The Unseen Side of Pregnancy

Non-Communicable Diseases and Maternal Health





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PART ONE Non-communicable Diseases and Maternal Health: An Overview

Non-communicable diseases (NCDs), often referred to as chronic illnesses, could affect every person on the planet as their incidence continues to rise. While NCDs know no boundaries, women of reproductive age, and specifically women in the perinatal period (pregnancy and one year postpartum) are particularly susceptible.¹ Pregnant women with an NCD face many risks ranging from mild, temporary complications to permanent disability and/or death of both the mother and the newborn.

Globally, some 18 million women of reproductive age die each year from NCDs² and two in every three deaths among women are due to an NCD.³ Everywhere in the world, except on the African continent, NCDs are the leading cause of death for both men and women,⁴ and by 2030, Africa is projected to join the rest of the world as NCDs surpass infectious diseases as the primary cause of death.⁵ Disturbingly, women's specific challenges and needs are often dismissed in conversations about NCDs. Women are excluded from or underrepresented in clinical research, and the way medical conditions affect women is often not considered.⁶ In addition, NCD-related symptoms during pregnancy are commonly misinterpreted as normal (by women themselves) and women's reported symptoms during pregnancy, and in general, are often dismissed by clinicians.^{7, 8}

According to the World Health Organization (WHO), although NCDs have been the leading cause of death among women globally for at least the past 30 years, three enduring myths help explain why NCDs in women have been ignored:

1

The persistent view that health-related issues of importance to women are defined through their reproductive capacity;

2

The misperception that NCDs, especially cardiovascular diseases, are primarily men's diseases; and

The myth that NCDs in women are an issue only in high-income countries and result from lifestyle choices.⁹

Non-communicable Diseases (NCDs): non-infectious and non-transmissible diseases that may be caused by genetic or behavioral factors and generally have a slow progression and long duration. The NCDs that most significantly affect pregnancy are **cardiovascular disease**, **hypertension**, **diabetes**, **cancer**, **mental health disorders**, **thyroid disease**, and **multiple sclerosis**.















Reducing NCDs and maternal deaths are both key objectives of the ambitious 2030 Sustainable Development Goals (SDGs). Currently, more than half of the world's countries are on pace to miss the SDG targets on the reduction of NCDs,¹⁰ which has implications for maternal health and mortality. The rising incidence of NCDs in perinatal women directly affects the global number of maternal deaths. Each day, approximately 810 women die from mostly preventable complications during pregnancy, delivery, or the postpartum period.¹¹ Annually, that's around 300,000 preventable deaths of women. Over the last 25 years, global maternal mortality rates have decreased by 43 percent, but this decrease has slowed, and a few countries have actually seen a recent rise in maternal death ratios. In the United States, the maternal mortality ratio has risen by more than 25 percent between 2000 and 2014 and has doubled since 1987.¹²

The International Federation of Gynecology and Obstetrics (FIGO) update on NCDs: Maternal and child health is inextricably linked with NCDs and their risk factors. Prenatal malnutrition and low birth weight will affect both mother and child, creating a predisposition to obesity, hypertension, heart disease, and diabetes later in life. Also, pre-term birth is associated with similar risks. Therefore, any efforts on NCD prevention and control must begin with and substantially focus on preconception and maternal health.¹³ Globally, black women experience maternal disease, disability, and death at higher rates than their white counterparts. This racial disparity in outcomes is seen across income, education, and geographical location—factors that typically indicate higher levels of healthcare and better outcomes do not protect black women.^{14,15} Black women in New York City with advanced education are still more likely to die due to pregnancy and postpartum complications than white women with less than a high school education.¹⁶ In Brazil, the maternal mortality ratio for black women is almost five times higher than for white women and the rate of death from hypertensive disease is eight times higher.¹⁷ In the United States, black women are two-and-a-half times more likely than white women to die from pregnancy-related conditions¹⁸ (some studies show an even higher difference)¹⁹ and they bear the brunt of serious complications.²⁰

Consequences related to chronic illnesses and complications of pregnancy don't always lead to death, and the avoidance of death shouldn't be the sole indicator of a successful or healthy pregnancy and delivery. While exact numbers are unknown, estimates suggest that for each mother who dies, 100 mothers experience pregnancy-related complications that can cause lifelong, debilitating injuries (severe maternal morbidities).²¹ Globally, some 30 million women survive pregnancy and then suffer from these lifelong injuries each year. Severe maternal morbidities during pregnancy, delivery, and postpartum include uterine prolapse, stress incontinence, hypertension, severe anemia, and fistula. These morbidities are often exacerbated by NCDs.

The ongoing incidence of preventable global maternal morbidity reflects a clear failure to achieve the global public health goal of ensuring equitable access to high quality healthcare for women during and after pregnancy. While medical intervention has focused on clinical response to obstetric complications and prenatal and postnatal care, trends point to the need to address the complex indirect causes of maternal deaths, injuries, and disease. A more holistic, systemic approach to improving maternal health must address the global burden of NCDs contributing to maternal mortality and morbidity,²² as well as the extended effects on newborns and children of women with NCDs.²³ Better data systems, patient education about signs and symptoms, and support for evidence-based, culturally appropriate interventions like midwifery, group prenatal care, and social and doula support are required to meet this challenge.

Women must be included in research on NCDs and specific considerations of female anatomy and pregnancy must be addressed. Policy makers, program implementers, and healthcare providers need to recognize the variety of symptoms specific to women and address racial variations. Most critically, women must not be blamed for their own deaths, particularly as systems around them fail to keep them alive. This report serves as a guide to the current effect of NCDs on women of reproductive age, specifically addressing challenges women face during pregnancy and in the postpartum period.* It includes three sections: 1) an introduction to the effects of NCDs on perinatal women; 2) global trends and the rise of NCDs, behavioral risk factors, social determinants of health, and health systems; and 3) strategies and recommendations to prevent, treat, and reduce the incidence of NCDs in women of reproductive age.

* We should note that not all pregnant people identify as women, and while transgender and nonbinary people face unique barriers during the perinatal period, this paper focuses on extensive research that predominantly refers to participants as "women."

Non-Communicable Diseases and Maternal Health by the Numbers



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18 million women

of reproductive age **die each year from NCDs** and two in every three deaths among women are due to an NCD.

810 women

die each day from mostly preventable complications during pregnancy, delivery, or the postpartum period.

more than 25%

of all pregnancy-related deaths in the United States result from cardiovascular diseases.

30 million women

experience severe maternal morbidities

each year, approximately 100 women for every maternal death.



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Cardiovascular diseases are responsible for more than 25 percent of all pregnancy-related deaths in the United States.²⁴ Cardiovascular diseases (CVDs)—which

include coronary heart disease, cerebrovascular disease, rheumatic heart disease, and more—are one of the largest contributors to maternal morbidity and mortality.²⁵ During pregnancy, the human body undergoes drastic changes in terms of blood volume, cardiac output, and blood pressure.^{26, 27} Research shows that women are susceptible to complications from CVDs throughout their pregnancy and up to five months postpartum.²⁸ In particular, women with CVDs are at a higher risk of developing blood clots, arrhythmias (irregular heart rhythms), and pulmonary edema (fluid accumulation in the lungs) during pregnancy.^{29, 30} Many of these potentially life-threatening complications can be prevented or at least managed with early detection.³¹ Despite their high prevalence, CVDs often go undiagnosed and untreated in women.³² Many physicians fail to either recognize the symptoms of CVD in women or talk to their female patients about their risks.³³

Diabetes complicates 1 in every 6 pregnancies around the world.³⁴ Approximately 200 million women are currently living with diabetes, and 1 in 3 of them are of reproductive age.³⁵ The rate of diabetes in pregnancy is currently on the rise and affects about 14 million women every year.³⁶ Any form of diabetes, including type 1, type 2, and Gestational Diabetes Mellitus (GDM), during pregnancy increases risks to the health of both the mother and the fetus. Ninety percent of diabetes cases in pregnancy are GDM, and women with gestational diabetes have four times the risk of a stillbirth or death of a baby in its first week of life than those without it.³⁷ Women with high blood pressure or kidney disease before pregnancy are more likely to develop GDM. ³⁸ Screening for GDM is routine in many countries during prenatal care visits, with tests taking place anywhere between 24 and 28 weeks.³⁹ Untreated GDM not only increases a baby's risk of death, it also increases the mother's risk of developing both GDM in future pregnancies and type 2 diabetes as she gets older.⁴⁰ Once diagnosed with gestational diabetes, a woman has a greater risk of being diagnosed with type 2 diabetes (up to 60 percent greater risk) later in life.⁴¹

Hypertensive disorders result in approximately 76,000 global maternal deaths each year.⁴² Hypertensive (high blood pressure) disorders affect up to 10 percent of pregnancies globally.⁴³ Preeclampsia, a serious blood pressure condition, can occur after the 20th week of pregnancy or after giving birth. Ten million women develop preeclampsia each year around the world.⁴⁴ Studies show that women with diabetes, obesity, older than 40 years old, or a family history of gestational hypertension have a greater risk of developing preeclampsia.^{45, 46} Women who survive preeclampsia face three to four times the risk of chronic hypertension, two times the risk of stroke, and two times the risk of coronary heart disease compared to those with normal pregnancies.⁴⁷ Preeclampsia affects both mother and fetus and can result in premature birth, placental abruption (separation from the uterus), low birth weight, and even infant death. Eclampsia, the onset of comas or seizures in pregnant women, may follow preeclampsia and put women at an even higher risk for fetal complications and stroke.⁴⁸

One in eight women will develop thyroid complications in her lifetime.⁴⁹ During pregnancy, the function of the thyroid, the gland that controls the body's metabolism, is critical.⁵⁰ During pregnancy, women often have lower levels of thyroxine and thyroid stimulating hormones, which increase the risk of developing thyroid disorders.⁵¹ If left untreated, both hyperthyroidism and hypothyroidism (a thyroid's overproduction and underproduction of hormones, respectively)⁵² can lead to hypertension, placental abruption, preterm birth, and heart failure during pregnancy and labor.⁵³ Women with mild hypothyroidism are three times more likely to have a placental abruption-related complication and two times more likely to have a preterm birth than those without it.⁵⁴ Hypothyroidism has also been linked with higher pre-pregnancy weight, as well as more weight gain during pregnancy.⁵⁵ Also, more than 10 percent of women experience postpartum thyroiditis, in which the thyroid swells in the first year.⁵⁶



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Cancer diagnoses complicate up to 1 in every 1,000 pregnancies worldwide.⁵⁷ Over the

last 50 years, the rate of cancer diagnosis has increased globally, making cancer one of the leading causes of death.⁵⁸ Almost 3 in every 100 maternal deaths can be attributed to cancer.⁵⁹ In particular, breast, cervical, ovarian, and colorectal cancers contribute most significantly to maternal mortality.⁶⁰ Estrogen production is increased during pregnancy which can contribute to estrogen-dependent cancers like breast cancer and melanoma.⁶¹ In many cases, the diagnosis of cancer during pregnancy is delayed, as the symptoms of undiagnosed cancer and pregnancy (like nausea, fatigue, and headaches) often overlap.⁶² While rare, hormonal changes associated with pregnancy can stimulate some cancers to grow.⁶³ Pregnancies become high-risk once a cancer diagnosis is made, and women often face the difficult decision of which treatment to use and when to begin treatment, while also taking into account the health of the fetus. Pregnancy also acts as an immunosuppressant, which can lessen the body's ability to fight cancer.⁶⁴

Multiple Sclerosis (MS) is two to three times more prevalent in women than in men.⁶⁵

MS is often disabling with symptoms that can include difficulty walking, vision problems, bladder dysfunction, and cognitive changes.⁶⁶ MS affects women of childbearing age more than any other group.⁶⁷ In 2016, there were 2.3 million diagnosed cases.⁶⁸ MS is not genetic, but studies show women have an increased risk of developing MS if a parent or sibling also has/had MS.⁶⁹ MS does not affect a person's fertility, but women with MS tend to experience more pregnancy-related complications than those without MS, particularly infections during pregnancy, premature labor, and fetal malformations.⁷⁰ The period of pregnancy is associated with a decrease in MS relapses due to the protection pregnancy-related hormones provide. The postpartum period however, is associated with an increase in relapses, as many mothers stop disease-fighting medicine while breastfeeding to avoid transferring medications to their babies.⁷¹ Relapse symptoms like mobility issues, mood disturbance, and fatigue can greatly affect a woman's ability to properly care for a newborn baby.⁷² Symptoms of MS can be confused with symptoms of the postpartum period, making it difficult to diagnose.⁷³ Pregnant women with MS also have increased incidence of caesarean deliveries, because affected pelvic muscles and nerves make it hard to push during active delivery.⁷⁴

Mood or anxiety disorders affect about 10 percent of pregnant women.⁷⁵ Major mental health disorders associated with pregnancy include, but are not limited to, depression, anxiety, obsessive-compulsive disorder, post-traumatic stress disorder, and bipolar disorder.⁷⁶ Globally, 13 percent of postpartum women experience a mental disorder⁷⁷ and in developing countries, roughly 20 percent of women experience a mental health issue during or after pregnancy.⁷⁸ Women are more likely to develop anxiety or depression in the first year after childbirth than any other time of life⁷⁹ and globally, pregnant women are more likely to experience suicide ideation than the general population.⁸⁰ Hormonal changes during and after pregnancy, plus sleep deprivation, adjustment to life changes, and body image all play into this increase in mood or anxiety disorders.⁸¹ Oxytocin levels are normally enhanced after childbirth to protect against stress, pain, and maternal mental health disorders.⁸² Women with certain genetic mutations produce less oxytocin, putting them at risk for perinatal mood and anxiety disorders. Over 40 percent of women in the United States who experience postpartum depression will experience a recurrent episode after a subsequent pregnancy, and past or family history of depression means an increased risk of postpartum depression.^{83, 84, 85} Globally, several studies indicate that women with depressive symptoms are significantly more likely to deliver preterm than women without them.^{86, 87, 88, 89} Women with histories of mental illness who discontinue psychiatric medications during pregnancy and breastfeeding are also particularly vulnerable.⁹⁰

PART TWO Contributors to Increased Incidence of NCDs

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This report addresses factors contributing to the rapidly rising prevalence of NCDs, why it is affecting a relatively young population, and how NCDs are impacting women, particularly during the perinatal period. Many publications, including this one, include statistics showing that rising numbers of women enter pregnancy older, sicker, and heavier than in years past. This report does not intend to blame women. Rather it aims to illuminate how healthcare systems and social networks have failed to address changing demographics, trends, social determinants of health, and behavioral risk factors that leave too many women at a heightened risk for chronic illnesses.

GLOBAL TRENDS

Obstetric Transition: A key component of the changing landscape of maternal health is the obstetric transition, when countries gradually shift from a pattern of high maternal mortality to low maternal mortality, from direct causes of maternal mortality (like hemorrhage) to indirect causes (like NCDs). This transition has five stages:

Few resources dedicated to the prevention of maternal death;

Lack of access to facility care due to limited numbers of hospitals or health centers, low levels of education about pregnancy, childbirth and obstetric complications that cause delays in seeking care, and weak health systems where quality of care is low;

(3)

Challenges of accessing care and lack of quality care in facilities (stages 2 and 3 are described by the Three Delays Model, defined as delays in seeking care, accessing care, and receiving care);⁹¹ Women dying from complications of pregnancy and delivery, as well as from pre-existing and chronic illnesses. Currently, most of the world is experiencing stage four and moving toward stage five;^{92, 93} and

5) NCDs as the main causes of maternal death.

Obesity: Obesity, which usually refers to a body mass index of 30 and above, is among the major contributors to NCD-related obstetric mortality and morbidity. Obesity has nearly tripled since 1975; in 2016, almost 2 billion adults were overweight and 600 million of these adults were considered obese.⁹⁴ In fact, most of the world's population lives in countries where overweight and obesity kill more people than underweight.⁹⁵ The worldwide prevalence of obesity is higher among women than men⁹⁶ and almost one-third of women of reproductive age are obese at the start of pregnancy.⁹⁷ A study in Mexico found that threequarters of women with high-risk pregnancies were also overweight or obese when they became pregnant.⁹⁸ Obesity during pregnancy can lead to negative health outcomes for both the mother and baby. Starting a pregnancy overweight is associated with several major NCDs, including type 2 diabetes, cardiovascular disease, hypertension, and several cancers.^{99, 100}

Urbanization: Urbanization is a key factor in rising rates of obesity and overweight and has been shown to increase the incidence of gestational diabetes, diabetes type 1 and type 2, and cardiovascular disease.¹⁰¹ Populations moving from rural settings to cities have limited access to green spaces and healthy, affordable nutrition is often scarce, creating "food deserts."¹⁰² These restrictions lead to increased weight gain from reduced physical activity, poor nutrition, and increased exposure to environmental contaminants. In Bangladesh, a study found prevalence of diabetes was four times higher in urban vs. rural populations.¹⁰³



FOOD IN THE CITY: URBANIZATION AND NUTRITION

By Amanda King and Lauren Herzer Risi

For the world's population, 2007 marked a pivotal year. For the first time, there were more people living in cities than in rural communities.¹⁰⁴ By 2050, 68 percent of the world's population will live in urban areas, up from 55 percent today.¹⁰⁵ Most of that growth will occur in developing countries. A number of factors are influencing urbanization around the world. In countries like Niger and Somalia,¹⁰⁶ natural growth is occurring as a result of high fertility rates. Countries like Brazil and Indonesia are seeing high levels of rural to urban migration, often influenced by a combination of social, political, economic, and environmental factors.¹⁰⁷

The rate of urbanization in many developing countries is outpacing governments' capacity to provide adequate health and social services, resulting in more than 1 billion people currently living in informal, unplanned settlements with inadequate infrastructure, and insufficient access to water and sanitation systems.¹⁰⁸ By 2030, estimates suggest that one-quarter of the world's population will live in these informal settlements.¹⁰⁹ Those moving to cities must adapt to new methods of accessing affordable and nutritious food, clean drinking water and safe sanitation,¹¹⁰ and overcome multiple physical, socioeconomic, and cultural barriers, some of which will be exacerbated by climate change impacts.¹¹¹

Additionally, those living in cities are much more susceptible to food price shocks¹¹² than those living in rural communities. Fluctuations in international food prices and imports limit urban residents' food purchasing choices. Women are especially susceptible to these changes as they often reduce their nutritional intake¹¹³ to accommodate other household members (either by choice or through gender norms). Poor nutrition leads to anemia and other conditions that can cause pregnancy-related complications, as well as harm newborn and child health.¹¹⁴



Maternal Age: Maternal age, specifically the steady increase in pregnancy at an older age, is another global trend affecting maternal health. Increased participation in the workforce, later age of marriage, fertility struggles, economic and environmental stressors, and increased autonomy and reproductive control contribute to delayed childbearing. Over the last 30 years, first births among women ages 35-39 years have risen by 30 percent in the United States, and women ages 40-45 have experienced an even higher increase (70 percent).¹¹⁵ Studies show that women older than 35 years face an increased risk of gestational hypertension, gestational diabetes, placental abruption, perinatal death, preterm labor,¹¹⁶ as well as pre-existing conditions at the start of pregnancy.¹¹⁷



FREEZING FOR THE FUTURE: FERTILITY AND NCDs

By Allison Catherino

Non-communicable diseases are stressful for the body and can sometimes impact fertility, particularly if they cause weight loss. Drugs used to treat some NCDs can also cause fertility problems.¹¹⁸ Thyroid disorders can stop ovulation, as can chronic liver and kidney diseases. Advances in reproductive medicine continue to create opportunities for women with chronic illnesses to become parents to biological children. In the last decade, oocyte cryopreservation (egg freezing) and mature oocyte banking have become viable options for women with specific medical conditions and those undergoing certain treatments to combat NCDs, like chemotherapy and/or radiation. Women undergoing chemotherapy or radiation may EMD Serono

be able to take hormones to stop ovulation during treatment or choose a chemotherapy drug that is gentler on the reproductive system, which will improve chances of conceiving later.¹¹⁹ For some women, such as those with severe cardiovascular disease who cannot carry a child to term, a gestational carrier may be appropriate. Donor eggs and embryos are available for women when using her own oocytes is not recommended. The American Society of Reproductive Medicine suggests that women and, if available, partners of women have access to counseling and clearly understand the risks and benefits of egg freezing and the utility of such a strategy in her specific situation.

BORN TOO SOON: NCDs AND PRETERM BIRTH



By Dr. Lisa Waddell

Preterm birth is birth that happens too soon, before 37 weeks of pregnancy. Increasingly, women of childbearing age in the United States have chronic health conditions at the onset of pregnancy. While they can have healthy pregnancies and healthy babies, the risk of premature birth is increased. The 2012 Global Action report on Preterm Birth, Born Too Soon, found that 15 million babies worldwide are born prematurely each year, and more than 1 million die due to complications from premature birth. In the United States, more than 380,000 (1 in 10) babies were born prematurely in 2018. Premature birth and its complications are leading causes of death in children under age 5 globally.¹²⁰ Premature birth can cause low birthweight; while some low-birthweight babies are healthy, others may have serious health problems that need treatment and require long hospital stays.

Some face long-term health issues involving the brain, lungs, hearing, vision, dental problems, intestinal issues, and risk infections. NCDs that may cause a woman to have a baby with low birthweight include autoimmune diseases (multiple sclerosis, lupus, diabetes); conditions that affect the blood, blood vessels, heart and lungs (heart disease, hypertension, respiratory diseases); chronic pain; conditions that affect hormones (diabetes and thyroid conditions); and mental health conditions. To reduce the risk of preterm labor and premature birth, as well as maternal health complications, screening and treatment for chronic health conditions is highly recommended. Ensuring that women have access to quality care and education on key health issues before, during, and after pregnancy is key to preventing preterm birth.



BEHAVIORAL RISK FACTORS

Pregnancy is considered a "stress test," meaning that the physiological and emotional demands of pregnancy can accelerate NCDs that were underlying or undiagnosed before pregnancy.¹²¹ Human behavior is a key contributor to NCD prevalence worldwide.¹²² The NCDs covered in this report, namely cardiovascular disease, hypertension, diabetes, mental health, cancer, and multiple sclerosis, can be linked to or exacerbated by tobacco and alcohol use, inadequate nutrition, inactivity, and poor sleep. All of these behaviors may be motivated by chronic stress.¹²³ A growing body of evidence indicates that the toxic stress of poverty can cause and worsen many NCDs, especially mental health disorders.¹²⁴



Tobacco and alcohol use are associated with higher risks of cardiovascular disease,¹²⁵ hypertension,^{126,127} gestational diabetes,^{128,129} mental health disorders,¹³⁰ and cancer,^{131,132} and have been shown to exacerbate symptoms of MS. ^{133,134} **Poor diet and nutrition** also contribute to increased incidence of these same NCDs,^{135,136} while **physical activity during pregnancy** has been shown to reduce the risk of each of the NCDs.^{137,138,139,140,141}

Inadequate sleep is linked to cardiovascular disease,¹⁴² hypertension, ¹⁴³ gestational diabetes,¹⁴⁴ mental health disorders,¹⁴⁵ and cancer. ¹⁴⁶ Poor sleep is a common side-effect among MS patients, which may put pregnant women with MS at a heightened risk for additional NCDs. ¹⁴⁷



THE HIDDEN NON-COMMUNICABLE DISEASE: MENTAL HEALTH AND PREGNANCY

By Birdie Gunyon Meyer and Wendy Davis

Perinatal Mood and Anxiety Disorders (PMADs) include depression (including postpartum depression), anxiety, panic, obsessive-compulsive disorder (including intrusive thoughts), post-traumatic stress disorder, bipolar disorder, and psychosis. The incidence of these disorders increases during pregnancy and the postpartum period. A recent study showed that 21 percent of women during pregnancy and postpartum developed a PMAD. More rare, postpartum psychosis occurs in one to two women per thousand. The baby blues (not a disorder) occur in about 80 percent of new moms.¹⁴⁸ Many people confuse these terms and the causes of these disorders. The commonly used terms "postpartum depression" and "baby blues" do not reflect the physiological and social determinants of perinatal mental health disorders. Perinatal depression alone ranks as the most underdiagnosed complication of pregnancy in the United States and may not manifest itself until many months after delivery.¹⁴⁹

The impact of perinatal mental health disorders is both acute and long-term, affecting not only the health of mothers but also the mental and physical health and development of infants and children and the overall health of the entire family. The toxic stress of poverty can exacerbate these conditions in women in low-resource settings.¹⁵⁰ Untreated perinatal mental health disorders are a significant contributor to maternal mortalityand can increase the risk of suicide, maternal and infant death, and morbidity.¹⁵¹ Despite the impact and prevalence of perinatal mental health disorders, there are significant gaps and disparities in public awareness, professional education, research, and access to screening, diagnosis, treatment, support, and prevention services. Even though there are effective treatments, less than 30 percent of women who test positive for depression and anxiety seek or receive treatment.¹⁵² Leading perinatal mental health organizations, such as Postpartum Support International (PSI) and professional associations of obstetric care providers, call for integrated screening, referral, and treatment to be a routine part of pregnancy and postpartum care.

POSTPARTUM SUPPORT



SOCIAL DETERMINANTS OF HEALTH: GENDER AND RACE

Medical and physiological barriers to health are just the tip of the iceberg. Many NCDs are exacerbated by environmental, political, social, and economic factors beyond the control of individuals. Social determinants of health are "under the iceberg" conditions that influence health risks and outcomes.¹⁵³ Social determinants of health include racism, gender inequality, systemic barriers in health systems, economic inequality, and variants in environmental exposure. Bias related to social factors such as education level, income, sexual orientation, disability, social support, and immigration status can also negatively affect patients' treatment in healthcare settings, as well as their health outcomes.

Gender: Evidence demonstrates that gender disparities are a key factor in women's health around the world. Women's health has long been ignored or undervalued by medical and epidemiological research, medical professionals, and societies at large.¹⁵⁴ According to a recent United Nations index report, 90 percent of men and women worldwide hold biases against women.¹⁵⁵ Countries with higher Inequality Index scores were also found to have higher rates of



maternal mortality.¹⁵⁶ Gender bias, negative attitudes toward reproductive health, and the low social status of women have led to insufficient care of women and the rising impact of chronic illness on women of reproductive age.

Historically, medical studies relied heavily on men or male animals, which has slowed progress in women's health care.¹⁵⁷ For example, 70 percent of diagnosed cases of chronic pain impact women, but 80 percent of chronic pain research is conducted on male mice and men.¹⁵⁸ Even though chest pain is the most common symptom of heart attacks for both men and women, ¹⁵⁹ women are more likely to experience "unusual" symptoms such as nausea, fatigue, back pain, and heartburn;¹⁶⁰ and pain down the right arm (not just the left).¹⁶¹ These symptoms are considered atypical simply because men don't report them. Furthermore, women are often ignored or not taken seriously by medical professionals. Women have been taught to deny or downplay feeling pain, whether physical or mental, stemming from a history of misclassifications of hysteria and the seclusion of women during menses and pregnancy.¹⁶² Parity in research is critical to understanding how illnesses affect women differently than men and how women respond differently to treatment.

"Women have distinct needs for health services throughout their life because of the need to access sexual, reproductive and maternal health care. They are also typically the primary caregivers for children and others, which affects their health needs and access to health services, including for non-communicable diseases. However, gender inequalities and discrimination often impede access to appropriate care for women, as well as for their children."¹⁶³ Another critical gender-based barrier to women's health is gender-based violence (GBV). Globally, one in three women and girls will experience GBV in her lifetime, reaching up to 70 percent in some countries.¹⁶⁴ GBV is a global phenomenon, deeply rooted in gender inequality, and involves sexual, physical, and/or psychological violence, including intimate partner violence (IPV).¹⁶⁵ Worldwide, women experience increased risk of abuse and violence during pregnancy and directly afterwards.¹⁶⁶ In the United States, a woman is beaten every nine seconds and IPV is a leading cause of death for pregnant and postpartum women.^{167, 168} An extensive body of evidence demonstrates the extensive linkages between violence and women's mental and physical health.

"There are other things I'd rather write about, but this affects everything else. The lives of half of humanity are still dogged by, drained by, and sometimes ended by this pervasive variety of violence."¹⁶⁹

- REBECCA SOLNIT, writer, historian, and activist

INTIMATE PARTNER VIOLENCE DURING PREGNANCY: THE CRITICAL ROLE OF THE HEALTH SECTOR

By Upala Devi

Intimate partner violence (IPV) during pregnancy is widespread and an indicator of increased risk of homicide.¹⁷⁰ Some research suggests pregnancy itself can be a stimulus for the onset of violence and IPV during pregnancy.¹⁷¹ An especially alarming form of abuse during pregnancy targets a woman's abdomen.¹⁷² IPV during pregnancy has serious negative impacts on women (depression, injuries, and other physical health problems) and their babies (premature birth, low birthweight, poor health outcomes). Global estimates published by WHO show that 35 percent of women have experienced either physical and/or sexual IPV or non-partner sexual violence in their lifetime¹⁷³ and global estimates suggest that between 4 and 9 percent of women experience IPV during pregnancy.¹⁷⁴ Some smaller studies in pre- and postnatal care settings detected a higher prevalence, from 63 percent in Zimbabwe,¹⁷⁵ 35 percent in Brazil,¹⁷⁶ 18 percent in Nigeria,¹⁷⁷ and 12 percent in India.¹⁷⁸

The health sector is often the first point of contact for formal services for women experiencing IPV. Overall, three domains are essential to successful prevention and response to IPV during pregnancy: training of health service providers, screening, and care and referrals. Providers must be trained on clinical protocols, sensitive communication, and appropriate referrals to additional services where available. Screening for IPV should be integrated into existing screening practices such as HIV/AIDS, family planning, and maternal mental health. Healthcare interventions and gendernorm transformative programs are not effective in isolation and must engage the wider community, including opinion leaders, men, and other household decision-makers and cultural gatekeepers. Targeted interventions designed to reflect the limited resources, economic status, and social/gender norms of low- and middle-income countries have reduced the frequency and severity of violence during pregnancy.¹⁷⁹

Race and Ethnicity: Women of color face inequitable access to care and health outcomes for pre-existing and newly diagnosed NCDs during and after pregnancy. Maternal mortality statistics reflect racial, ethnic, and nativity-related disparities within the U.S. healthcare system.¹⁸⁰ Racial and ethnic disparities also impede women's access to quality care in high- and low-resource countries.¹⁸¹ Black women in South Africa utilize the maternal healthcare system at lower rates.¹⁸² Recent reports have also highlighted issues of implicit bias among healthcare providers who ignore black women's concerns about their health during pregnancy.^{183, 184} Women of African and Caribbean descent in the United Kingdom have significantly higher rates of severe maternal morbidity.¹⁸⁵ Research indicates that skin color affects maternal outcomes in Brazil.¹⁸⁶

Black and American Indian/Alaskan Native women also experience higher rates of and more severe pregnancy-related complications than any other ethnic group in the United States. For example, black women are three times more likely to die from



In the United States, **black women are two-and-a-half times more likely than white women to die from pregnancy-related conditions**

and they bear the brunt of serious complications. Black women are more likely to have cardiovascular disease (including high blood pressure, enlarged heart, and irregular heartbeat) before, during, and after pregnancy. "Research shows us what Black women have always known: We can't buy or educate our way out of dying in childbirth or having our babies die. Black women who live in affluent neighborhoods, receive prenatal care in the first trimester, are normal weight, and have advanced degrees are still more likely to die or have their baby die than white women in poor neighborhoods, with no prenatal care, who are obese, and don't have a high school diploma."

— DR. JOIA CREAR-PERRY, Founder and President, National Birth Equity Collaborative¹⁸⁷

preeclampsia than white women due in part to being disproportionately affected by associated risk factors (e.g., diabetes, obesity, chronic hypertension) and inequalities in access to prenatal care.¹⁸⁸ Even before pregnancy, women of color face chronic stress and "weathering," a hypothesis that the health of black women may decline during early adulthood because of cumulative socioeconomic and racial disadvantage.¹⁸⁹

Historical segregation in neighborhoods may also affect quality of care, with a majority of black women delivering their children at a concentrated set of hospitals that have been shown to provide lower quality of care.¹⁹⁰ Racially biased pain management of black women also affect a woman's pre- and postnatal care. Constant discrimination can impede care. One study found that if a black woman experiences perceived discrimination, she is two times more likely to skip postnatal visits for her own health.¹⁹¹ Women who do not receive adequate prenatal care are up to four times more likely to suffer pregnancy-related death.¹⁹²

HEALTH SYSTEMS, QUALITY OF CARE, AND UNIVERSAL HEALTH COVERAGE

Ensuring equitable access to affordable, comprehensive, and high-quality health care and medicines is a global challenge and is a part of individuals' right to health.¹⁹³ It is vital to decreasing maternal and infant mortality, improving healthcare for underserved populations, and eliminating racial disparities in outcomes. Across the United States, healthcare providers are lacking, as more hospitals and maternity units in rural and urban areas close. Some 5 million women currently live in "maternity care deserts," counties where no hospital offers obstetric services and where no maternal health providers work.¹⁹⁴ In low- and middle- income countries, distances to facilities where women can obtain the quality care they need can be even farther.^{195,196}

Barriers to accessing healthcare increase the risk of undiagnosed NCDs in pregnant women.¹⁹⁷ Universal health coverage would increase access to essential services including maternal health care and would greatly benefit the poor, as research demonstrates that poorer households utilize maternal health services at a lower rate than wealthier households.¹⁹⁸ In the United States, expansion of Medicaid to one year post-partum is necessary to ensure that women and newborns have continuous access to care, which has been proven to improve infant and maternal outcomes.¹⁹⁹



"WHO's approach to UHC [universal health coverage] means designing, planning and delivering health services to meet all the needs of women and girls, including mental health and non-communicable diseases as well as reproductive health. And these gender norms and practices will have an influence on the health of men and boys too."²⁰⁰

- DR. TEDROS ADHANOM GHEBREYESUS, Director-General, World Health Organization (WHO)

The health system only works with a strong health workforce. Currently, there are 28 million nurses and 2 million midwives globally who are responsible for delivering more than 80 percent of health care in lowresource settings and account for more than half of the world's healthcare workforce.²⁰¹ However, estimates predict a shortage of between 7.6 million²⁰² and more than 9 million²⁰³ nurses and midwives by 2030. The "Three Delays Model" outlines barriers to, access to, and quality of maternal healthcare services-the delay in seeking care (due to lack of information, fear, perception of poor or disrespectful care or stigma), the delay in reaching a care facility (due to bad roads, inadequate transport, costs of transport, long distance to health facilities), and the delay in receiving care (lack of workforce, bad conditions, etc.). Too often women are mistreated. Or they even face violence in healthcare facilities, which only further impedes their desire to seek care in facilities.

Another factor in rising rates of maternal mortality and morbidity is the overuse and underuse of cesarean delivery. In some countries, including the United States, higher rates of death and disease are caused by cesarean rates that are too high.²⁰⁴ In low-resource settings, rates of cesarean delivery are often too low,²⁰⁵ causing severe disabilities, disease and death due to prolonged obstructed labor and other complications.²⁰⁶ Studies show that birth by cesarean may increase the risk of NCDs later on in life for children.^{207, 208}

LISTEN TO WOMEN: WOMEN WANT RESPECTFUL CARE

By Elena Ateva and Stephanie Bowen

Receiving respectful, dignified healthcare throughout her life is vital to a woman's overall health and wellbeing. This is particularly true during pregnancy, childbirth, and the postpartum period. Disrespect and abuse in maternal care include physical abuse; care that is non-consented, non-confidential, or nondignified; stigmas and discrimination; physical, sexual, and verbal abuse; abandonment and detention in health facilities; failure to meet professional standards of care by providers; and inadequate infrastructure in healthcare facilities. Women often refuse to deliver in facilities due to the lack of respectful, safe care-even if facilities are accessible.²⁰⁹ Caregivers can empower and comfort, or inflict lasting damage and emotional trauma, adding or detracting from a woman's confidence and self-esteem. Historically, public health and development efforts to reduce maternal mortality have emphasized clinical expertise and infrastructure. As gains in reducing maternal deaths stalled, a growing call to understand and address issues of emotional, physical, and psychological harm to women during facility-based childbirth has led

to a mounting body of research on respectful care, including robust landscape analyses and multi-country studies, as well as review of how care is delivered by healthcare providers and how that care is experienced by patients.²¹⁰

RIBBON

Multi-sector efforts to provide tools to address abuse have been released, including the groundbreaking Respectful Maternity Care Charter, clearly tying women's rights during childbirth to established human rights conventions and recently updated to delineate the rights of newborns. At the same time, there is a groundswell of women demanding their rights to respectful, dignified care. It was the number one priority of the 1.2 million women who responded to the global What Women Want campaign survey in 2018. Respectful care begins with listening to women and responding to their self-articulated needs, not just during pregnancy and childbirth, but throughout their lives. Respectful care must be protected, even in times of crises when chaos, fear and misinformation may inadvertently deem it as a luxury. It is not.



PART THREE Strategies and Recommendations

Through our research and the CODE BLUE series,* we have developed a series of strategies and recommendations for researchers, policymakers, healthcare providers, and public health professionals to address NCDs and maternal health. The most significant constraint of this work is the limited data available, particularly outside the United States. To rectify the lack of research and data, our hope is that this report will serve as a reference to highlight the importance of NCDs and maternal health and a motivation for stakeholders to take urgent action to address gaps.

* The CODE BLUE series includes multiple Wilson Center events, expert articles, and podcasts focused on NCDs and women of reproductive age.



Strategy 1—Collaboration and Integrated Care

Collaboration among primary care, chronic disease, and maternal health providers can increase awareness of risks and symptoms of NCDs, positively impact pregnancy for both women and healthcare workers, ²¹¹ and improve prevention and treatment for various NCDs that impact pregnancy.²¹²

Recommendations:

- Integrate NCD interventions within prenatal care (screenings, diagnosis, treatment) to increase prevention. Integration has been effective at reducing the risk of gestational hypertension and diabetes.^{213, 214, 215}
- Expand collaboration between maternal and child health and NCD/chronic disease departments in public health agencies to increase diagnosis and treatment.
- Provide women with more information on how chronic illness impacts pregnancy²¹⁶ and educate and empower women as change agents regarding their health and that of their family.
- Identify barriers to accessing maternal mental health services.



Strategy 2—Increase Access to and Quality of Care

Healthcare providers at all levels must be provided tools and training to provide quality, equitable, respectful, and culturally appropriate care to all women. Women must be empowered to demand that their needs be met and be included in informed decision-making around their care.

Recommendations:

• Ensure providing respectful maternity care is an indicator for quality measures in all facilities.

- Address racial and ethnic disparities in NCD care and Maternal and Child Health care:
 - » In the United States, increase implicit bias training and cultural competence.
 - » Globally, educate healthcare providers on how to treat all patients with respect.
 - » Acknowledge racism as the underlying cause of many maternal and infant deaths.
 - » Create policy solutions that can effectively eliminate racial disparities.²¹⁷
- Implement Universal Health Coverage—ensuring that all people have access to quality healthcare without financial hardship.
- Continue and fully fund Medicaid and programs to support children, like the Children's Health Insurance Program (CHIP).



Strategy 3—Invest in and Support the Maternal Health Workforce

Improving the skills and capacity of the global health workforce is a key component to achieving several Sustainable Development Goals related to health, employment, education, and reduction of inequalities.²¹⁸ WHO designated 2020 as the Year of the Nurse and the Midwife in recognition of these important, yet under-recognized, underfunded, and overburdened professionals. Midwives particularly face enormous challenges to providing quality care, including difficult working conditions, low wages, expanding responsibilities with minimal resources, and exclusion from decision-making tables.

Recommendations:

- Provide appropriate clinical skills training and support for midwives, nurses, doulas, and other non-physician clinicians to provide care triggered by identification of early warning signs and referral mechanisms for obstetric emergencies.
- Train healthcare teams, including emergency room staff, on recognition of Maternal Early Warning Signs²¹⁹ and ensure that infrastructure is available at all facilities to rapidly respond to emergency complications.
- Recruit a more diverse workforce to represent the patient population and increase customerfocused, culturally acceptable care.
- Review appropriate remuneration for healthcare workers, including community health workers who are tasked with providing healthcare services.
- Provide incentives for healthcare providers to serve rural and underserved communities.
- Train nurses, midwives, OBGYNs, and other facility staff on their unique roles, emphasize collaboration between the professions, and increase the representation of nurses and midwives at decision-making tables.



Strategy 4—Emphasis on Prevention and Preconception Care

In the United States, \$4 out of every \$5 spent on pregnancy and childbirth revolves around labor and birth,²²⁰ leaving few resources for prenatal and postpartum care, including screenings for non-communicable diseases, mental health screenings, and educating women and healthcare providers about warning signs.

Recommendations:

- Ensure women have access to pre-conception care and education on prevention and treatment of NCDs, so that they are healthier before pregnancy.²²¹
- Support access to affordable contraception for family planning and birth spacing (per WHO guidelines of 18–24 months between pregnancies).²²²



Strategy 5—Enhanced Routine Screenings for NCDs

Screening and monitoring for hypertension in the preconception period can help prevent and manage hypertensive disorders during pregnancy.²²³ Early identification of women at risk for perinatal mood and anxiety disorders (PMAD) and postpartum depression (PPD) is crucial to successful prevention of PPD and suicide following pregnancy.²²⁴

Recommendations:

- Enhance routine screenings at preconception and the perinatal period to provide early detection of both existing NCDs and to capture the onset of disease.
- Expand payment for postpartum screenings for chronic illness not just at six weeks postpartum, but for at least one year post-delivery, and up to two years post-delivery for those with an elevated risk or pre-existing condition.
- Review insurance payment models for obstetricians and pediatricians to enhance referral mechanisms for women experiencing PMAD.
- Create more programs that focus on NCDs in pregnancy and ensure that women's health programs include NCD prevention and treatment.²²⁵



Strategy 6—Global and National Policies to Control Marketing of Unhealthy Products and Promote Healthy Behaviors

More awareness of the impact of nutrition and alcohol and tobacco use, and their ramifications for NCDs and pregnancy needs to be a cornerstone in policy and marketing strategies.

Recommendations:

- Tax tobacco and alcohol to reduce consumption, thereby reducing the incidence of NCDs.²²⁶
- Expand messaging on health effects of tobacco and alcohol consumption and increase regulation of advertising.
- Educate and promote the importance of good sleep habits.



Strategy 7—Create, Pass, and Implement Protective Policies

WHO recommends that pregnant women have eight prenatal visits and four postpartum visits up to six weeks following delivery. Medicaid (used by almost 50 percent of American women) does not kickin until late into the prenatal period and ends shortly after childbirth in many states, making it difficult for women to receive the recommended number of pre- and postpartum visits and regular screening and treatment for NCDs.

Recommendations:

- Mandate insurance coverage for pregnant women and new parents that ensures continuous maternal and newborn care.
- Promote policies and programs to safeguard access to healthcare for all, regardless of gender, race, ethnicity, national origin, etc., and address implicit bias in delivery of healthcare.
- Strengthen Maternal Mortality Review Committees and Maternal Mental Health Interagency Task Forces and create them where they do not yet exist.
- Expand Medicaid coverage extension to one year postpartum.



Strategy 8—Improve Research and Investments in Strategies 1–7 to Integrate NCD Prevention and Treatment and Maternal, Newborn, and Child Health

While NCDs are a leading killer worldwide, the global response is much smaller in scale, approach, and funding than other global efforts, such as the responses to malaria and HIV/AIDS.²²⁷ Investment in and research on the intersection of chronic illness and maternal health is even more bleak.

Recommendations:

- Invest in more research on women's health, reproductive health, and the data systems needed to improve data collection and analysis.
- Ensure that women, including women of color, are included in research studies on NCDs.
- Improve screening to detect signs of maternal mental disorders, to improve the data on the prevalence of mental health disorders, and integrate maternal mental health with primary care mental health.²²⁸

Strategy 9—Increase and Improve Data Collection and Analysis

Continued efforts to improve the standardization of data and review processes related to U.S. maternal mortality are a necessary step to achieving the goal of eliminating disparities and preventable maternal mortality.²²⁹ In low-resource settings, electronic data collection and analysis for continuity of care, decision support, and clinical management are lacking.

Recommendations:

- Increase data collection at the patient level and ability of patients to maintain their health records for better continuity of care.
- Increase data sharing capabilities between care providers for improved coordination of care while ensuring privacy regulations.
- Collect disaggregated data by gender, race, and ethnicity (and other demographics) to demonstrate differences and inform targeted care.
- Provide safety measures to minimize false data disseminated through social media and noncredible sources.

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