“Patient-Centered Practice Informs Community-Based Health Research: The Development of I. D. E. A. to Improve Maternal Health Outcomes”

Karen Tabb Dina, School of Social Work
Brandon Meline, Champaign-Urbana Public Health District
David Huang, College of Education
IHSI: Catalyzing, Supporting, and Uniting Illinois Health Sciences Research

SYNERGIZING HEALTH SCIENCES: WHAT WE DO

**CATALYZE**
We CATALYZE health research by identifying common interests and strengths at Illinois.

**CONNECT**
We CONNECT investigators and labs with clinical partners and resources, for greater collaboration.

**SUPPORT**
We SUPPORT research projects and studies from novel ideas to successful collaborations.

**ENGAGE**
We ENGAGE local and global communities in participatory health sciences research and through outreach.
In 1966, Dr. Martin Luther King Jr stated “Of all forms of discrimination and inequalities, injustice in health is the most shocking and inhuman.”

Health disparities are large, persistent, and intergenerational.
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PATIENT CENTERED PRACTICE INFORMS COMMUNITY BASED HEALTH RESEARCH

THE DEVELOPMENT OF I.D.E.A TO IMPROVE MATERNAL HEALTH OUTCOMES
DISCLOSURES

• NO CONFLICTS TO DISCLOSE
INTERDISCIPLINARY TEAM

- School of Social Work
- Champaign-Urbana Public Health District
- College of Education
SETTING

• Champaign-Urbana Public Health District
• Division of Maternal Child Health (MCH) of a public health clinic in Illinois.
• This clinic provides free and low-cost services to at-risk mothers living in Champaign County, including family case management, perinatal home visits, WIC (Women, Infant, and Children), immunizations, lactation, and nutrition counseling.
UNIVERSITY-COMMUNITY PARTNERSHIP

• Community Engagement
• Improving Clinical Practice
• Broadening the Horizon of Public Health Districts and Research Involvement
DISPARITIES IN CHAMPAIGN COUNTY

- RACE
- ETHNICITY
- INCOME
- PLACE
- LIFE EXPECTANCY
DISPARITIES IN CHAMPAIGN COUNTY

• RACE
• ETHNICITY
• INCOME
• PLACE
• LIFE
• EXPECTANCY
DISPARITIES IN CHAMPAIGN COUNTY

- RACE
- ETHNICITY
- INCOME
- PLACE
- LIFE EXPECTANCY
DISPARITIES IN CHAMPAIGN COUNTY

- RACE
- ETHNICITY
- INCOME
- PLACE
- LIFE EXPECTANCY
DISPARITIES IN MATERNAL MENTAL HEALTH

• AGE
• RACE
• ETHNICITY
• INCOME
• PLACE
PERINATAL MENTAL HEALTH DISORDERS

• Perinatal mental health disorders are the leading causes of maternal morbidity and mortality.
  • Perinatal Depression
  • Perinatal Anxiety
  • Bipolar Disorder
  • Perinatal Psychosis

• Perinatal Depression - 8-14%
  • 30-50% any treatment
Ivanka Trump reveals struggle postpartum depression

By Susan Scott, CNN
Updated 1:41 AM ET, Thu September 21, 2017

Ivanka Trump revealed she had postpartum depression in an interview with Dr. Oz.
UNTREATED PERINATAL DEPRESSION: NEONATAL RISKS

- Preterm birth
- Lower birth weight
- Lower APGARs
- Intrauterine growth restriction
- Increased admission to NICU
- Excessive crying, more inconsolable

UNTREATED PERINATAL DEPRESSION: OBSTETRIC RISKS

- Gestational DM
- Substance use
- Poor nutrition, weight gain
- Poor prenatal care
- Preeclampsia
- Increased C-section
- Decreased pain tolerance

UNTREATED DEPRESSION AND CHILDREN

- Bonding
- Breastfeeding
- Cognition and development
- Depression and suicide in offspring
DEPRESSION SCREENING

• Public health approach
  • State mandates to screen for depression

• Perinatal Mental Health Disorders Prevention and Treatment Act of 2008

• Hotline for assistance

Perinatal depression affects as many as one in seven women.

ACOG recommends all pregnant women be screened at least once during the perinatal period.
BARRIERS TO SCREENING
Perinatal depression screening in a Women, Infants, and Children (WIC) program: perception of feasibility and acceptability among a multidisciplinary staff

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POORLY COORDINATED SERVICES

- PRIMARY CARE
- COMMUNITY MENTAL HEALTH
- SUBSTANCE ABUSE TREATMENT
- SOCIAL SERVICES
Who are we?
- PATIENTS, researchers, clinicians, and administrators.

Collaborators come from:
- Patients
- Local non-for-profits
- Treatment providers
- University of Illinois-Urbana Champaign (including students)
- Champaign-Urbana Public Health District
- Promise Francis Nelson (FQHC)
PATIENT CENTERED OUTCOMES RESEARCH INSTITUTE (PCORI)

- Authorized by Congress in 2010 as part of the Patient Protection and Affordable Care Act (PPACA)

- PCORI supports “research that addresses the questions and concerns most relevant to patients, and we involve patients, caregivers, clinicians, and other healthcare stakeholders, along with researchers, throughout the process”.

PCORI Pipeline to Proposal and Research Engagement Awards

- PIPELINE (TIER A)
- CAPACITY BUILDING WORKSHOP
- PERINATAL DEPRESSION CER NETWORK
- SCIENTIFIC PROPOSAL

2017 → 2023
I.D.E.A. Women’s Coalition

- Awareness Campaign
- Research Development

<1 YEAR!

Activities:
- Pregnancy Expo
- Town Hall
- Happy/Coffee Hours
- Advisory Board
- Maternal Mental Health Month
- Capacity Building Workshop
PATIENT-ENGAGED RESEARCH CER

- Community Engagement
  - Pregnancy Expo
    - Town Hall
    - Coffee Hours
    - Happy Hour
- Patients as Partners
  - Design
  - Dissemination
  - Capacity Building
- Comparative Effectiveness Research
  - Shared research questions
PATIENT-ENGAGED RESEARCH CER

• Community Engagement
  • Pregnancy Expo
  • Town Hall
  • Coffee Hours
  • Happy Hour

• Patients as Partners
  • Design
  • Dissemination
  • Capacity Building

• Comparative Effectiveness Research
  • Shared research questions
PATIENT-ENGAGED RESEARCH CER

• Community Engagement
  • Pregnancy Expo
  • Town Hall
  • **Coffee Hours**
    • Happy Hour
• Patients as Partners
  • Design
  • Dissemination
  • Capacity Building
• Comparative Effectiveness Research
  • Shared research questions
PATIENT-ENGAGED RESEARCH CER

- Community Engagement
  - Pregnancy Expo
  - Town Hall
  - Coffee Hours
  - Happy Hour
- Patients as Partners
  - ADVISORY BOARD
    - Design
    - Dissemination
    - Capacity Building
- Comparative Effectiveness Research
  - Shared research questions
EXPECTATIONS OF THE ADVISORY BOARD

• ENGAGE IN RESEARCH
  • COME UP WITH CER RESEARCH IDEAS

• Set a Governance Structure
• 1-3 hours per month
• Attend monthly meetings
• Complete action items (homework) between meetings
• Assist in building the coalition increasing membership
COMPARATIVE EFFECTIVENESS RESEARCH

Comparing two or more options?

Studying the risks and benefits (outcomes) of the options?

Comparing options proven to be effective?

Assessing which options are better for your population?
CER ideas must be important to BOTH patients and researchers. Ideas must include all of the following:

| Health topic | Population who will benefit from the research | Importance of CER idea to your partnership(s) | Description of how the ideas may lead to a CER question |
ORGANIZATIONAL DEVELOPMENT

- Best practice with multiple stakeholders
- Process-Oriented/Process Exploration
- Group decision-making
- Empowering underrepresented populations
- Documentation
EDUCATIONAL INTERVENTIONS

- Stakeholders’ buy-in
- Learner-centered
- Formal and informal learning opportunities
- Transfer & transformation of performance at community level
- Evaluation for continuous improvement

Sustainable  Transformational  Accessible
THANK YOU

KAREN TABB DINA, ASSISTANT PROFESSOR, UNIVERSITY OF ILLINOIS SCHOOL OF SOCIAL WORK

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PATIENT CENTERED OUTCOMES RESEARCH INSTITUTE
NATIONAL INSTITUTE FOR MINORITY HEALTH DISPARITIES
REFERENCES


DEPRESSION AND PERINATAL HEALTH OUTCOMES

- Very preterm birth leading to mortality
- Tobacco and Alcohol Use
- Worsening Depression
- Suicide
  - 20% postpartum deaths

Bottorff et al 2014, LaViest 2006, SUICIDE CITATION
## Screening Tools

<table>
<thead>
<tr>
<th>Screening Tool</th>
<th>Number of Items</th>
<th>Time to Complete (Minutes)</th>
<th>Sensitivity and Specificity</th>
<th>Spanish Available</th>
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<tbody>
<tr>
<td>Edinburgh Postnatal Depression Scale</td>
<td>10</td>
<td>Less than 5</td>
<td>Sensitivity 59–100%, Specificity 49–100%</td>
<td>Yes</td>
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<tr>
<td>Postpartum Depression Screening Scale</td>
<td>35</td>
<td>5–10</td>
<td>Sensitivity 91–94%, Specificity 72–98%</td>
<td>Yes</td>
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<tr>
<td>Patient Health Questionnaire 9</td>
<td>9</td>
<td>Less than 5</td>
<td>Sensitivity 75%, Specificity 90%</td>
<td>Yes</td>
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<tr>
<td>Beck Depression Inventory</td>
<td>21</td>
<td>5–10</td>
<td>Sensitivity 47.6–82%, Specificity 85.9–89%</td>
<td>Yes</td>
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<tr>
<td>Beck Depression Inventory-II</td>
<td>21</td>
<td>5–10</td>
<td>Sensitivity 56–57%, Specificity 97–100%</td>
<td>Yes</td>
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<tr>
<td>Center for Epidemiologic Studies Depression Scale</td>
<td>20</td>
<td>5–10</td>
<td>Sensitivity 60%, Specificity 92%</td>
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<tr>
<td>Zung Self-rating Depression Scale</td>
<td>20</td>
<td>5–10</td>
<td>Sensitivity 45–89%, Specificity 77–88%</td>
<td>No</td>
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