Undergraduate and graduate students who participated in Georgetown University medical humanities courses were invited to participate in student-moderated peer focus groups. During these sessions, moderators assessed student perceptions of medical humanities, including relevance, significance concerning the personal field of study and professional development, the importance of allopathic medical doctorate education, areas for curricular improvement, and commitment to social justice. In this paper, we present diverse student perceptions of medical humanities, emphasizing the role medical humanities plays in informing student perceptions and engagement in social justice and health equity. These perceptions are crucial to guiding professional educators on how better to engage current students in the field of medical humanities and to inform the Medical Humanities Initiative on improvement opportunities.

“Developing an Asian American and Pacific Islander (AAPI) Health Curriculum for Medical Students in the COVID-19 Era”

Isabela Bumanlag, Megan Jiao, McGovern Medical School, The University of Texas Health Science Center at Houston

The COVID-19 pandemic has exacerbated preexisting health inequities, particularly pertaining to race and socioeconomic status. Asian American and Pacific Islander (AAPI) health continues to be overlooked in medical school curricula despite recognition of racism as a public health threat by the American Medical Association and the dramatic rise in anti-AAPI violence and xenophobia attributed to the pandemic. To address the dearth of AAPI health education, we developed and implemented a student-run elective at a large medical school in Houston, Texas, one of the most diverse cities in the United States.

The elective primarily targeted preclinical students to engage them in productive conversations on contemporary AAPI health-related issues early in medical school. Sessions consisted of lectures, panels, and workshops addressing AAPI health disparities, advocacy, identity, and cultural practices. We recruited lecturers from our own institution and beyond to provide expertise from the perspective of practicing physicians, researchers, and policy advocates. Additionally, we collaborated widely with minority student organizations as well as diversity and inclusion administration for effective outreach and intergroup allyship.

Based on course evaluations, student reception to the elective was overwhelmingly positive. The elective is currently in a new iteration for this academic year under a new cohort of student leaders, with plans of renewing the course annually. Given the success of the elective, our curriculum can offer a blueprint for other institutions to adapt to their respective contexts and continue spreading awareness on AAPI health issues, ultimately equipping future physicians to better address them at the national level.

5E PAPER SESSION: Pragmatic Solidarity for Health Equity

“Towards an Ethic of Accompaniment in Surgery”

C. Phifer Nicholson Jr., Monica Bodd, Duke University School of Medicine/Duke Divinity School

Ellery Sarosi, Michigan Medical School/Duke Divinity School

Martha Carlough, UNC Gillings School of Public Health/Duke Divinity School

Surgical ethics as a discipline focuses on the nature of consent, surgical decision-making, and research ethics. Although important, these questions often fail to address questions regarding racial and economic disparities that deeply impact health care. Yet, recent movements to consider social justice in surgical care mostly call for increased diversity within the ranks of the surgical profession, failing to center the questions of surgical and health care equity in the agency of the communities most directly affected by injustice. Accompaniment is an ethic born from Latin American liberation theology and Latinx theology that has been shown to improve health outcomes in those at the margins through its emphasis on listening, solidarity against systemic drivers of disease, and proximity to individuals and communities. It was brought to bear on medicine through the thought and work of the late Paul Farmer, and powerfully demonstrated in organizations like Partners in Health that seek to improve health equity through “pragmatic solidarity.” However, accompaniment within healthcare has generally been applied to chronic and communicable disease management. It has far fewer prior applications to the world of surgical care. In this paper we argue that an ethic of accompaniment offers a framework to address the more traditional questions of surgical ethics, the problem of health disparities and structural violence, as well as challenge the relational and epistemological distance between surgeons and patients that reinforces these disparate realities.

“Envisioning Pragmatic Solidarity in Health Care Through the Lens of Ollas Comunes in Peru”

Michael Gilbert, Duke University

It is well known that food insecurity and malnutrition are urgent global health concerns that disproportionately affect marginalized populations. In response to such issues being exacerbated by the COVID-19 pandemic, there has been an emergence of Ollas Comunes (OCs) — Common Pots — in impoverished Latin American communities. OCs are grassroots community kitchens that provide meals and a sense of solidarity to individuals and families living in poverty. As collective support networks operating out of necessity and as a means for social justice, OCs actively combat disparities associated with social determinants of health.

Pushed to the outskirts of Lima, Peru, and the margins of society by political, economic, and social forces, Collique is a shantytown consisting of over 200,000 migrants. To alleviate the effects of poverty here, Operación San Andres (OSA), a nonprofit organization, has been providing holistic (physical, emotional, and spiritual) care to Collique for over 20 years. With OSA’s support, Collique’s community members have established and operated over 60 OCs since March 2020. The work of Collique’s OCs, along with OSA’s support, exemplify “pragmatic

solidarity,” a framework that works towards improving access to quality health care for all. This paper will explore pragmatic solidarity through the lens of the holistic care provided by OSA in Collique’s OCs during the pandemic to offer an encouraging example of how communities can and have assembled to improve health outcomes and foster a sense of belonging and dignity.

“Designing Health Justice: COVID-19, ‘Racial’ Disparities, Sociogenomics, and Beyond”
Rosalynn Vega, The University of Texas Rio Grande Valley

This presentation, drawing from 27 months of digital ethnography and my experience as Program Coordinator of Medical and Health Humanities at the University of Texas Rio Grande Valley, uncovers calls for collective action and structural change among functional medicine providers and explores pedagogical strategies for educating future healthcare leaders on the relationship between structures, health, and disease. I turn to public discourse among doctors who are actively critiquing how systemic racism—in the healthcare system and beyond—set the stage for disparate exposures and outcomes during the COVID-19 pandemic. Specifically, the ongoing pharmaceutical management of chronic disease and toxic environmental exposures disproportionately placed people of color at risk for poor COVID outcomes, including death. The providers I observed simultaneously emphasize sociogenomics—the potentially healing effects of community on genomic expression—thus emphasizing the biological imperatives behind collective action. Ultimately, this presentation traces how the functional medicine community began to mobilize in response to disparate health outcomes and racial violence to identify pedagogical opportunities for the medical and health humanities. How do we train future healthcare providers, leaders, administrators, and champions who are equipped to dismantle structural inequality and systemic violence? How do we design Health humanities programs that provide the intellectual resources for creating health justice in the future?

5F WORKSHOP: Deconstructing Systems: An Art-Based Approach to Inequities in Health

Corinne Zimmermann, Corinne Zimmermann Consultancy
Kamna Balhara, Johns Hopkins University School of Medicine

Inequities in health and healthcare are dictated by individual bias and entrenched systemic and structural forces. While visual arts-based approaches have been frequently applied as a means by which to challenge personal biases and assumptions, the use of art as a pedagogical framework to interrogate systems is less common. In this highly interactive workshop, presented by a museum educator with expertise in health professions education and a physician who works on issues in health equity, we will explore how art can be a powerful mirror and lens by which to understand, critique, and dismantle individual and systemic contributors to disparities in healthcare. We welcome all participants including clinicians, health professions educators, scholars and researchers, as well as anyone curious about the use of museum-based strategies in the service of healthcare and/or systems.

The workshop will include an introduction to museum-based methodologies such as the Visual Thinking Strategies (VTS) and Thinking Routines developed at Project Zero, Harvard University; large and small group discussion; and individual reflection. Systemic change is complex and can seem insurmountable. Through this workshop, participants will discover

concrete strategies that can help break down various components of systems, enabling us to imagine concrete actions and solutions.

Participants will not only have the opportunity to think creatively and critically in collaboration with colleagues attending the workshop, but will also leave the workshop with an understanding of how the demonstrated approaches can be used as an educational tool for broad audiences as well as a method of scholarly inquiry about the sociocultural determinants of health.

Concurrent Sessions 6 – Saturday, March 18, 2:45-4:00 p.m. EDT

6A FLASH SESSION: Education

“Use of Narrative Medicine as an Education Tool at Different Levels of Medical Education”

Shwetha Bindhu, Case Western Reserve University School of Medicine

Narrative medicine, as a discipline centered on bridging gaps in communication within healthcare, can be a powerful tool in improving medical education. In the era of increased patient autonomy and emphasized shared-decision making models, mastering these skills is essential in building fruitful patient-physician relationships.

However, the implementation of narrative medicine lessons is not consistent across the transition from pre-medical programs to medical school to residency. Therefore, in this flash presentation, I will present the design for a research study quantitatively and qualitatively analyzing narrative medicine pedagogy used by institutions at different levels of the physician training process.

The goals of this study would be to 1) identify programs at the undergraduate, medical school, and residency levels that implement narrative medicine pedagogy and 2) analyze how this education is conducted (through courses, lectures, clinical practice, etc.). Such research goals offer a better understanding of how students are taught narrative medicine as they move from the realm of broad inquiry at the collegiate level to clinically focused inquiry at the post-graduate level and beyond.

“Developing Collaborative Competencies in Interprofessional Trainees through a Visual Arts-based Observation Activity”

Nicholas R. Mercado, University of Rochester School of Medicine and Dentistry

Aleena Paul, New York Medical College School of Medicine

Lauren Block, Gabrielle Goldberg, Donald and Barbara Zucker School of Medicine at Hofstra/Northwell

Barbara DeVoe, Hofstra Northwell School of Nursing and Physician Assistant Studies

Nancy Richner, Independent Art Museum Educator

Trainees in healthcare professions must be prepared to work collaboratively to care for patients and families in our complex healthcare system. It can be challenging to develop interprofessional education (IPE) curricula that engage learners with varying levels of experience. Humanities and arts-based activities can improve learners' powers of observation, communication skills, team-building skills, and build self-awareness. This pedagogy has not been commonly used with interprofessional learners. We developed an innovative art of observation session for over 400 interprofessional healthcare trainees.

Each 90-minute session consisted of a large group visual arts-based observation activity facilitated by an art museum educator, followed by small group interprofessional discussions with 8 learners and 2 facilitators. Groups explored how their observations were influenced by personal, cultural, and professional identities, and how lessons learned applied to their work. After the session, students were invited to complete a retrospective pre/post-survey including items adapted from the Interprofessional Collaborative Competency Attainment Survey (ICCAS).

80% of 211 respondents agreed or strongly agreed that "the art of observation activity is an effective means of starting discussions with interprofessional teams." Learners' rating of their interprofessional collaborative abilities significantly improved [before (M=45.73, SD=8.05); after (M=51.46, SD=7.97) ($p < .001$)]. Qualitative analysis of learners' takeaways identified themes of open-mindedness, hearing other opinions and perspectives, collaboration/teamwork, patient-centeredness, and awareness of biases.

The visual arts can be a valuable tool in IPE with learners of varying experiences. The integration of the health humanities into IPE activities with learners from diverse disciplines is feasible and helpful for developing collaborative competencies.

"Local Impact of a Global Pandemic: Health Inequities & COVID-19"

Yujia Song, Tina Reid, Salisbury University

The COVID-19 pandemic provides an invaluable opportunity for students to understand the local impact of a global health crisis, especially the challenges ranging from health care disparities to difficulties in delivering and accessing health services. An Interprofessional Education (IPE) Experience was developed for students to not only learn from local experts on these issues, but also from their peers in other disciplines.

The two-hour event began with a keynote lecture by a local healthcare expert, who discussed the local hospital's COVID response including testing and vaccinations and the lessons learned about inequities because of lack of access; barriers to access such as language, Internet access, and transportation; the disproportionate impact on shift workers in essential sectors such as poultry processing; and how the hospital worked with the Vulnerable Populations Task Force to reach the most disadvantaged communities. The lecture was followed by a presentation by a leader of a community organization that serves immigrant workers. Based on the information given and drawing on knowledge, skills, and perspectives from their own disciplines, students then discussed the moral and social problems in the case, stakeholders and parties responsible for the problems, and the roles their respective professions play in local public health concerns. Additionally, they explored the ways in which health outcomes could be improved and what they learned about other disciplines from the discussions.

Our study aims to evaluate the effectiveness of an IPE event in promoting IPE competencies: roles and responsibilities, ethical practices, conflict resolution, communication, and collaboration/teamwork.

“How to Integrate Arts and Humanities Resources into Existing Medical Curricula”

Shannon Fang, Case Western Reserve University School of Medicine

Health humanities is often integrated into medical education to increase perspective-taking, empathic understanding, and social advocacy. However, many of the pedagogical practices for incorporating arts and humanities require trained personnel, extensive programmatic time, or additional funding. Further, many health humanities approaches take the form of specialized courses or seminars, which are often self-selective and do not engage the entire student body. In this flash presentation, I describe how I, as a second-year medical student, collaborated with faculty at my medical school to integrate arts- and humanities-based resources into existing weekly seminars in the medical school curriculum to promote cultural humility among all students when treating diverse populations. I will present an example of the changes made to the LGBTQI+ Healthcare seminar, including incorporation of written narrative and graphic medicine resources with discussion questions. Particularly, I will focus on the methodology of identifying gaps in the curriculum, exploring humanities resources, and generating discussion questions. Additionally, I provide examples of how this process is replicable and may be extrapolated to medical curricula at other schools to incorporate health humanities. Cultural humility is a key aspect of providing high-quality, culturally-competent care, which is foundational for addressing health inequities. Discriminatory structures within hospital systems and communities intersect with individual identities to affect one’s health and health care. These factors generate a widely diverse patient population with varying needs, which health professionals must learn how to care for. I argue the universal integration of health humanities curriculum can help build cultural humility in healthcare professionals.

“Diversifying Diversity Curriculum”

Nathaniel Davis, Case Western Reserve University School of Medicine

One reason that systemic racism exists within the US healthcare system is inadequacies in medical student diversity curriculum. Research shows many medical students feel unprepared to treat diverse populations, and the health outcomes of minority populations suggest that physicians are doing a disservice to those communities. While our diversity curriculum addresses populations defined by race and ethnicity, sexuality and gender, ability, and more, it does not reach beyond biomedicine itself. I argue that a lack of exposure to and training with non-traditional medicine poorly prepares medical students to treat certain minority populations. The Hmong population is one example of an underrepresented minority within medicine who suffers poor health outcomes in many major categories including cancer mortality, rates of infectious diseases such as hepatitis B, rates of chronic disease such as diabetes and hypertension, and screening for primary prevention. Previous research demonstrates specific cultural beliefs in the Hmong population such as reluctance to undergo surgery and hesitancy to adhere to Western medicine that exacerbates these problems. As

globalization continues, and as our society becomes increasingly medically pluralist, training physicians better prepared to address healthcare issues facing populations with diverse approaches and relationships to healthcare becomes increasingly important. Through the lens of the disparities and healthcare outcomes associated with the Hmong population, I will describe ways in which our current medical education system poorly prepares us to treat populations that do not strictly adhere to traditional Western medicine and propose possible solutions to train more well-rounded physicians.

“Empowering Trainees to Confront Structural Ableism in Medicine: A Curricular Approach”

Perna Mamileti, Independent Scholar

Devika Nandwana, Case Western Reserve University School of Medicine

The medical model of disability is the dominant lens through which disability has been conceptualized among healthcare professionals. This model views disability as an individual, medical deficiency that necessitates rehabilitation or medical treatment to bring disabled individuals closer to what is deemed “normal.” Frequently, medical education presents disability solely within the context of clinical pathology, resulting in internalized ableism among trainees. While disability has been recognized as a necessary dimension of diversity, equity, and inclusion, few medical schools have implemented specific disability curricula or standardized education on anti-ableism.

Here, we propose a preliminary curricular outline for anti-ableism in medical education consisting of three essential components. First, we provide students with a clear definition of ableism in order to deconstruct the stark dichotomy between able-bodied and disabled individuals. Second, we delineate specific mechanisms of ableism in medicine and enable students to recognize disability injustice in their own clinical practice. Finally, we suggest the implementation of workshops or longitudinal care experiences where disabled patients are involved as educators who share their lived experiences. With this curriculum, we hope to provide a comprehensive framework for medical students and physicians to understand and challenge ableism in their clinical practices and improve healthcare delivery for disabled patients.

“Exploring Challenges in Health Humanities Through Medical Readers’ Theater”

Cheryl Dellasega, Lisa Erdman, Roberta Chardulo Dias de Andrade, Daniel George, Kayla Krause, Penn State College of Medicine,
John Messmer, Penn State Health

Background: Medical Readers’ Theater (MRT) offers a novel approach for exploring professional challenges from a humanities perspective. For this reason, Dr. Todd Savitt (2002) curated and scripted a selection of stories to be used as MRT for medical student and health care professional education.

Aim: To further examine the use and impact of MRT, “A Face of Stone,” by the physician-poet-author William Carlos Williams was selected. The script was chosen because it portrays a difficult patient-physician scenario framed by bias around immigration and class.

Although the story takes place between WW1 and WW2, these tensions continue to present themselves within present-day medical environments

Process: The MRT was presented to aa Schwartz Center Rounds (<https://www.theschwartzcenter.org/>) which attracts a robust audience of diverse health care professionals. After dramatizing the 20-minute script, actors remained in their roles for a Talkback session. Prejudice, miscommunication, fear, interpersonal power dynamics, and love were identified as themes.

Outcomes: The use of MRT allowed for a safe and humanistic space to explore patient-provider dynamics. For the actors, playing the roles of a vulnerable patient, a protective husband, and a harried physician prompted deeper insights to the patient-provider dynamic. Standardized evaluations of effectiveness as well as feedback from the actors and audience illustrate beneficial outcomes specific to MRT.

Conclusion: MRT provides a safe “third space” (Leavy, 2020) that can foster the development of insight and engagement around challenges experienced by practitioners of the health humanities and the people they serve.

6B PANEL: The Power of Health Narratives to Illuminate Social Structures and Lived Experiences

Kristine Muñoz, Janet Weaver, University of Iowa

Daena Goldsmith, Lewis & Clark College

Brian Park, Elaine Waller Uchison, Pam Pierce, Elizabeth Lahti, Oregon Health & Science University

Janet Weaver, University of Iowa Libraries

It is a central tenet of the health humanities that stories about health matter. The contemporary fascination with memoir and the explosion of online platforms for storytelling make health narratives widely available; yet not all voices are equally heard based on social identities (e.g., race/ethnicity, gender identity, ability). It can be difficult to find stories from structurally excluded groups or of counter-narratives, which may complicate restoration and resilience themes or implicate health disparities and systemic discrimination. This panel responds directly to the conference call to explore the stories people tell about the relationships between social structures and lived experiences of health, illness, healing, and disability.

The projects on this panel invite and make available health narratives, including stories that are structurally silenced, ignored, or misunderstood. By collecting and archiving stories, creating digital libraries, and sharing teaching resources, these panelists make narratives accessible to teachers, community leaders, clinicians, and healthcare professionals. There is power in amplifying the voices of those who go unheard; to model co-conspiratorship by expressing: “Your story matters. We want to make space for it so others can hear it.” Incorporating these narratives into education, professional training, and clinical practice can humanize health care practice. Collections of stories can reveal broader systemic patterns and points of intervention.

Our panelists will: describe how they invite, find and make available stories that might otherwise be overlooked or forgotten, and the practical and ethical challenges they encounter; demonstrate what is available in their collection; and engage the audience in discussing how

these projects can illuminate connections between social structures, individuals, and communities in regards to health, wellbeing, disability, and illness.

HEALTH STORY HUB (Muñoz and Goldsmith) provides resources for teaching health narratives in English and in Spanish. It includes a searchable database and a portal for sharing narratives (written fiction, non-fiction, poetry; audio and video recordings; images; links to websites and social media) and teaching materials (syllabi, assignments, workshop outlines, lesson plans, community programming).

POWER WITH ANTHOLOGY (Park and Uchison) is a collection of multimedia stories that highlight the lived experiences and perspectives of community members, patients and healthcare workers most impacted by harmful, “power over” structures in and outside of our healthcare systems. The project also focuses on stories that imagine what a system that embraces a “power with” dynamic might look like.

THE ACCESSIBLE NARRATIVE MEDICINE DIGITAL LIBRARY (Pierce and Lahti) is a program in three parts. The first is the creation of an inclusive digital narrative medicine library featuring creative work by BIPOC, LGBTQ+, and persons with disability and curriculum that incorporates those works; the second is making the library available; and the third is utilizing the library in facilitator trainings and community workshops.

The IOWA WOMEN’S ARCHIVES (Weaver) preserves primary source materials, including oral histories relating to Iowa Latinas/os, their families, and organizations. Many IWA collections relate to health, well-being, disability, and illness and the Archives collaborates with communities and school districts across Iowa to develop public programs and build instructional resources for K-12.

6C PANEL: Equity, Diversity, and Inclusion in Healthcare Education: A Longitudinal Health Humanities Approach

Sarah L. Berry, Connecticut College

Charlene K. Green, University of California, Davis and Los Rio Community College District

Kamna S. Balhara, Johns Hopkins University School of Medicine

Elianna Sanchez, New York Institute of Technology College of Osteopathic Medicine

Overview: The HHC has recently made strides in developing practices of equity, diversity, and inclusion (EDI). These efforts include new areas of scholarship in JMH and other journals, an inclusive range of presentations, speakers and themes at conferences, and two new committees (EDI and Arts & Health Equity). In addition, new projects on curriculum and placement of health humanities graduates aim to chart the current landscape and demographics of the field. Given this growing emphasis on diversity and inclusion within the organization as well as the well-suitedness of health humanities inquiry to address pressing needs for equity in healthcare, we are primed to begin investigating best practices in equity, diversity, and inclusion across the continuum of education. This panel addresses EDI work in health humanities longitudinally, from the baccalaureate level as preparation of and support for a diverse student body, to holistic medical school admissions processes, through educational interventions in graduate medical education. The longitudinal arc of this panel ultimately moves toward a call for creating an interprofessional community of practice. A health humanities evidence-based set of shared

best practices, we propose, can be an effective way to create a more diverse healthcare workforce and positively impact health equity.

Panelist 1: Opens the panel with an overview of ways in which the health humanities supports EDI work at two levels: 1) possibilities for leveraging baccalaureate and masters' data from health humanities programs nationally to increase student/trainee diversity; 2) developing curriculum and pedagogical training to support diversity in training and the workforce, in order to impact health equity through provider diversity and equity training. This provides a context for a call for longitudinal study of EDI work in health humanities; the next panelists offer fuller perspectives at each level.

Panelist 2: Continues the arc with evidence-based best practices for medical school holistic admissions driven by workforce needs, including recruiting and training providers from underserved communities and advancing health equity through culturally-consonant care.

Panelist 3: Continues the arc by sharing her experiences of navigating into and through the medical education system, an unfamiliar concept in her Latina family, which gives insight into the struggles that underrepresented and minority students face. She also shares what opportunities and tools have been useful on this journey, especially sustained mentoring that builds a relationship attuned to a student's specific needs, talking through steps, creating a plan, and support through the application and writing stages.

Panelist 4: Completes the arc with a look at how the health humanities provide an ideal framework for education around anti-racism, health equity, and social determinants of health within an interprofessional environment, using illustrative examples from graduate medical education to describe aims, implementation, and outcomes.

We conclude with brief comments on moving toward creating a community of practice and evidence-based longitudinal study of EDI work in health humanities education. We then facilitate discussion with the audience around questions of EDI work at the intersection of health humanities at other institutions, ideas for sharing data and best practices, and ways in which health humanities education can become a strategy for advancing health equity and health justice in our communities, healthcare settings, and the professions.

6D PAPER SESSION: Care, Story, Identity, and Social Change

“Exploring Caring Through Story: The Meaning(s) of Relationships Between “Essential Caregivers” and People Living with Dementia in Long-Term Care”

Melanie Lalani, University of Toronto

The COVID-19 pandemic brought strict visitation protocols of unprecedented duration to long-term care (LTC) homes as part of infection prevention and control policies. In Ontario, Canada, at their most extreme, protocols only permitted scheduled phone or virtual visits with residents, the occurrence and length of which were subject to the availability of electronic devices, wireless technology and overburdened staff. Critiques of these restrictions have importantly identified concerning health impacts of social isolation on residents, which contributed to revised protocols that enabled carers designated as ‘essential’ to visit LTC residents, albeit still following strict public health measures. Following these reforms, there has been little exploration of the experiences of essential carer visits with residents of LTC, leaving much unknown about how caring as an intersubjective, reciprocal and embodied phenomenon

is expressed and experienced by family during the ongoing COVID-19 pandemic. In this paper, I draw on insights from narrative inquiry to explore these experiences. Stories drawn from this methodological approach enable us to see a complexity and richness of caring that challenges the one-dimensional tragedy narrative that has been predominant in analyses of visitation protocols. To this end, exploring experiences of caring through stories offers a powerful resource to challenge prevalent perspectives, potentially inform visitation policies in future outbreaks, and to contribute new understandings of the very nature of caring.

“LGBTQ Aging: Pandemic Narratives through Poetry”

Al Ogawa, Stephanie Clark, University of Rochester School of Medicine and Dentistry

Historical and modern discrimination have contributed to present day health disparities for LGBTQ+ older adults. Resulting differences in family, community, health and wealth along with intersections between race, class and disability often place LGBTQ+ older adults in vulnerable positions easily exacerbated by the Covid-19 Pandemic. Despite this concern, little elaboration is available of this population’s lived experience, health and wellbeing during this time.

Story-telling and story-listening are key to improving health inequity and promoting social change. This creative presentation employs storytelling through mixed medium (poetry, photography, and prose) to explore how LGBTQ+ older adults’ life narratives were both shaped by and formative of their experience during the pandemic. The creative work is based on (IRB exempted) qualitative research and creative reflection done through semi structured interviewing of 30 LGBTQ+ older adults in New Mexico during 2021-2022. The poet-medical-student-researcher will interweave stories generously shared during research with their own personal narrative, reflection, and learning. This is couched within a larger bio-psycho-social commentary that highlights themes of resilience, grief, and community. The goal of this creative presentation is not to build a singular narrative of LGBTQ+ aging during disrupted times, but rather to push against the commonly cited experience of unbridled vulnerability told in the medical literature.

“Metagnosis: How Retrospective Revelations Empower Individuals to Mobilize and Transform Structures of Health and Identity”

Danielle Spencer, Columbia University

In *Metagnosis: Revelatory Narratives of Illness and Identity* (Oxford UP, 2021) I coined the term “metagnosis” to describe the revelation of a long-standing undetected condition. This may occur with diagnosis of some previously un-detected pathology, such as becoming aware that one is colorblind, or when diagnostic boundaries have shifted, as when an adult realizes that they meet the current criteria for ADHD. As Charles Rosenberg describes, “in the act of diagnosis, the patient is necessarily objectified and recreated into a structure of linked pathological concepts and institutionalized social power,” and a sudden metagnostic revelation illuminates this transformation. It often effects a change in the terms of knowledge,

productively unsettling categories such as health, impairment, disability, and pathology, enabling the individual to re-define them.

Here I look beyond individual diagnosis to explore ways in which metagnosis empowers individuals to mobilize and transform structures of health. What are the effects of surprising genetic revelations, and the implications for our understanding of identity? How can we leverage individual experience to resist genetic determinism? How does metagnosis offer a framework to understand the illumination of longstanding societal inequities, such as the disease of systemic racism? How might we explore these effects through popular fiction and film?

We must all strive to be better readers and find new ways of bringing lived experience and structural competency into conversation with healthcare. As literary movements such as metafiction expose the fallacies and limitations of literary realism, metagnosis constructively exposes medicine's realist claims as a profoundly liberatory practice.

6E PAPER SESSION: Psychiatry and Politics

“Politics in and of the Clinic: Public Psychiatry and the Anglophone Crisis in Central Africa”

Elizabeth Durham, University of Michigan

This paper examines the impact of political violence on the provision and experience of public healthcare in Yaoundé, the mostly Francophone capital city of the Republic of Cameroon. Since late 2016, the Republic has been engaged in an armed conflict, commonly known as the Anglophone Crisis, with secessionists in the country's two English-speaking administrative regions of Northwest and Southwest Cameroon, which many secessionists claim as the independent Republic of Ambazonia. Drawing on 24 months of anthropological fieldwork from 2016 to 2019 with patients and clinicians at the Republic of Cameroon's flagship public psychiatric hospital, I walk the audience through four key questions. First, how have extraclinical political conditions shaped patients' attitudes and access to public psychiatric services, including those of patients living in active conflict zones and those of English-speaking patients faced with a largely French-speaking team of psychiatrists? Second, how have clinicians taken these conditions into account in their hospital encounters? Third, how has the Republic of Cameroon sought to hold clinicians accountable as state employees, and to instrumentalize public psychiatry in a moment when “the public” is a particularly unstable collective? Fourth and finally, how has the Anglophone Crisis driven patients and clinicians—on their own and in tandem—to rethink the limits and possibilities of clinical practice, as well as the internal and external politics of psychiatry itself?

“Beyond Mental Health: Psychotherapy as a Moral and Political Technology”

Ulrich Koch, George Washington University

Mental health is again a matter of politics. Recent events have not only brought into view unmet mental health needs but also glaring gaps and inequities in the provision of mental health care. The relation between mental health treatment and politics has long been

contentious, however. Clearly, more than treatment is needed to meet the current mental health crisis. Indeed, some critics argue that the narrow focus on “mental health problems” distracts from the systemic and structural issues the SARS-CoV-2 pandemic has exposed, and effectively individualizes and de-politicizes the social problems that cause mental suffering. This line of criticism is not new. To challenge the idea that the turn to psychotherapy and psychiatry inadvertently has a depoliticizing effect, the paper roughly sketches the contours of the recurring debate concerning the societal function and cultural impact of the ‘psy’ disciplines. Critical Theorists (Adorno, Marcuse, Jacoby) first pointed to psychotherapy’s supposedly conformist tendencies and the “social amnesia” it may foster. Whereas others have problematized the self-absorption psychotherapy arguably promotes (Rieff, Lasch). More recently, critics suggested that psychology has been complicit in establishing neoliberal forms of governance (Rose, Sugarman). Yet there is also another, often overlooked, current that stresses the ethical nature of psychotherapy (Szasz, late Foucault, Cushman). Building on the observation that psychotherapy is an inherently ethical undertaking and has often served as a site of politics in the past, the paper closes by surveying the possibilities, challenges, and dangers of employing psychotherapeutic practices to politically “mobilize selves”.

“Inpatient Psychiatric Unit Design: A New Role for the Medical Humanities”

Grayson Holt, Case Western Reserve University

Jeffrey Zabinski, Columbia University Irving Medical Center

From asylums to modern inpatient psychiatric units, the architecture of facilities that treat patients with mental illness is often overlooked, yet has a significant role in creating an environment that encourages or discourages healing. Current inpatient psychiatric design often creates an atmosphere of detention rather than rehabilitation, reinforcing the oppression of those it aims to serve. In this paper presentation, we show how the often punitive environment of current inpatient psychiatric unit design may contribute to worse patient outcomes, disproportionately affect marginalized communities, and represents a call to action for the medical humanities. Individuals with bipolar disorder and schizophrenia are ten times more likely to be in a correctional setting than a hospital bed. Therefore, when hospitals greet patients with dull grey metal doors and security dressed like correctional officers, these conditions are further stigmatized. This effect is compounded for minority populations, particularly Black Americans who are overrepresented in psychiatric emergency rooms, but underserved in voluntary, community-based mental health facilities. The medical humanities are uniquely positioned to bridge gaps between disciplines, welcoming new perspectives to inpatient psychiatric design while still centering the voices of those being served. Uniting the arts, humanities, and social sciences around inpatient psychiatric design could create new solutions. Given the characteristics of psychiatric patients served in an inpatient setting, safety concerns are of the utmost importance, but this can be done with compassion. The medical humanities can honor the safety needs of staff and patients while finding ways to humanize psychiatric treatment and restore dignity.

6F WORKSHOP: Parallel Play: How Humanistic Science Labs Brings Faculty Together to Increase Teaching Satisfaction, Improve Student Outcomes, and Disrupt Healthcare Education (In a Good Way)

Jeremiah Davie, Joshua Gooch, Gina Camodeca, D'Youville University

Briana Jegier, Baptist Health Sciences University and D'Youville University

We believe that the COVID-19 pandemic proved health inequity itself is a plague and interventions at the individual level are insufficient. How, then, do we intervene at the systemic level in healthcare education to address health inequity? We argue that we must create systemic disruptions in healthcare education and offer case studies from our curriculum at an historically liberal arts university whose programs are primarily healthcare professions, including nursing, pharmacy, health services administration and pre-graduate medical pathways into programs like physical therapy (DPT). A recent redesign of core competencies for students incorporated Liberal Arts Learning Labs (LALL). LALL represent integrative educational offerings that combine introductory level discussions of contemporary topics in science and medicine yet remain grounded in humanist-focused contexts. Each course includes a thought-lab component (3 + 1 credit model). We have previously demonstrated that these courses provide an educational foundation that increases student retention and persistence. In 2021, we developed a pre-med/healthcare professions program (BS/BA) that builds on the LALL. The goal is to integrate science and humanism at all levels of a pre-medical undergraduate education. In this presentation, we will describe several LALL (e.g. B.O.O.B.s – Breasts: Objects or Biology, Graphic Medicine, Care Work, The Black Death) offered in the past 24 months. The LALL paradigm fosters holistic, multidisciplinary research collaborations that are not commonly feasible in traditional reductionist approaches and foster the career prospects of marginalized faculty in smaller departments or academic units.

We will provide artefactual evidence of student submissions and their success at achieving varying levels of mastery in corresponding learning outcomes, including critical thinking and scientific reasoning, through intentional creativity. Our approach is adaptable: we pair faculty from disparate disciplines and give them a common object of health concern (e.g., Death), then task them with a didactic and an applied course structure in which students will approach the subject matter in creative discomfiting ways. The presenters will supply example curricular materials to support the implementation of the LALL concept at interested institutions. Supporting materials will include examples of the usage of cartooning to demonstrate scientific reasoning and interpretation of data, as well as integration of traditional wet-lab STEM exercises to specifically support multidisciplinary humanities courses. We will also present examples of structured and unstructured critical creative projects to foster critical thinking skills, such as:

- group videos where students imagine an economy that better values care work,
- “unessay” projects that allow students to work across disciplines and in a variety of forms to make meaningful connections in their learning, and
- graphic medicine comix in which students conduct thought experiments.

We hope workshop participants will leave this workshop with outlines for LALL course proposals and the urge to create systemic disruptions at other institutions.

Concurrent Sessions 7 – Sunday, March 19, 9:00-10:15 a.m. EDT

7A FLASH SESSION: Clinicians, Patients, and Identity

“Race and Medicine in the Physician Memoir: Stories and Silences”

Marie E. McAllister, University of Mary Washington

This paper examines what physician memoirs have to say about the intersections of structural racism and medicine.

The physician memoir is a popular genre read by aspiring pre-meds, fellow practitioners, and ordinary readers. Yet a study of 40 representative memoirs by U.S. doctors published during the last quarter century reveals a wide disparity in what stories physicians chose to tell. One hundred percent of Black and Native American doctor-memoirists in the study (N=9) addressed health equity, race as a co-factor in health and patient care, and workplace bias experienced or witnessed. Whether their memoirs focused chiefly on the experience of becoming a doctor, on interesting patient cases, on personal development, or on ways to improve healthcare, structural racism was consistently an important topic. In contrast, only 39% of memoirs by White, Asian, and Latinx physician writers (N=31) ever mentioned race, let alone structural racism or racial health equity.

The stories Black and Native doctors tell are vivid. They say important things about medical education, the healthcare system, and the need for health equity—things physicians of other races are surely aware of, but mostly chose not to mention in their memoirs. Looking at some of these stories reveals what could be gained if not only physician memoir writers but also all of us who write in other contexts could become more comfortable addressing structural inequities.

“Sexism in Medicine: Autistic Women's Lived Experiences with an Adulthood Diagnosis”

Elizabeth Mathews, Case Western Reserve University

“Why is a diagnosis important to you?” “It would mean I am not a total failure at being human.”—Jennifer Cook O’Toole, author of *Autism in Heels*.

Women have been treated differently due to their sex and gender within medicine for generations. One place this is most prevalent is in the diagnosis of autism. Thought to be a “boy’s disease” autism is not thought to exist in women. Due to this misconception, autistic women have been misdiagnosed and overmedicalized; all to keep them compliant.

Via Facebook, I asked 72 autistic women about their experiences with pursuing an adulthood diagnosis. Many women reported a loss of employment, loss of family and friends, and even the loss of their children via child protective services for being misdiagnosed and untreated. In this paper, I highlight the trauma and survival tactics these women are forced to use to pass as “human” for the comfort of their peers.

Due to the cost of diagnosis and lack of understanding of autism in women by doctors, the autistic community accepts self-diagnosis as valid. In my research, the themes include

medical negligence, stigma, trauma, and masking. I will be examining how these themes have negatively impacted autistic women in their pursuit of diagnosis, recognition, and treatment.

The purpose of this paper is to expand knowledge on autistic women's lived experiences and to inform others as to the beneficence and non-maleficence from acknowledging women's trauma and understanding that their experiences are real and unique to them as an individual.

“More Than A Clinician, More Than A Patient: Humanizing the Hospital Experience with Tell Me More”

Bryana Belin, Ishi Aron, Shyam Bhagat, Taranjeet Kalra Ahuja, Alice Fornari,
Donald & Barbara Zucker School of Medicine at Hofstra/Northwell

As the golden rule says, treat people how you want to be treated. This is also applicable to medicine. Patients want to be treated like humans. In the hospital, patients want to be seen beyond their chief concern, differential diagnoses, and definitely as an individual with a unique journey. However, the structure of the healthcare system often prevents meaningful community building among staff and patients. The Tell Me More[®] (TMM) program provides a template for medical students and clinicians alike to connect with their patients beyond their illness to obtain an expanded social history that can impact patient care. Medical students ask questions such as, “what would constitute a ‘perfect’ day for you”, “If you could travel anywhere in the world, where would you go”, and “what has been most meaningful to you in your life,” which they depict in visual form on a large poster displayed by the patient's bedside. Past research shows that TMM improves patient experience with their healthcare team. Our aim was to measure the impact of TMM on clinical staff connectedness with patients during their hospitalization through pre- and post-intervention survey distribution at four diverse hospital sites. We found that TMM, as a patient-focused intervention, increased staff knowledge of patients, patient knowledge of staff, and increased staff memory of patients. Meaningful patient-provider relationships may improve patient experience and decrease provider burnout. Therefore, short interventions like TMM can rehumanize the hospital experience for patients/families and remind staff why they chose to be in healthcare.

“Agency Through Homeopathy in the German Romantic Era: Connecting Patients' Stories to Today's Allopathy”

Claire Staresinic, Case Western Reserve University School of Medicine

As science has taken major strides towards expanding the possibilities of allopathic medicine, many institutions and practitioners devote little or no attention to complementary and alternative medicine (CAM). One of the most well-known forms of CAM, homeopathy, was pioneered by physician Samuel Hahnemann and first rose to popularity during the German Romantic period of the early nineteenth century in response to the harsh therapies and reliance on opioids that dominated the era. By contrast, homeopathy offered patients a gentler option along with greater agency in their own care through its unique patient-physician dynamic reliant on patient reporting and education. It also allowed women, a population excluded from medicine at the time, to play a greater role in this academic sphere. Homeopathy was championed by two of the most famous women writers of the era, Bettina von Arnim and

Annette von Droste-Hülshoff, both of whom were well-known for their poetry, prose, and epistolary writings. This flash presentation will demonstrate through the stories told in these women's letters highlight the positive influence homeopathy had on their relationships with healthcare and on expanding women's role in medicine. I will then elucidate how these lessons can be applied to the current state of medicine, which mirrors the conditions Hahnemann challenged. Ultimately, I argue that greater awareness of and openness to alternative medicine can improve allopathic care and help heal the relationships between medicine and traditionally underserved and underrepresented populations.

“A Humanistic Inquiry of Chronic Pain Management: (Re)Examining the Quadruple Aims through a Feminist Relational Lens for Enhanced Provider Well-Being”

Vinita Agarwal, Alison Sutton-Ryan, Salisbury University

Chronic pain implications of the COVID-19 pandemic highlighted challenges faced by medical professionals including moral distress and an inability to act in ethical ways consistent with their training (Vittone & Sotomayor, 2021), leading to rising rates of provider burnout and negative patient outcomes. Chronic pain was reported by 73% of primary care physicians at Veterans Affairs (VA) clinics to be a significant frustration in delivery care (Mattias et al., 2010). The collaborative care paradigm shifts the emphasis from clinical pain management protocols and structured decision-making to privileging patient voice and lived experience; however, these have not been meaningfully integrated into shared decision making and personalized care planning (Walton & Lazzaro-Salazar, 2016). Feminist examinations of knowledge/power in the clinical domain have critiqued the institutional regulation of patient autonomy in healthcare relationships (Lupton, 1995). A relational care praxis that discursively (re)conceptualizes the pain experience through provider awareness/reflexive self-engagement has the potential to re-envision the knowledge/power relations characterizing clinical encounters (Agarwal, 2018a). A closer examination of the quadruple aim with its systemic focus on patient experience, cost reduction, population health, and provider well-being (Menzin et al., 2020) alongside the whole-person feminist paradigm in the CAM therapeutic relationship (Agarwal, 2018b) may suggest empowering pathways for provider-patient well-being in the clinical context. By proposing a shift in collaborative patient-provider decision-making toward a relational paradigm centered on the intersubjectivity of the pain experience (Agarwal, 2018a), we hope to open pathways for decreasing provider moral distress through a mutually constitutive approach in the chronic pain management domain.

“Disembodied Data-fication: Consequences of Virtual Grief on the Future of Telehealth”

Katie Xu, Case Western Reserve University School of Medicine

Under isolation restrictions enforced by hospitals during the COVID-19 pandemic, families had no choice but to “visit” their dying loved ones through video calls – a catalyst for an accelerating cultural movement toward digital sociality. In this presentation, I analyze the improvised rituals of virtual grieving that have emerged out of quarantine culture to investigate how we fulfill our innate emotional, social, and cultural needs in an increasingly digitized world. Only when deprived of the ability to hold hands and give hugs did we realize how heavily we

rely on these basic elements of human connection. Through interviews and first-person recounts of the death of a loved one under COVID-19, I reveal the “jarring,” “strange,” and “really, really sad” experience of virtual grief and its compromised healing.

Through an analysis of the tragedy of virtual, disenfranchised grief under COVID-19, I argue that the continued proliferation of virtual encounters in healthcare must be checked by the dystopian reality of entirely virtual encounters. I warn that virtual visits ushered in by deaths under COVID-19 have catalyzed a mass cultural migration toward data-fied social gathering – disembodied conversations that temper the emotional intimacy of embodied human connection. In healing spaces of healthcare, virtual conversations deprive patients, loved ones, and caregivers the therapeutic solace of visceral, in-person connection. While the expansion of telehealth appointments has afforded greater equity and convenience of access in its own right, I caution that virtual meetings dampen the experience of raw emotion in grief, healing, and celebration.

“Shaping Pediatric ECMO Decisions through Multidisciplinary Perspectives”

Julie M. Aultman, Adiaratou Ba, Northeast Ohio Medical University

Patricia Raimer, Daniel Grossoehme, Ryan Nofziger, Sarah Friebert, Akron Children's Hospital

There is a critical need to pause for reflection and establish a space to engage in careful deliberation amid exciting, important, necessary, and groundbreaking technological and clinical advances in pediatric medicine. Extracorporeal Membrane Oxygenation (ECMO) is one such technology that began in pediatric settings nearly 50 years ago. And, while not void of medical and ethical examination, both the symbolic progression of medicine that ECMO embodies and its multi-dimensional challenges to patient care requires more than an intellectual exercise. What we propose and illustrate, then, is a person-centered framework that incorporates the philosophy and practice of palliative care and care-based ethical approaches that contextualize ethical rules and clinical concepts. This person-centered framework is valuable for identifying and understanding challenges central to ECMO, guides collaborative decision-making, and recognizes the value of relationships within and between patients, families, healthcare teams, and others who impact and are impacted by ECMO and the effort to reduce suffering and promote quality life in pediatric settings. This person-centered approach enables caregivers to provide compassionate and effective support in critical, and often urgent, situations where conflicts may emerge among healthcare team members, families, and other decision makers. We present three cases that posed challenges unique to pediatric ECMO care including disability bias, non-beneficial treatment, and moral distress among family and team members. We aim to fill a current gap in the pediatric ECMO literature by presenting a person-centered framework that promotes caregiving relationships and is supported through the philosophy and practice of palliative care and clinical ethics.

“Structural Issues, Policy Changes, and Living Without Dignity in Nursing Homes during COVID-19”

Millie Sun, Case Western Reserve University

The COVID-19 outbreak has greatly affected residents' and nursing staff's experiences of dignity and care given at nursing homes. The exacerbation of deep-rooted, pre-pandemic structural issues in American nursing homes, such as nursing shortages and financial burdens, left nursing homes without proper nursing staffing levels and protective equipment. These shortages subsequently caused the rise of nursing agencies, which diminished the quality of nursing care and the quality of life for residents and staff during the pandemic. Additionally, the implementation of inadequate state and federal policies that lack understanding of these deep-seated structural issues as well as nursing home resident and staff experiences hindered meaningful progress in this dire situation. In this paper, I argue that the dignity and quality of life of residents and caregivers have been negatively affected during the pandemic due to unresolved and worsening pre-pandemic structural issues as well as insufficient state and federal policies. I hope to not only provide an analysis of existing literature, but also share personal experiences and observations from shadowing a wound care physician and volunteering at a nursing home in Ohio from 2019-2022. With a growing aging population, especially with the oldest baby boomers soon approaching 80, the need for proper nursing home care will continue to grow. Moving forward, there needs to be an exploration of better ways to deal with these structural issues in nursing homes such as increased community-based involvement to reduce staffing ratios and improved communication between residents, families, nursing staff, and governmental agencies.

7B PANEL: Transforming Disability-Focused Health Professions Education: Mobilizing Insight from the Intersection of Disability Studies and the Health Humanities

Kenneth Richman, Massachusetts College of Pharmacy and Health Sciences

M. Ariel Cascio, Shay Dawson, Neli Ragina, Central Michigan University College of Medicine

Rachel Conrad Bracken, Rebecca Fischbein, Northeast Ohio Medical University

Rebecca Garden, SUNY Upstate Medical University

Research demonstrates the need for health professions education (HPE) focused on improving access to and quality of care for people with disabilities [1-4]. Most curricula lack disability-focused education [5-7] and there is little research establishing best practices for disability education in the health professions [8]. Health humanities education offers strategies to address knowledge and skills gaps, reduce stigma and ableism, and respond to structural inequities in health and healthcare for people with disabilities. Drawing on the work of health professions educators in medicine, public health, nursing, and physician assistant programs, this panel showcases innovative methods for teaching disability grounded in Disability Studies and the Health Humanities.

The first presentation will describe the materials and concepts used to help students in allied health professions begin to think about disability. Because health sciences students tend to approach disability as dysfunction that needs to be fixed, the presenter shares materials that challenge this medical model by connecting disability-related concepts to familiar ideas, including published scholarship and discussions with people with disabilities. This presentation models how to introduce the social conception of disability in the context of the Americans with

Disabilities Act and challenge students' understanding of a providers' duty of beneficence through discussion of neurodiversity and autism.

The next presentation describes the Healthcare Education Engaging Disability Studies (HEEDS) program, which provides didactic disability studies education to healthcare professions students (medicine, nursing, physician assistants) and hands-on experiences working with people with disabilities to medical students in standardized patient (SP) encounters. The presenters will share a video from parents with disabilities, then describe how they leverage this and other stories in HPE with a focus on the participation of disabled people as advisors, storytellers, and SPs. Preliminary feedback suggests this program may be a point of hope for leveraging such experiences in HPE.

The third presenters share their experience developing disability-focused SP encounters from focus groups with recent medical and pharmacy alumni and members of local disability community organizations. Building on existing research demonstrating the value of SP encounters to increase student knowledge and awareness of disability-related health concerns, reduce stigma, and improve attitudes towards individuals with disabilities [9-10], this presentation outlines learning objectives for disability-focused SP encounters, as well as practical guidance for developing case narratives; recruiting and training SPs with disabilities; and evaluating the effectiveness of SP encounters to develop cultural humility and communication skills.

The final presentation demonstrates how public health humanities can align with disability studies frameworks to help students to scale out to analyze structural and systemic inequities and scope into more granular views of the lived experiences of ableism and atypical embodiment through narrative and arts-based methods. This presentation describes educational interventions, including a unit in a bioethics and public health course, an interdisciplinary accessibility mapping expedition, and an arts- and narrative-based elective course in disability and Deaf studies perspectives on health and healthcare inequities.

7C PAPER SESSION: Self-Care and Peer Care

“The Politics of Self-Care in Women’s Chronic Illness Narratives”

Jess Libow, Haverford College

“Caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare.” In this paper, I build on recent work by Jina B. Kim and Sami Schalk that revisits this famous quote by the Black feminist writer Audre Lorde within its original context, when the writer was living with cancer in 1988, in order to show the radical implications of self-care for women with poorly understood chronic illnesses. Across Meghan O’Rourke’s personal essay, “What’s Wrong With Me” (2013); Nafissa Thompson-Spires’s short story, “The Body’s Defense Against Itself” (2018); and Porochista Khakpour’s memoir, *Sick* (2018), conventional self-care practices such as diet and exercise are far from indulgences. Rather, they represent women’s efforts to manage conditions such as autoimmune disease, endometriosis, and post-treatment Lyme disease that expose the American medical system’s limitations. While the twenty-first century has seen self-care morph into a product marketing strategy and a capitalist mandate, these writers invoke an earlier history, when twentieth-century health

activist groups such as the Black Panther Party, the Boston Women's Health Collective, and ACT UP cared for themselves and their communities where existing American infrastructures failed to do so. Strikingly, chronic illness narratives engage some of the most conspicuous and frequently derided forms of self-care such as yoga and "clean eating" but recast these as urgent medical interventions. Far from symptoms of an overly individualistic consumer culture, chronically ill women's commitments to self-care illuminate the dangerous cracks in American healthcare and the need for alternative structures.

"Undergraduates Under Stress: Discursive Boundary Work and Rhetorical Care of the Self"

Kimberly Emmons, Case Western Reserve University

According to the Fall 2020 "Healthy Minds Study," 28% of undergraduate students say that "emotional or mental difficulties have hurt [their] academic performance" six or more days in the previous four weeks (Eisenberg et al). These and other indicators, including reports of dramatic increases in student visits to campus counseling services for anxiety, depression, and stress-related illnesses (Novotney, Reilly), suggest that today's undergraduates are, in the vernacular, "all stressed out."

As a label for a wide variety of experiences and mental states, as well as the physical and emotional responses to those experiences and states, "stress" haunts the borders between mental health and illness, between medical care and lived experience. Because of its ubiquity and resistance to definitional precision, the concept of stress deserves robust rhetorical interrogation. This project analyzes survey data and narrative responses from two IRB-approved studies of undergraduate well-being at a mid-sized research university to explore the rhetorical boundaries of stress as a health-adjacent phenomenon.

In this presentation, the speaker will summarize findings and explore the rhetorical strategies that students use to identify and cope with stress in their lives. Attending to students' own words, the project highlights the rhetorical work of self-care and illuminates the ways that stress is taken up and articulated in a complex discursive structuring of illness experiences and wellness activities.

"Boundaries, Equity, and Lived Experience in Peer Mental Health Support"

Maia Delegal, Case Western Reserve University Department of Bioethics

Peer support facilitators, or "peers", are those with lived experience of mental illness and/or substance use disorders who provide support to others pursuing recovery. Peers are often economically disadvantaged, compounding burnout stemming from compassion fatigue and utilizing difficult—if not traumatic—lived experiences to benefit others. Drawing on data from an ongoing qualitative study on ethics of mental health peer support, I will explore how financial inequity and systematic marginalization affect peers' ability to provide this undervalued form of care. I will particularly focus on how peers practice boundary setting to maintain their well-being, while those with more traditional caregiving roles in mental healthcare benefit from the assumption of professional boundaries. Methods include semi-structured interviews of both peers and staff members of non-profit mental health

organizations across Ohio and autoethnographic reflections written by lived experience researchers. I will also employ perspectives from the field of disability studies to deepen the analysis. Attendees from all backgrounds in the health humanities will learn more about mental health peer support in this presentation, as well as the unique challenges in this growing modality of care.

7D PAPER SESSION: New Perspectives on Health History

“Ethiopian Healing Scrolls as Graphic Visualizations of Illness Narratives”

Xiaoli Pan, Case Western Reserve University

Ethiopian healing scrolls have been inscrutable for centuries to anthropologists and historians alike. They are easy enough to describe; also called “magic scrolls,” Ethiopian healing scrolls are a part of traditional medicinal practice whereby scrolls are made to cure patients suffering from illnesses. However, past and current scholarship have always ended with the descriptive. Thus far, there has been no holistic examination of the position the scrolls occupy in Ethiopic cultural understanding of religion, healing, and illness. Are they medicine? If so, what is the relationship between patients experiencing illness, the medical practitioners, and the scrolls themselves?

I suggest that the Ethiopic ethnomedical system envisions the natural world and disease as malleable. Because of this, the scrolls give illness “structure,” which renders disease into narrative and intelligible images. Conversely, medical practitioners also require the individual patient’s pathography to effect healing. This dialectic between patient and practitioner rejects the universalizing tendencies of western bio-medicine to show that healing requires both the secret, localized knowledge encapsulated within the scrolls, and the patient’s particular story. The healing scrolls mediate the relationship between the individual and the larger cosmological universe. Using an exemplar healing scroll as a case study, I shall attempt to tease out how these structural themes manifest visually. I will also ground them in the bioanthropological world they emerged from by using primary, religious, and anthropological sources/studies. This case study will show healing scrolls are graphic visualizations of illness narratives; a physical token to restructure the sickness role of the patient.

“The Feminization of Frontal Lobotomies: A Critical Analysis of the Role of Gender and Queerness in the Lobotomy Era”

Missy Tepe, Loyola University Chicago

The history of frontal lobotomies is fraught with unsafe medical practices and the stigmatization of mental illness. Frontal lobotomies were largely used as a last resort intervention for those diagnosed with severe mental illness for whom psychotherapy wasn’t effective. Transorbital lobotomies, coined “ice pick” lobotomies, were primarily used starting in 1935 until the mid-1950s. A modified ice pick instrument was used, as it was inserted between the eye and the top of the eyelid, intended to be done at a specific depth and angle. Using these techniques, physicians often left patients mentally incapacitated due to inaccuracy and the lack of sterile conditions. Harms included frontal lobe damage that led to the loss of personality and

identity, leaving patients with a calm, docile demeanor that made their clinical management easier for caretakers. Women, gay men, and lesbians were largely targets of this practice, as they were more likely to be diagnosed as having aberrant, inappropriate behaviors or sexual attractions that required "correcting."

My presentation will critically evaluate aspects of the lobotomy era such as the political and social atmosphere for women and the practice as a form of conversion therapy used to "treat" lesbians and gay men. I will compare transorbital lobotomies as a form of conversion therapy to transphobia in contemporary medicine, concluding that, far from going away, the gender biases against women and negative attitudes toward queer patients that informed the practice of lobotomy are still at work today.

"Exploring the Interdependence of Disability, Spirituality, and Community at Lourdes Sanctuary"

Liz Hutter, University of Dayton

In response to an invitation from a cousin to join a diocesan pilgrimage to Lourdes as a healing intervention for her progressively debilitating Lupus, American fiction writer Flannery O'Connor shrewdly remarked, "About the Lourdes business. I am going as a pilgrim, not a patient" (O'Connor 1957). O'Connor's assertion echoes a familiar binary associated with making a pilgrimage to Lourdes sanctuary, the shrine commemorating historical apparitions of the Virgin Mary to Bernadette Soubirous in 1858. As a therapeutic and spiritual landscape, Lourdes has a long history of uniquely entwining individual experiences of illness with institutional rituals around healing and faith, all of which are authorized by systemic structures of expert medical knowledge and Catholic doctrine. My presentation's examination of the publications of the Lourdes Medical Bureau and case studies of unexplained cures, employs a disability studies perspective to destabilize a rigid distinction between "pilgrim" and "patient," and relatedly, between "spiritual" and "therapeutic". On the one hand Lourdes is a key site for examining the ways in which it reflects historically situated medical knowledge (Garrigou-Kempton 2020). On the other hand, studies have foregrounded the mental, emotional, and less visible therapeutic impacts on persons visiting Lourdes (Rahtz et al. 2021; Goldingay et al. 2014). Because disability is not a fixed category but theorized as a fluid concept responsive to situation and purpose (Withers 2012), the lens of disability opens a means to recognize and understand the co-construction and co-existence of pilgrim and patient identities among Lourdes visitors and volunteers.

7E PAPER SESSION: Envisioning Clinical Interventions

"Primary Care Needs Neurodiversity: Implications of the Double Empathy Problem in Autism Spectrum Disorder (ASD)"

Alyssa Harbaugh, Case Western Reserve University School of Medicine

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that involves impaired social interaction and communication. Autistic individuals (the community prefers

identity-first language) often struggle in social environments and are rejected by their allistic (non-autistic) peers. The medical model of ASD places the responsibility for this rejection on autistic people, citing their social deficits.

However, new research suggests that ASD-related communication breakdowns do not happen in all contexts. When autistic people speak with each other, they transfer information just as effectively as pairs of allistic people. Communication only decreases when autistic and allistic people are paired together. This suggests that ASD communication challenges are not a result of autistic deficits. Instead, they are due to a bidirectional empathy gap between autistic and allistic people. This has been coined 'the double empathy problem'.

In healthcare settings, miscommunication between autistic patients and allistic providers can have dangerous consequences. Autistic people often express pain and emotional distress differently than allistic people, which can lead allistic providers to misdiagnose their medical conditions. Addressing the double empathy problem has the potential to decrease the frequency of these errors.

In this paper, I examine the origins and consequences of communication breakdown between autistic patients and allistic primary care providers. I place particular emphasis on the double empathy problem and how it impacts autistic patients seeking primary care. Finally, I argue that key solutions to the double empathy problem involve the deliberate inclusion of autistic students in health professions education and autistic providers in patient-facing specialties.

"Sitting With Grief: Towards an Infrastructure of Intimacy on the Oncology Unit"
Doria Charlson, Northeastern University

This paper considers how the act of sitting -- at a patient's bedside, with a nurse at the charting station, or in a family meeting -- invites and cultivates embodied intimacies that can function as modes of transformational change within the clinical context of the hospital. I contextualize the act of sitting within lineages of spiritual deepening and political undoing. Sitting is a radical position in both its potential as a site of refusal and as a move towards restoration and empathy. As an oncology chaplain, my role is to be present to the grief, sadness, and pain of bodily destruction and the emotional ravaging that cancer performs upon an individual and their family. In my work, sitting cannot be equated with stillness or passivity; rather, it is a modality of movement that engenders a rupture in the infrastructures of the academic medical center by creating the space for emotions to emerge, aerate, and change in their own time. Creating a collective of care for patients centered on/in the unfurling of relations that come from sitting with grief is, as of yet, an infrastructure that I'm dreaming into being. The constraints of increasing compartmentalization by clinicians as a result of health care systems built upon capitalist modes of relation is deeply felt by patients and providers. Through an exploration into the spaciousness that can emerge when we sit with another, I imagine alternative structures that strengthen the connection between relationality, healing, and infrastructure in the hospital setting.

"Biomedicine's Languid Approach to Gender-Affirming Care Advancements"
Daniel Hamilton, Case Western Reserve University

Using data collected from ethnographic fieldwork conducted with transgender and gender non-conforming individuals engaged in biomedical gender-affirming care and taking an actor-network-theory approach to explore the ways in which human and non-human actors interact within clinical space to create meaning and communicate shared patient/provider goals, this paper will explore the ways in which the tools meant to standardize, have led to a proliferation of practices to circumnavigate challenges cause by the disconnect between academic and medical research and the social and political lives of transgender and gender non-conforming individuals in the United States.

Diagnostic criteria, treatment protocols, and clinical research are all engaged in clinical spaces during interactions between biomedical providers and patients. These non-human social actors have shown to be less flexible than the human actors in addressing lived patient experiences and addressing the needs of some medicalized populations. These tools begin to be seen as part of a legacy of medical authority disregarding the lived experience of patients, this is particularly evident in gender-affirming care where case studies, research, and medical discourse are mainly products of cisgender doctors, researchers, and experts.

The result of these practices and tools within biomedicine are highly knowledgeable patients, underinformed providers, and a Wild West of treatments being offered.

7F WORKSHOP: Why Aren't I making Art? The Problem with Artists in Medical Education

Katherine Burke, Cleveland Clinic Lerner College of Medicine

Gretchen Case, University of Utah School of Medicine

Employing artists in health professions education and other medical settings can be beneficial for many reasons, including teaching health humanities, engaging in therapeutic practices for patients and families, and helping students to express themselves creatively and effectively. The art of theater in particular not only offers a valuable opportunity to exercise creativity and expression, but theater training imparts a variety of practical and useful skills, such as collaboration, problem-solving, technical abilities, and organization. This workshop's presenters, trained theater artists, currently work in medical education. Though the presenters once utilized their artistic and creative skills in their medical school work, they now find themselves using predominantly the practical skills, helping others to develop their creativity while simultaneously losing opportunities to exercise their own.

Community-based theater methods are an effective means of exploring challenging societal and personal circumstances, imagining better futures, and rehearsing ways to advocate for oneself and others. In this workshop, participants will discuss experiences of being or working with artists in health professions education or health care settings. Using theatre-based methods, we will engage in storytelling and theatrical exercises, and identify the benefits and drawbacks of being/working with artists in medical settings. Drawing on techniques from Augusto Boal's *Rainbow of Desire*, we will examine participants' stories closely, and brainstorm ways to nurture and support artists in medical and health professions education settings.

Concurrent Sessions 8 – Sunday, Mar. 19, 10:45 a.m.-12:00 p.m. EDT

8A ROUNDTABLE: (Dis)abled Minds: Lived Experience and Institutional Harm

Julia Knopes, Kristi Ninneman, Case Western Reserve University

Ariel Cascio, Central Michigan University College of Medicine

Neşe Devenot, University of Cincinnati

Austin Wiley Duncan, University of Arizona College of Medicine

Laura Guidry-Grimes, Cleveland Clinic

Governments, economies, and global biomedicines are some of the many social structures that deeply impact the lives of people who experience mental illness, neurodevelopmental (dis)abilities, and cognitive differences, such as schizophrenia, bipolar disorder, autism, traumatic brain injuries, and psychological distress without a formal diagnosis. For instance, biomedical healthcare systems pressure patients to take psychiatric medications to conform to culturally accepted ideas of behavior and cognition, while neoliberal politics undervalue the lives and labor of people with psychological and neurological conditions, and local governments retain the right to involuntarily institutionalize people in crisis. These are some of the institutional challenges that people with psychological and neurological disabilities and differences routinely encounter. While social structures do not always fail to meet the needs of people who have mental illness and neurodevelopmental conditions, these individuals are especially vulnerable to institutional violence and disenfranchisement. People of color, queer folx, and individuals from the Global South who experience psychiatric and neurodevelopmental disabilities can encounter significant difficulties as they navigate social systems to meet their health and support needs.

In the face of these societal harms, people who experience mental illness, neurodevelopmental differences, and intellectual and cognitive disabilities often seek to resist the social structures that seek to alienate, devalue, and marginalize them. They form inclusive and interdependent social communities, develop new ways to manage symptoms and participate in social life while preserving individual identity, navigate complex social services to access resources, and find meaning in everyday life. In this roundtable session, presenters from both the social sciences and humanities will reflect upon how their scholarship on mental difference and disability addresses the multidirectional relationships between social structures, individuals, and communities. Throughout the discussion, the presenters and audience members are invited to contemplate the nuances of autonomy and agency in social and cultural settings where the power of people with psychological and neurological conditions, and their caregivers, can be structurally limited.

The session will explore questions regarding the deleterious impacts of institutions on the lives of people with psychological and neurological (dis)abilities, and the creative ways in which these individuals and their caregivers resist the detrimental effects of hegemonic social structures on their lives. These questions include: How do people with lived experience of psychological and neurological conditions come to lead fulfilled lives, in ways that may subvert biomedicine and other established social structures? What form(s) does structural violence take in the lives of people with psychological, neurological, and cognitive disabilities and differences?

What kinds of emotions, behaviors, and cognitive abilities do societies prize or marginalize? And, importantly: how can health humanities scholarship elevate the voices of people who inhabit diverse brains and minds? Throughout the discussion, the presenters encourage academics, artists, and activists to share their thoughts on the complicated interactions between structures and selves in relation to disability, mental illness, and neurodiversity.

8B PANEL: Poetry of Equity: Transformations From Within Healthcare and Medical Education Systems

Yvette Perry, Elizabeth Pringle, Zina Mercil, Jenny Heglan, The Good Listening Project

I'm in a place not made for me
doing the work I was made to do.
I'm wondering how to keep going.

What meanings about equity can we make through poetry based on the experiences of individuals within healthcare and health education systems? In this panel discussion, poets from The Good Listening Project (TGLP) will begin to answer this question by sharing conversations related to issues of diversity, belonging, and healthcare equity that we have had with providers, patients, researchers, and health educators. The Good Listening Project (TGLP; <https://www.goodlistening.org/>) is a non-profit organization cultivating resilience and wellbeing in healthcare. Listener-Poets from the organization hold one-on-one conversations with participants ("poemees"). Following the conversation, Listener-Poets compose custom poems based on the interaction.

We open our sessions by asking these participants, "What would you like your poem to be about?" For some poemees, the topic they most want to talk about involves how they are navigating healthcare systems characterized by inequities of many kinds. Some, like the person from the poem excerpted above, must act simultaneously from the margins of healthcare structures (for example, as a woman from a racial or ethnic group underrepresented in medicine) and from the upper rungs of the health system hierarchy (for example, as a physician). Other poemees reflect on providing care and compassion as a systems insider but an outsider with regard to the populations they serve, as illustrated by the line of another poem: "In the center of this most intimate moment/I serve/Uncentered/I look nothing like them." Still other poemees are patients who—despite their lack of formal expertise—know when they are recipients of substandard care: "some doctors/cannot see me--/I am not visible from where they have/put me in their/preconceived notions bucket."

By sharing case examples from sessions with poemees as well as live and recorded readings of several of the poems, we will weave a story of how individuals are engaged in actions for transformation. We will explore these actions through five themes:

- 1) Listening and Questioning
- 2) Witnessing and Remembering
- 3) Being and Becoming
- 4) Advocating and Storytelling
- 5) Showing Up and Doing the Work

We assert, based on our many interactions with individuals in a variety of roles within healthcare and health education systems, that there is no “health” and “wellbeing” without equity. Through actions both big and small, individuals confront current healthcare structures—structures that are often inadequate to meet the many needs of people within them. The poems that we write for poemees bring this relationship between health and equity to light in unique ways that other forms of inquiry and documentation might not be well equipped to do.

8C PAPER SESSION: Critiquing Representations

“Unassisted Surgery in Fact and Fiction”

Pedro Ponce, St. Lawrence University

A staple of genre films, scenes of unassisted surgery represent the ultimate rejection of institutions (whether medical, cultural, or political) in favor of radical individuality asserted against a system that no longer affords the hero a means to survive. This can be seen in films like *Shooter* (2007), in which the marksman protagonist (Mark Wahlberg), framed for an assassination attempt, must treat his own gunshot wounds while evading pursuit by authorities. At the same time, unassisted surgery can also be used to dramatize a character’s lack of individual agency—the body gives itself an update, much like a cyborg, as when Javier Bardem’s assassin treats his own wounds in the Coen brothers’ 2007 adaptation of *No Country For Old Men*. A more complicated example is seen in *Prometheus* (2012), in which the archaeologist Elizabeth Shaw (played by Noomi Rapace) must extract an alien fetus from herself, aided by an advanced surgical device aboard her spaceship. Human and machine work together to save the protagonist, but the mission to understand human nature that brought Dr. Shaw into this situation is nevertheless doomed. I will use examples such as these to ground a preliminary overview of unassisted surgery as medical practice and literary trope, and I will explore how this trope reflects anxieties about individual bodies and how they relate to institutional systems of power.

“The Vagina: An Anatomy of Misunderstanding”

Alexis Doyle, Carmen Thong, Stanford University

‘Vagina’ is the most used term for the whole female genitalia. Yet, it is the wrong term. Why did it alone proliferate and become so highly sexualised, when many men and women barely know the word ‘vulva’ and lack basic anatomical knowledge of the female genitalia? The International Vagina Dialogue Survey interviewed nearly 10,000 women and found that 65% of women think that “society has too many misconceptions about the vagina” and 78% thought that taboos regarding the vagina contribute to women’s ignorance about their own genital anatomy. In this project, we sketch a history of this ignorance and misunderstanding in order to contribute to better mediations between cultural and medical understandings of the female reproductive anatomy. We review the available literature on our associations with the words vulva, vagina, and clitoris. We will also be adding to that story by text mining a large corpus of women’s magazines in the United States from the 19th century onwards. Using computational methods like most distinctive words or collocates, we will be looking for the conceptual

histories of the words vulva, vagina, and clitoris when it comes to how women have historically consumed them through women's magazines. By tracing these words through their discursive past, we aim to clarify the factors that enabled such a history of misunderstanding so as to encourage medical professionals to take a more active role in countering the centuries of misinformation, shame, secrecy, and mystery surrounding these parts of the female body.

"Pathologized Desires"

Ira Halpern, Northeastern University

"Pathologized Desires" takes up the ways that U.S. novelists have critically responded to the medicalization of non-normative sexualities and identities. In Jennie June's autobiography, we find both a critique of the pathologization of desire and the strategic mobilization of medical knowledge. June claims, regarding queer populations that the "majority of the medical profession have been in almost entire ignorance." But June recounts continuing to visit doctors, conducting research at medical libraries, and gleaning critical information from the latest developments in *The Journal of the American Medical Association* and the *American Journal of Urology and Sexology* in order to learn about their body and desires. In this presentation, I account for a series of neglected queer literary encounters with medicine that critically responded to, and revised, the disciplinary and often violent logics of sexology and other sciences of sexuality. In *A Scarlet Pansy* (1933), Robert Scully resists the pathologization of queer populations and imagines the trajectory of its protagonist, a queer doctor, who works toward transforming modern medicine from within. Harold Kham's *Secrets of a Society Doctor* (1935/50), parodies psychoanalysis' pathologization of homosexuality. This novel, in portraying a doctor-patient relationship that is also a love plot, suggests that queer patients need not be reformed, regulated, or cured; they need to be able to safely express their desires. I end with a brief discussion of Djuna Barnes' *Nightwood* (1936), which insists not that there is anything healthy about queer desire, but that all desire is inevitably sick. Frequently, fiction writers reclaimed rather than resisted the language of medicine, health, and even pathology in order to subvert stigmatization.

8D PAPER SESSION: Turning to Texts to Understand, Critique, and Heal

"*Wuthering Heights* and Medical Noncompliance: Considerations for Empathetic Engagement"

Crystal Veronie, The University of Southern Mississippi

Structures in Emily Brontë's 1847 novel *Wuthering Heights* have held the attention of scholars in literature since C. P. Sanger's 1926 essay. The family homes—Wuthering Heights and Thrushcross Grange—represent substantial structures that give form to the Yorkshire community. While these structures persevere, the first part of the novel charts the destructive force of their communal division on the youthful Catherine Earnshaw. The way that Catherine's illnesses are depicted as attempts to regain control has been productively explored by scholars such as Susan Rubinow Gorsky and can be useful in discussions regarding the ways that social structures influence how individuals act, change, think, and feel. As such, Catherine and the

illness that claims her life can be a touchstone for discussions in health humanities that consider how best to approach health disparities in the post-pandemic era.

In this paper, I argue that *Wuthering Heights* offers key insights for health humanities on issues ranging from how to maintain empathetic relationships with patients to further considerations about the complexities of continued post-pandemic confinement for high-risk populations. Close readings of the rebellious Catherine Earnshaw provide helpful vignettes for discussions of medical non-compliance and resistance to vaccination in healthcare settings. Further, they provide opportunities to explore the structural links between health disparities and persistent social systems, such as health care.

"Pedagogical Reflection: Mirrors, Cadavers, and the Surgical Instruments of Whiteness"
Heather Glenny, University of Chicago

"Pedagogical Reflection: Mirrors, Cadavers, and the Surgical Instruments of Whiteness" asks how the hermeneutic logic of cadaver dissection has opened the body to biological racism and been absorbed beyond the medical field. At the intersection of empiricism and structuralism, medico-pedagogical dissection in American medical schools offers viscera as an otherwise inaccessible "truth" of the body. How has this pedagogy been leveraged to validate biological determinants of race and affirm the overdetermination of "standard" anatomy as white? This paper focuses on one particular step in dissection—reflection, the capacity to "see" oneself or one's curricula (e.g. "standard" anatomy) reflected back from the learning object—to examine the ontological and material demands it makes on the cadaver. Then, looking at scenes of medical teaching, reflective mirrors, and screens in Toni Morrison's *Bluest Eye* (1970), I argue that reflection is a pedagogical method that gets absorbed into the aesthetics of cultural production. Where else does reflectivity produce white anatomy as unmediated, "standard" fact? Rather than looking for literal dissection, I track its reflective logics: instances where mirrors and reflections become transparent lenses into empirical truths, where anatomical materiality gets taught as refractions of racial categories. What does Pauline's childbirth scene reveal about reflective identification, projection, and substitution as practices of medical seeing? What does Pauline see when she styles her hair to mirror white film stars but can't see her own decaying tooth? In the post-structuralist thrust of the late twentieth century, where does faith in the body's "truth" still linger in cultural viscera?

"Attending to Wounds: Contemporary Narratives of Trauma and Healing in AfroBoricua Literature"
Roberta Hurtado, SUNY Oswego

Puerto Ricans often speak of the island's cultural heritage as having three roots—African, Arawak, and Spanish—when asked about racism on the island. A colony of the United States since 1898, the island first experienced what Aníbal Quijano describes as "coloniality of power" in 1493 following the arrival of the Spanish. The history of violence on the island has been long and palpable, and includes the decimation of the indigenous population and its replacement by the Spanish with enslaved Africans starting in 1511 to create wealth for Spain. Since these early moments, and the rise of what María Lugones describes as

coloniality of gender, the flesh of colonized and enslaved women on the island has been used to foster the rise of modernity in Europe and the United States. Yet, the wounds wrought in this process have rarely been accounted for or taught by those with power even as they remain in both cultural knowledge and the institutionalization of structural oppression across generations. Nor have processes of healing been addressed. This presentation engages studies in historical trauma, racial trauma, and Latina decolonial feminist theory to consider how Dahlma Llanos Figueroa attends to these wounds in her novel, *A Woman of Endurance*, in order to both expose the impact of historical violence against Afro-Puerto Rican women on the island and create a moment for creative healing as a decolonial social justice praxis in our current moment.

8E PAPER SESSION: Interrogating the Terms of Research

“Trauma Informed Abortion Research: Transforming Structures Shaping Debates”
Elizabeth Lanphier, Cincinnati Children's Hospital Medical Center

In a 2007 Supreme Court decision Justice Kennedy wrote that although “we find no reliable data to measure the phenomenon,” it nonetheless “seems unexceptionable to conclude some women come to regret their choice to abort the infant life they once created and sustained.” Qualitative and quantitative research collected since then, like that conducted in the Turnaway Study, shows that most people who have abortions do not come to regret them (notably this was not the primary research question the study set out to answer). Yet the idea of potential “abortion regret” persists in the collective imagination regarding abortion. And “abortion regret” continues to be a topic of qualitative, quantitative, and normative research.

This project interrogates the persistent body of scholarship perpetuating the concept of “abortion regret” through its continued study. I argue that the very research question reflects, but also shapes, a particular communal narrative regarding abortion. While this research may be well-intended to counter harmful or false narratives, it also upholds ideas reflecting both abortion stigma and “abortion exceptionalism.”

By describing and leaning on principles and practices of trauma-informed care, this paper explores how a trauma-informed approach (focusing on trust, transparency, voice, choice, inclusivity, and attention to historical and cultural stereotype, exclusion, or bias) could transform individual research projects related to “abortion regret” and yield necessary structural change regarding the very questions abortion research interrogates. It further argues that such a trauma-informed research approach is necessary for reshaping broader the cultural and collective imagination, experience, and debate about abortion.

“‘Control, Control, Control, Where’s Your Control?’ Drug Trials and the White Man’s Burden from *Arrowsmith* to AIDS”
Phillip Barrish, University of Texas at Austin

Sinclair Lewis’s 1925 bestselling novel *Arrowsmith*, for which Lewis famously rejected the Pulitzer Prize but which was a central factor in his 1930 Nobel Prize award, is the first prominent work of American fiction centrally to concern itself with both the supposed scientific necessity and the human implications of maintaining a “control” group of patients who do not

receive a therapeutic element being assessed, a research protocol not yet universally accepted as necessary in the early twentieth century. I argue that *Arrowsmith* elevates rigorous adherence to the controlled model of drug testing as the epitome of white imperial masculine toughness—indeed, a medical researcher’s version of Kipling’s “white man’s burden”— even, or especially, during the exigencies of a deadly epidemic, when withholding a promising treatment from an experimental control group may cost lives.

More than sixty years after the publication of *Arrowsmith*, HIV-AIDS activists powerfully challenged rigid adherence to testing protocols that required untreated control groups even as patients suffered and died for lack of approved treatments. I will argue that Lewis’s novel helps us to understand the prehistory of the cultural and ideological forces arrayed against those who called for alternative protocols for evaluating potential AIDS treatments.

“The Changing Identity of ‘Refugee’: A Structural Problem in Healthcare and Research”
Julie Aultman, Northeast Ohio Medical University

This paper examines the meaning and representation of the contextual, situational, and transitory identities of "refugees" and related labels (e.g., displaced persons, asylum-seeking, resettled refugee) of persons who have been compelled or forced to leave their countries of origin. "Refugee," as defined by national and international governments and organizations, is embodied by persons who are hopeful to acquire basic human needs and be protected in a safe environment so long as their plight and "well-founded fear of persecution" is acknowledged. Being identified as a refugee signifies both an entitlement to receive aid and an identity that becomes marginalized until a new identity emerges - citizen. The subjective criterion of how refugee is defined not only lends itself to the exclusion of persons who are entitled to basic human rights but perpetuates injustices within and external to resettlement structures. Because of how persons are labeled, the identities they choose or are forced to embody to survive, and the changes of status they experience over time (e.g., citizenship), there is often a lack of recognition of the trauma and re-traumatization our refugee populations experience during and following resettlement and the how their identities are shaped over time. These factors can impair healthcare delivery and research practices despite the value among persons to hide or change their "refugee" label in the effort to gain equality and respect within a new resettled environment. Thus, this presentation presents these dilemmas and challenges the very systems that contribute to injustice and disrespect of persons seeking refuge.

8F WORKSHOP: The Joy of Dementia: Creating a New Performance of Life (and Dementia)
Mary Fridley, East Side Institute

As viewed through a biomedical lens – which remains the dominant way in which dementia is seen – Alzheimer’s and related dementias (ADRD) is seen primarily as a condition of loss of capabilities within an individual: of speech, of cognitive abilities, of physical capacities and, eventually, of life while research and treatment is largely directed toward the individual. Dementia activists across the globe are now raising the question: How do we create radically humanistic alternatives to the shame- and stigma-laden “tragedy narrative” that has succeeded

in keeping dementia surrounded by a “cone of silence” even though millions are impacted by it across the world?

People living with dementia, care partners, activists, academics and artists are developing and advocating for approaches to practice and policy that support everyone in the “dementia ensemble” to grow and to creatively express their humanity. We will present one of the approaches and a project it has helped inform: The Joy of Dementia (You Gotta Be Kidding!), a workshop/conversation series that offers a playful, philosophical, and conversational collective exploration of the dementia experience through the lens of community-building and development.

Through this lens, humans are viewed, not as discrete and isolated individuals whose condition is “inside them,” but as relational beings, connected to one another in ways that allows us to build and grow with, rather than fear, dementia and other “conditions of uncertainty.” Participants are supported to challenge deeply held assumptions about what we and others “know” about the dementia experience, and it is within this collaborative ensemble building activity that the joy that comes with creating new performances of dementia is discovered.

In our view, we won’t get rid of stigma, or shame, or labeling, but we can play with them and in play, create something new, and then create and create and create again And if we stop, then we are vulnerable to the very ugly ways we know how to relate to each other.

So this experiential workshop will use improvisational games, creative exercises and philosophical/performed conversation to help participants experience in real time what it means to create an environment which supports everyone involved in the “dementia ensemble” to enjoy the “non-knowing growing” that is possible with improvisational play. This is especially important because people living with dementia all agree that, while the diagnosis presents its own set of challenges, it is the negative environments they often find themselves in that create the most hurt.

We welcome everyone – program staff, advocates, caregivers, people with dementia, academics, artists, activists, dementia and health care professionals and family and community members – looking for more intimate and compassionate ways to live with memory loss, aging and dementia; who are interested in using diagnosis as a starting point for creativity; and who want to discover together how to have more connection, growth, inclusion, hope...and yes, joy in even the most difficult of life situations.