

# ***Ethics of Seeking and Assessing "Quality of Life"***

## ***Annual Medical Ethics Conference – 2019***

**Friday, March 29, 2019 | 8:30 am – 4:20 pm**  
**Scaife Hall – 11<sup>th</sup> Floor Conference Center**  
**University of Pittsburgh**



**Plenary Lecture:**

***Quality of life: What is it, how is it measured, and how are the results used?***

Joel Tsevat, MD, MPH  
Professor of Medicine  
Joaquin G. Cigarroa, Jr., MD, Distinguished Chair  
Director, ReACH Center  
Director, KL2 Program, UT Health San Antonio  
Professor of Population Health, Dell Medical School, UT Austin

**Ira R. Messer Lecture:**

***Can We Avoid Death with Dementia?***

Dena S. Davis, JD, PhD  
Presidential Chair in Health  
Professor of Bioethics  
Lehigh University  
Duke University

**Keynote Lecture:**

***Accessing Justice: Reassessing "Quality of Life" through Disability Studies***

Robert McRuer, PhD  
Department of English  
George Washington University

## CONFERENCE OBJECTIVES

Following the conference, participants will be able to:

1. Understand the how different ways of conceptualizing and measuring quality of life—subjective and objective—affect both clinical decision-making (by patients, their surrogates, and clinicians) and health policy
2. Understand and be able to engage with disability studies perspectives in interpersonal interactions, policy discussions, and both academic and clinical contexts
3. Appreciate sociocultural and religious components of quality of life and the role they play in decision- making regarding health and healthcare

## The 28<sup>th</sup> Annual Medical Ethics Conference

Providing attendees with an opportunity to learn from national and local experts about pressing medical ethics issues, the Center's annual Medical Ethics Conference features morning plenary lectures with ample time for discussion and afternoon concurrent sessions. This course is designed for clinicians and researchers, health policy analysts, disability studies scholars, patient and disability rights advocates, lawyers, clergy, community members, and students of the humanities and health and social sciences.

### Medical Ethics 2019 is Co-Sponsored by:

Ira R. Messer Fund of the Pittsburgh Foundation  
Consortium Ethics Program, Center for Bioethics & Health Law, University of Pittsburgh  
Master of Arts in Bioethics Program, University of Pittsburgh  
Schools of Dental Medicine, Law, Medicine, and Social Work of the University of Pittsburgh  
School of Medicine Center for Continuing Education in the Health Sciences, University of Pittsburgh  
Center for Ethics & Policy, Carnegie Mellon University

## CONFERENCE SCHEDULE

<b>8:00 – 8:30 am</b>	<b>Registration and Continental Breakfast</b>
<b>8:30 – 8:35 am</b>	<b>Welcome</b> <a href="#">Lisa S. Parker, PhD*</a> Professor of Human Genetics Director, Center for Bioethics & Health Law University of Pittsburgh
<b>8:35 – 9:10 am</b> Opening Plenary Lecture	<b><i>Quality of Life: What is it, how is it measured, and how are the results used?</i></b> <a href="#">Joel Tsevat, MD, MPH</a> Professor of Medicine Joaquin G. Cigarroa, Jr., MD, Distinguished Chair Director, ReACH Center Director, KL2 Program, UT Health San Antonio Professor of Population Health, Dell Medical School, UT Austin
<b>Abstract:</b> Quality of life is a simple yet complex paradigm, with philosophers, ethicists, sociologists, psychologists, economists, theologians, clinicians, health services researchers, and lay persons all having different conceptualizations. As such, numerous measures of quality of life have been developed. This presentation will compare various definitions, concepts, measures, and uses of quality of life, with a particular focus on healthcare.	
<b>9:10 – 9:50 am</b>	<b><i>Disciplinary Perspectives on Quality of Life</i></b>

Panel	<p><b>Intellectual history:</b>  <a href="#">Jeff Aziz, PhD**</a>  Lecturer II, Department of English  University of Pittsburgh</p> <p><b>Religious Studies:</b>  <a href="#">Clark Chilson, PhD**</a>  Associate Professor of Religious Studies  University of Pittsburgh</p> <p><b>Bioethics:</b>  <a href="#">Mark Wicclair, PhD*</a>  Professor, Center for Bioethics &amp; Health Law  University of Pittsburgh</p>
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**Abstract:** On this panel, University of Pittsburgh faculty, drawn from different disciplines of the humanities, will trace the history of the concept of quality of life, discuss how the concept is employed in their disciplines, and examine the role played by “quality of life” in bioethical debates and decisions.

<b>9:50 – 10:00 am</b>	<b>Break</b>
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<b>10:00 – 11:00 am</b> Ira R. Messer Lecture	<p><b><i>Can We Avoid Death with Dementia?</i></b></p> <p><a href="#">Dena S. Davis, JD, PhD</a>  Presidential Chair in Health  Professor of Bioethics  Lehigh University</p>
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**Abstract:** For many Americans, dementia is incompatible with an acceptable quality of life. However, advance directives and death-with-dignity laws make it difficult if not impossible to shorten one’s life if one has dementia but is physically healthy. Is there any way out?

<b>11:00 am – noon</b> Keynote Lecture	<p><b><i>Accessing Justice: Reassessing “Quality of Life” through Disability Studies</i></b></p> <p><a href="#">Robert McRuer, PhD</a>  Department of English  George Washington University</p>
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**Abstract:** This talk will examine the connections between an increasingly-global movement for what has been termed “disability justice” and the interdisciplinary field of disability studies. It will place particular emphasis on the workings of ableism in culture, considering how bioethicists and disability studies scholars can work together to counter ableism.

<b>12:00 – 1:00 pm</b>	<b>Lunch on your own</b>
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<b>1:00 – 2:00 pm</b>	<b>Concurrent break-out sessions #1 – 3</b>
<b>Session #1</b>	<p><b><i>Life Immeasurable: The temptation to quantify quality</i></b></p> <p><a href="#">Jessica Benham, MA</a>  Doctoral candidate in the Department of Communication</p>

	<p>Master of Arts Program in Bioethics University of Pittsburgh</p> <p><a href="#">Robert McRuer, PhD</a> Department of English George Washington University</p> <p><a href="#">Candace Skibba, PhD**</a> Associate Teaching Professor Carnegie Mellon University</p>
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**Abstract:** In an era defined by measurable outcomes and metrics, heavily mediated by technology, has quality of life been over-quantified? This panel will attempt to disrupt the “metric crutch” by prompting discussions regarding the immeasurable aspects of quality of life, discrepancies between patient and doctor evaluations of QoL, and practical strategies for understanding QoL outside a quantifiable framework.

<b>Session #2</b>	<p><b><i>Spiritual Dimensions of Quality of Life</i></b></p> <p><a href="#">Joel Tsevat, MD, MPH</a> Professor of Medicine Joaquin G. Cigarroa, Jr., MD, Distinguished Chair Director, ReACH Center Director, KL2 Program, UT Health San Antonio Professor of Population Health, Dell Medical School, UT Austin</p> <p><a href="#">Clark Chilson, PhD**</a> Associate Professor of Religious Studies University of Pittsburgh</p> <p>Other Panelist TBD</p>
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**Abstract:**

<b>Session #3</b>	<p><b><i>Quality of Life in Chronic Illness: When patient and caregiver appraisals differ</i></b></p> <p><a href="#">Jennifer Lingler, PhD, RN**</a> Professor of Community &amp; Health Systems School of Nursing University of Pittsburgh</p> <p><a href="#">Amar D. Bansal, MD</a> Assistant Professor of Medicine Section of Palliative Care and Medical Ethics University of Pittsburgh</p> <p><a href="#">Marci Nilsen, PhD, RN**</a> Assistant Professor of Acute &amp; Tertiary Care School of Nursing University of Pittsburgh</p>
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**Abstract:** Chronic illness affects the physical, psychological, and social domains of life for persons with chronic illness. Quality of life assessments by patients or their family caregivers (as proxy raters) can be used in both research and clinical practice to evaluate patient needs, measure the effect of interventions, and guide decision-making about care. However, patients and their caregivers may not provide concordant appraisals of the patient’s quality of life, thus raising questions about how and by whom quality of life should be assessed. In this session we will present findings from a study of quality of life assessments for patients with early stage Alzheimer’s disease, which compares patients’ self-assessments to assessments made by their family caregivers. Panelists with expertise in diverse chronic illness populations will offer a response to issues raised by the findings presented, including the possibility that caregivers’ appraisals can be influenced by how the patient’s condition has impacted their own quality of life. A moderated panel discussion will address the implications of this work for research, decision-making and clinical care.

<b>2:00 – 2:10 pm</b>	<b>Break</b>
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<b>2:10 – 3:10 pm</b>	<b>Concurrent break-out sessions #4 – 6</b>
<b>Session #4</b>	<p><b><i>Decision-making on behalf of children: Complexity is in the eye of the beholder</i></b></p> <p>Ika and Charlie Lozinger Parents</p> <p><a href="#">Alexander R. Nesbitt, MD</a> Medical Director UPMC Susquehanna Hospice and Palliative Care</p>

**Abstract:** We will discuss the ethics of decision-making and complex situations that parents and healthcare professionals face when working with children with complex needs. What causes burden to families, with what unwitting biases do well-meaning clinicians muddy the water, and how/why might our best clinical intentions be misaligned or possibly harmful to patients and families?

<b>Session #5</b>	<p><b><i>Quality of Life in Hand Transplantation: Empirical and ethical challenges after 20 years of human experiments</i></b></p> <p><a href="#">Emily Herrington, MS</a> Doctoral candidate in the Department of Communication Master of Arts Program in Bioethics University of Pittsburgh</p> <p><a href="#">Jessie Soodalter, MD, MA**</a> Clinical Instructor of Medicine University of Pittsburgh</p> <p><a href="#">Warren Breidenbach, MD, MSc</a> The Metis Foundation San Antonio, TX</p>
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**Abstract:** The very notion that enhancing quality of life (QoL) could be the primary goal of what was deemed the ultimate life-saving intervention has been called “a quiet revolution in organ transplantation ethics” by prominent bioethics scholars. Nevertheless, twenty years after the first speculative discussions of the risks and benefits of hand transplantation, the specific nature of the tradeoffs among health, longevity, and QoL are still unclear. Despite having paved the way for face transplants, womb transplants, and penis transplants, fewer than 100 hand transplants have been performed to date, which complicates efforts to evaluate the results “objectively.” In this

panel we will discuss challenges to understanding QoL-related effects of hand transplantation and the importance of developing integrated assessment and evaluation tools in this still evolving field of reconstructive transplantation.

<b>Session #6</b>	<p><b><i>Quality of Life in Long-term Care: Mandates and measures</i></b></p> <p><a href="#">Howard Degenholtz, PhD*</a> Associate Professor of Health Policy and Management University of Pittsburgh</p> <p><a href="#">Tara McMullen, PhD, MPH</a> Centers for Medicare &amp; Medicaid Services</p> <p><a href="#">Rollin M. Wright, MD, MS, MPH, MA</a> Assistant Professor of Geriatric Medicine University of Pittsburgh</p>
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**Abstract:** Nursing homes may seem like the last place to seek quality of life. Traditionally, the medical model has focused on quality of care to the exclusion of quality of life. However, the introduction of preference items into the MDS 3.0, a health status assessment tool used in nursing homes, as well as tools for delivering person-centered care, have made quality of life not just objectively measurable, but achievable. This session will discuss the ethical challenges inherent in defining ‘the good life’ for people with varying levels of physical and cognitive function. It will also address national and state models for improving quality of life, and explore the opportunities and potential pitfalls of incentivizing nursing homes to prioritize quality of life relative to quality of care.

<b>3:10 – 3:20 pm</b>	<b>Break</b>
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<b>3:20 – 4:20 pm</b>	<b>Concurrent break-out sessions #7 – 9</b>
<b>Session #7</b>	<p><b><i>Inauspicious Beginnings: Perceptions and misconceptions regarding the quality of life of medically complex children</i></b></p> <p><a href="#">Michael A. Freeman, MD, MA</a> Assistant Professor of Pediatrics and Humanities Penn State Hershey Children’s Hospital Penn State College of Medicine</p>

**Abstract:** When making care decisions in medically complex infants and children, we must rely upon shared decision-making between families and healthcare teams, influenced by our incomplete understanding of issues such as prognosis and the expected burdens and benefits of treatment, that is to say the quality of life. Unfortunately, research has suggested that healthcare providers and families often have a divergent view of the quality of life in these children, which in turn has a profound influence on counselling and medical decision-making. Furthermore, decision-making may be different in the very young as compared to older children and adults, a finding which demonstrates the complex influence of relationship and concepts of “personhood” in medical decision-making. In this presentation we will review some of the research on this topic, explore the practical and ethical implications of these issues, and examine the influence of these issues within the context of children with kidney failure.

<b>Session #8</b>	<p><b><i>What Matters Most—Understanding and honoring our patients’ highest goals</i></b></p> <p><a href="#">Alexander R. Nesbitt, MD</a> Medical Director UPMC Susquehanna Hospice and Palliative Care</p>
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**Abstract:** This discussion will address the care of individuals with serious illness. Specifically, we will consider how those involved in their medical care ask about, understand, document, and work toward helping to achieve what matters most to the individual. We will discuss the “Serious Illness Conversation,” and the concept of “Goal Identification and Scaling.” We will work to address the theoretical importance of focusing on patients’ goals and the practical considerations of developing systems of care that routinely and thoroughly incorporate values-based discussions into the system of care.

<b>Session #9</b>	<p><b><i>Ethical Implications of Decisions Made in Constructing Quality of Life Measures</i></b></p> <p><a href="#"><u>Janel Hanmer, MD, PhD</u></a>  Assistant Professor of Medicine  Medical Director, UPMC Patient Reported Outcomes Center  University of Pittsburgh</p> <p><a href="#"><u>Barry Dewitt, MSc, PhD</u></a>  Postdoctoral Research Scientist  Engineering and Public Policy  College of Engineering  Carnegie Mellon University</p>
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**Abstract:** Preference-based health-related quality of life measures are used in healthcare technology assessment like cost-effectiveness analyses. Summarizing health-related quality of life into a single summary score requires that the developers make several design decisions that have ethical implications. In this presentation we will discuss three of these decisions: how to aggregate heterogeneous preferences, how to incorporate the utility of death, and if/how to apply exclusion criteria to survey responses.

<b>4:20 – 4:30 pm</b>	<p><b>Wrap-up and Evaluation</b></p> <p><a href="#"><u>Lisa S. Parker, PhD*</u></a>  Professor of Human Genetics  Director, Center for Bioethics &amp; Health Law  University of Pittsburgh</p>
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<b>4:30 pm</b>	<b>Conference Adjournment</b>
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**COURSE DIRECTOR**

\*Lisa S. Parker, PhD, Professor of Human Genetics and Director of the Center for Bioethics & Health Law

**CONFERENCE PLANNING COMMITTEE**

- \*Howard Degenholtz, PhD, Associate Professor of Health Policy and Management, University of Pittsburgh
- \*\*Paula Leslie, PhD, MA, CCC-SLP, FRCSLT, Professor and Director of Doctor of Clinical Science in Medical Speech-Language Pathology Program, School of Health and Rehabilitative Sciences, University of Pittsburgh
- Joann Prasad, DDS, MPH, Associate Professor, Assistant Dean for Academic Affairs, School of Dental Medicine, University of Pittsburgh
- \*\*Valerie Satkoske, PhD, Director of Ethics, Assistant Professor of Medicine and Associate Director of the Center for Health Ethics & Law, West Virginia University
- \*\*Jennifer Seaman, PhD, RN, Assistant Professor of Acute & Tertiary Care, School of Nursing, University of Pittsburgh
- \*\*Candace Skibba, PhD, Associate Teaching Professor, Carnegie Mellon University
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This program has been approved by the **Pennsylvania Continuing Legal Education Board** for (6) hours of substantive credit, available to those who have registered and paid the \$120 fee for processing CLE credit for this event.

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*Participation by all individuals is encouraged. Advance notification of any special needs will help us provide better service. Contact [bioethics@pitt.edu](mailto:bioethics@pitt.edu).*