

RESEARCH ARTICLE

## Motivated by a mandate: a university-clinic partnership to develop a perinatal depression registry at a community based hospital in the Midwest

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**Abstract:** Disparities in maternal mental health outcomes persist despite the myriad of existing evidence based treatments and recent public health prevention policy efforts. Integrated health care delivery models such as Collaborative Care and patient medical home models have the potential to reduce health disparities in clinic settings. These evidence-based approaches require multidisciplinary teams for successful implementation and to provide quality care to improve specified patient outcomes. However, strategies for successful collaboration and steps for critical reflection are often overlooked in clinical and health services research. Furthermore, a shared vision of social justice is essential in the process of building and sustaining patient-centered care models, but is often understated. The purpose of this paper is to describe the development and implementation of a social justice-informed hospital-based perinatal depression registry to address maternal health disparities. Our partnership is informed by community-based participatory research (CBPR) principles for carrying out health services research. We describe the steps for building a sustainable university-hospital collaboration between traditional and non-traditional researchers using principles from CBPR in a clinic setting.

**Keywords:** community-based participatory research, maternal mental health, perinatal depression, psychosocial screening

### 1 Background

Depression is one of the most common conditions in pregnancy, affecting up to 12.7% of pregnant women<sup>[1]</sup> and is the leading cause of disease-related disability during this period.<sup>[2]</sup> Women with depression during pregnancy face increased risk for preterm births and delivering both low birth weight and very low birth weight infants,<sup>[3]</sup> who are in turn at high risk for infant death in the first year of life.<sup>[4]</sup> Depression during pregnancy is

also a risk factor for depression in the postpartum period.<sup>[5,6]</sup> Adverse health outcomes as a result of untreated depression extend from mother to infant. For instance, postpartum depression is associated with delayed infant development,<sup>[7]</sup> impaired maternal-infant attachment,<sup>[8,9]</sup> and suboptimal breastfeeding.<sup>[10,11]</sup> Furthermore, women with psychiatric illness while pregnant are at increased risk for suicidal ideation.<sup>[12-14]</sup> Growing evidence shows that racial and ethnic minority women, in particular those of lower socioeconomic status, may experience increased risk for perinatal mood disorders.<sup>[15,16]</sup> Given the deleterious effects of depression during pregnancy on infants and mothers over the life course, recent preventive efforts have begun to more directly address perinatal depression.

### 2 Methods

#### 2.1 Depression screening policies in the perinatal period

In 2016, the U.S. Preventive Task Force recommended that adults (including pregnant and post-partum women) be screened for depression.<sup>[17]</sup> For many women, prena-

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tal clinic visits may represent their only encounter with health care professionals and are a critical point for assessing mood disorders.<sup>[18,19]</sup> Case detection of depression in the perinatal period can be followed by provision of evidence-based treatments to reduce maternal morbidity/mortality as well as adverse birth outcomes. Screening instruments for perinatal depressive symptoms include the Edinburgh Postnatal Depression Scale (EPDS),<sup>[20]</sup> the Patient Health Questionnaire-9 (PHQ-9),<sup>[21]</sup> the Center for Epidemiologic Studies Depression Scale (CES-D),<sup>[22]</sup> and the Beck Depression Inventory (BDI).<sup>[23]</sup> Many questions remain, however, about which instrument to use and in which trimester to screen. More studies are required to demonstrate the optimal method, timing, and utility of perinatal screening for mood disorders.

## 2.2 State mandates to screen for perinatal depression

Several new policy initiatives and state-level mandates have begun to address the need for detection of mental health problems during the perinatal period. Often times, the need for a state-level mandate emerges after highly publicized cases of maternal mental illness. One such example is the Melanie Blocker Stokes MOTHERS Act which became part of the Patient Protection and Affordable Care Act legislation in 2010.<sup>[24]</sup> Melanie Block Stokes was a young woman who committed suicide after several months of unsuccessful treatment for postpartum depression in 2001. The Melanie Blocker Stokes MOTHERS Act is a comprehensive policy to reduce the burden of post-partum depression through research, screening, and support services. Only recently have health policy experts begun to identify the associated benefits, costs,<sup>[25]</sup> and barriers to screening<sup>[26]</sup> because of state policy mandates for depression screening. In 2008, Illinois became the second state to mandate depression screening at least once during pregnancy and once during postpartum for women receiving any perinatal care. Although all women receiving care in Central Illinois clinics now complete a depression screening, best practices for screening and the prevalence estimates for perinatal depression in Central Illinois have not yet been established. Collaborative health services research has the potential to inform the broader clinical community and to identify possible disparities in the prevalence of depression and its treatment to inform state policy efforts.

## 2.3 The role of mental health registries

Since best practices for identifying perinatal women in need of depression care, clinics and hospital systems have taken the task upon themselves and created local efforts to screen for depression. The majority of findings from perinatal database registries tend to originate in urban coastal areas and/or well-resourced academic medical centers. The settings of existing registries complicate the applicability to rural or suburban areas in the Midwest. Despite detailed descriptions strategies to implement registries and use chart data to inform practice, the process can be more difficult in under-resourced settings that are not affiliated with academic centers. To address this limitation and to develop best practices in a large private hospital setting, we launched a collaborative effort to initiate perinatal depression screening in outpatient OBGYN clinics in Central Illinois. To make use of clinical data and work towards full implementation of a collaborative care model we initiated a depression registry. The guiding impetus in all of our discussions leading up to starting the registry was a shared commitment to social justice and improving health outcomes for patients.

## 3 Purpose

The purpose of a database registry is to gather and store large quantities of data related to a specific disease or conditions. This approach is commonly used in research conducted by traditional academic health services researchers (MD or PhD level researchers). Registry designs often require a team approach, drawing from the expertise of its members in order to provide certain contributions to the research. In our region, there remains a shortage of health care providers and an even smaller pool of health care providers with research interests. Because of these circumstances, we tried to be creative when building our team of research partners. In 2012, we established the Identifying Depression through Early Assessment (IDEA) Research Team as a collaboration between university faculty, nurse practitioners, physician assistants, psychiatrists and undergraduate and graduate students.

## 4 Procedures

### 4.1 Setting

The IDEA Research Team Perinatal Depression registry was developed at Carle Foundation Hospital, Urbana, Illinois with support from various local funding sources. Carle Foundation Hospital is a 345-bed re-

gional care hospital housing the area's only Level III perinatal services and Level I trauma care. The catchment area spans a 100-mile radius and serves nearly 8 million residents of mostly rural central Illinois. The main hospital is located in a suburban town but serves 13 surrounding rural counties. The Research Institute at Carle provided the infrastructure and support to develop the perinatal depression registry. In our initial conversations about health inequalities at the clinic level, we began an exploratory discussion with the Carle Research Institute and the Carle Department of Social Work. We began our conversations with the Department of Social Work because of the department's oversight on all perinatal depression screens. Since the implementation of the State Mandate to screen for depression, the perinatal social workers were charged with screening all postpartum women prior to discharge from labor and delivery. The Department of Social Work and the Carle Research Institute facilitated meetings with health care providers from the clinics.

## 4.2 Social justice and clinical research

A shared commitment to social justice is inherent to our collaboration and is also directly integrated into our partnership. Figure 1 provides an illustration of how our team integrates practice knowledge and Community-based participatory research (CBPR) principles in clinical research in our health services research collaboration. CBPR is an approach used in community research, but not commonly used in mainstream clinical and health services research.<sup>[27]</sup> The specific principles we draw from are Sharing Power, Capacity Building, Shared Dissemination, Shared Long-term Goals, and Sustainability. For example, starting with our very early discussions on health disparities and clinic research we have been committed to Sharing Power and Capacity Building as guiding principles for building our team.



**Figure 1.** Heuristic depiction of integration of social justice principles to improve perinatal mental health

From those early meetings we approached the clinic as the community and began a series of multiple key stakeholder meetings with practitioners to learn the perceived needs of the clinic and the potential role of research to improve both clinic practice and patient outcomes. We met with nurse midwives, physician assistants, nurses, obstetricians, and nurse managers in separate meetings to hear the collective opinions by practice area.

## 4.3 Valuing practice knowledge

After three months of discussions, six practitioners with an interest in clinical research remained as core team members. One of the most important drivers for participation as a part of a research team was the potential to address community needs through presenting evidence (*i.e.* research findings) of the level of need. Our remaining team represented a diverse set of practitioners from psychology, maternal fetal medicine, nursing, and social work. Our clinic-based team members described their motivation for becoming involved in research after years of practice in the same community. The providers described having witnessed vast changes in the socio-demographics of their patient population over time. The providers believe that the clinic is now more diverse culturally and racially than ever before. Along with the shifting demographics of the clinic, there are added challenges in patient communication such as language barriers and educational disparities. Providers in our clinic find it difficult to identify possible risks for pregnancy complications among foreign-born patients if they do not speak the language. Yet another motivation to participate in research is a desire to determine the extent of the increasing number of patients who have comorbidities associated pregnancy complications. Several members of our team sought to better understand the specific complicated cases and learn if the high-risk patients are reflective of epidemiological patterns across clinics in our catchment area. In our collaboration, the providers receive no incentives for participation in research and are driven by a desire to provide superior care. The practice knowledge of team members is highly valued and often shapes research questions.

## 4.4 Sharing power

Medical, psychological, and social work perspectives have come together to address pressing unmet health care needs in a large private hospital that serves a mostly rural catchment area. The team has come together to carry out health services research because there is a shared desire to address disparities in the local population. Given the different training backgrounds and roles within the clinic there are different norms and expectation of power. We

have taken several deliberate steps to address the power imbalance that is inherent in medical hierarchies. For example, in our monthly planning meetings and in communications we address one another by first name. In all of our discussions to design the research protocol, to propose research questions, or to request external funding, each team member has an active voice and all contributions are respected. In our collaboration, all team members are equal partners.

#### 4.5 Capacity building

Capacity building is central to our efforts to collaborate and address maternal health disparities by carrying out health services research based on the principles of CBPR. As a team, we decided early in the process that there was need for insider perspective and partnership when conducting the research. As a team of nontraditional researchers, we could gain from one another and the perspectives from peer-clinicians could improve our approach to conducting social-justice oriented research. Accordingly, from the very inception of the IDEA research team, capacity building of team members and affiliated practitioners has central to our mission. To this end, there is vertical mentoring across practice areas and within the team. Some members bring expertise with funding application preparation and others bring knowledge of psychotropic medications or how to interpret blood glucose levels. As a team, we are actively building the capacity of one another to conduct rigorous and meaningful research. For example, in the early stages of the registry project, and prior to ethics committee approval, all core team members were required to complete and pass a 20-module human subjects ethics training. The training proved challenging depending on years of education or previous experience with research. By the end of the training, most members of the team found it a rewarding experience. In other areas of capacity building, the PhD or MD level partners assisted with how to draft a research abstract or prepare a funding application. Now after nearly two years of partnership, the other members of the team are peer mentoring clinical colleagues on research methods and dissemination of case reports. Given the persistence of mental health disparities and the gap between research and practice, the increase in formation of partnerships such as ours are going to be necessary to improve our health care system.<sup>[19]</sup> Using or translational approach to understanding the extent of perinatal health disparities we jointly think through and discuss our research questions. For example, from a physician assistant perspective, the use of nutritional supplements to treat depression over pharmacological treatments during pregnancy was of specific

interest. For the nurse practitioners from maternal and fetal medicine, the role of polycystic ovarian syndrome and risk for depression was of keen interests. For now, the overarching aim of the perinatal registry is to gather data to analyze the prevalence of mood disorders and co-occurring health problems obtained from chart reviews from pregnant and postpartum women and their infants in a racially and ethnically diverse obstetrics and gynecology clinic in order to determine the prevalence of mood disorders and associated factors in this population and the impact on postpartum outcomes. All members of the research team bring their professional expertise and background to design research questions. Given the disciplinary diversity in the team, our current research questions are broad and range from examining the relationship between depression and diabetes to the association between depressive symptoms and advanced maternal age.

#### 4.6 Design

The IDEA Research Team implemented a database that utilizes a longitudinal cohort design. We enter chart data from women from the first pregnancy visit and from the women and their infants from post-partum visits up to six. Enrollment into the database is scheduled to continue for 5 years or after enrollment of 20,000 women. The proposed sample size of 20,000 will allow for complex nested and longitudinal statistical analyses. Clinic staff will provide the depression screenings to all patients as part of routine clinic care. The database is a list of de-identified patient participants whose pregnancy related clinic data, along with the infant data will be used for chart review research. We will examine the prevalence and the course of maternal mood disorders and their relationship with health status and medical conditions for both mother and infant.

### 5 Sustainability and dissemination

#### 5.1 Funding mechanisms

To date, the majority of our funding support is from internal grants and foundation funding. We have been successful in obtain pilot funds to establish the database registry and have applied for external federal funding and will continue to do so in the near future. Our research is also eligible for numerous federal and private awards. In recent years, there has been an increase in funding to strengthen the infrastructure for health services research to improve health outcomes aimed to reduce disparities. Examples of organizations that participate in this type system level research funding awards

are Patient Centered Outcomes Research Institute, the National Institute of Minority Health Disparities, and the Robert Wood Johnson Foundation. In addition, recent efforts both among government agencies and private interests are providing support for collaborative research.<sup>[28]</sup> Power sharing and capacity building are evident in our approach to funding. All members of the team actively seek opportunities for funding, are active co-investigators on applications, and contribute to the writing process.

## 5.2 Dissemination

Writing collectively to share the findings and a description of our research process must integrate different disciplinary perspectives which can sometimes result in a stew of varying concepts. To this end, our monthly meetings represent a space for our team to talk through ideas and share disciplinary knowledge to clearly convey our various perspectives. Once again power sharing is imperative to make sure that all voices are included in the writing process. The meetings inform research directions, but also serve as reflective practices for all team members.<sup>[29]</sup> As we move forward, it will become imperative for our team to develop and refine our model of dissemination so that we can write both across audiences and within our specific subfields.

## 5.3 Shared long term goals and sustainability

Our team came together as a band of researchers with a shared goal to reduce maternal health disparities to ultimately advance social justice. Our individual commitments to social justice oriented research and practice extend beyond the research partnership. Concurrently our collective commitments to social justice keep the team motivated to sustain the project for the long term. Our shared goal is to develop a Collaborative Care model where we can actively address maternal mental health disparities through reorganization of existing resources in the outpatient setting.<sup>[30]</sup> It is this vision to employ research to improve patients' outcomes that motivates our research team. The perinatal depression registry we have described in this paper is one social-justice oriented approach to directly address disparities in maternal mental health and attempt to test a novel concept of applying CBPR principle within a clinic setting. There is a need to increase these forms of partnerships to advance health services research and address health disparities, especially in non-metropolitan settings.

## 6 Conclusion

Social Justice informed approaches to health services research are essential to be able to forcefully address perinatal mental health disparities. In our example, our team was brought together through a shared purpose to determine the level of health inequality in our community. Moreover, the manner in which we engage with our research collaborators uses principles of the social justice for mental health framework. While our case study presents one example, future collaborations of multidisciplinary teams conducting social justice informed research are essential to tackle mental health disparities and improve health outcomes across all populations.

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