

Pregnancy and Zika: The Quest for Quality Care and Reproductive Justice

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On February 1, 2016, the World Health Organization (WHO) declared the ZIKV virus outbreak a Public Health Emergency of International Concern (PHEIC). Pregnant women and their infants, are vulnerable to the impact of this vector-borne illness (mosquito) and sexually transmitted viral infection. The uncertainty surrounding the possibility of congenital anomalies due to ZIKV infection during pregnancy bring a renewed debate about the rights of women to control their reproductive decisions. Current strategies, resources and services aimed at prevention priorities fall short of responding to a clear framework regarding sexual reproductive health, rights and justice. A comprehensive approach to reproduction, in times of Zika, needs to empower women of reproductive age and their families to make decisions and to act on those decisions.

This paper highlights the contributions of the Maternal-Infant Studies Center (CEMI-Spanish Acronym) in close collaboration with the Department of Obstetrics and Gynecology of the University of the Puerto Rico School of Medicine and the University Hospital in providing comprehensive health care to pregnant women with ZIKV or at risk of ZIKV, at the very onset of the epidemic. CEMI approaches the care of pregnant women from a reproductive justice perspective, integrating clinical services, education, research, and advocacy. Transformación Prenatal (Centering Group Prenatal Care, GPC) currently implemented at the Puerto Rico University Hospital High Risk Clinics has been pivotal to achieve this aim. Based on the health professionals' experiences and women's testimonies, we articulate a set of principles and key actions that would benefit women, their family and children. [*PR Health Sci J* 2018;37(Special Issue):S45-S50]

Key words: ZIKV, Pregnancy, Reproductive justice, Group Prenatal Care, Puerto Rico

The appearance of the Zika virus (ZIKV) epidemic in Puerto Rico has motivated a wide range of health care responses and public health initiatives. Parallel to these responses, there has been an outpouring of resources directed to the scientific investigation of the epidemic from a basic, clinical and behavioral sciences perspectives (1). Commentaries and media reports have inundated scientific and lay publications (2, 3). Often lost in this emerging and crucial literature are the experiences and circumstances of women in reproductive age, especially those infected with the ZIKV who are pregnant or have given birth to babies infected with ZIKV.

The evolving ZIKV epidemic in Puerto Rico presents challenges and dilemmas regarding pregnancy and reproductive options. Prevention of unintended pregnancies and preventing ZIKV infections in pregnant women has become a public health priority for areas with ZIKV outbreaks (3). Current and emerging actions, strategies, resources and services aimed at these preventative priorities fall short of responding to a clear framework regarding reproductive health, rights and justice (4, 5). A comprehensive approach to reproduction, in times of

Zika, needs to empower women of reproductive age and their families to make decisions and to freely act on those decisions.

This paper highlights the contributions of the Maternal-Infant Studies Center (CEMI-Spanish Acronym) in close collaboration with the Department of Obstetrics and Gynecology of the University of the Puerto Rico School of Medicine and the University Hospital High Risk Clinics in providing comprehensive health care to pregnant women with ZIKV or at risk of ZIKV, at the very onset of the epidemic. CEMI is a public women's health clinic in Puerto Rico that approaches the care of pregnant women from a reproductive justice perspective, integrating clinical services, education, research, and advocacy.

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Transformación Prenatal (Centering Group Prenatal Care, GPC), currently implemented in the University Hospital High Risk Clinics has been pivotal to achieve this aim.

In times of scarce scientific knowledge, poor epidemiological data, uncertain outcomes, contradictory guidelines, and lack of adequate resources earmarked for the ZIKV epidemic, CEMI took upon the challenge of empowering women and families. Following the tenets of reproductive justice, it encouraged women to exercise “the right to have a child; the right not to have a child; and the right to parent their children under the best circumstances”, (6, p. 6). Based on the health professionals’ experiences and women’s testimonies, we articulated a set of core principles and key actions that need to be in place for these women, their family and children to experience reproductive justice.

Aims

On February 1, 2016, the World Health Organization (WHO) declared the Zika virus outbreak a Public Health Emergency of International Concern (PHEIC). Pregnant women and their infants, were identified as the most vulnerable to the impact of this vector (mosquito) and sexually transmitted viral infection. ZIKV infection during pregnancy is a cause of congenital microcephaly and severe fetal brain defects, and it has been associated with pregnancy loss, ocular birth defects, and severe arthrogryposis in the extremities (7, 8). Since it was reported in Brazil in May 2015, ZIKV has spread throughout the Americas and the Caribbean. The Puerto Rico Department of Health (PRDH) reported the first case of autochthonous transmission of ZIKV in December 2015 (9, 10). The ZIKV epidemic is expected to affect 25% of pregnant women in Puerto Rico. As of August 2017, Puerto Rico reported 40,545 confirmed cases of ZIKV infection, more than any other US location, and the number is expected to rise. The highest number of cases were among women in the 20-29 years age range. Among the confirmed cases, 4,008 have been among pregnant women, and 47 cases of congenital birth defects have been reported (9, 10). It is evident that Puerto Rico faces an endemic disease-control challenge with unparalleled impact on reproduction and sexuality. Despite the fact that most pregnant women exposed to the ZIKV will have children without microcephaly, the uncertainty surrounding the possibility of congenital anomalies bring a renewed debate about the rights of women to control their reproductive decisions and the role of the state and the health care system in intervening on or facilitating those decisions (11-13).

The physicians and support personnel at the Maternal-Infant Studies Center (CEMI), a multidisciplinary clinic that has mainly provided care to women living with HIV (pregnant and non-pregnant), immediately identified the parallels between HIV and ZIKV as it affected women of reproductive age. At the beginning of the HIV epidemic there were no vaccines, treatment and diagnosis was cumbersome, posing similarities to the current ZIKV situation. Both viruses are sexually transmitted and can

have devastating effects on the pregnant women and fetus; causing stigma, anxiety, and social isolation (14, 15). As with the HIV epidemic, delay in response and ignoring the psychosocial impact on women, especially those who are pregnant, can have devastating effects on women and their families. There was an urgency to act. Leveraging on existing resources and accumulated expertise of 30 years with HIV, CEMI embraced the challenge of responding to the evolving epidemic with more questions than answers. Within this contextual reality and being pragmatic, three aims were pursued by the clinic: 1) establishing a multidisciplinary prenatal clinic to address the specific needs of pregnant women with ZIKV infection, 2) capture the voices of the pregnant women at the onset of the epidemic while providing them with empowerment skills and group prenatal care, and 3) advance the discussion of reproduction aiming to create a framework toward reproductive justice. As follows, the authors highlight and discuss some initiatives geared to achieve those aims. Special attention is given to identifying key actions related to reproductive decision-making.

Group prenatal care: Current services and Preliminary studies

In the initial months of 2016, Transformación Prenatal (Centering Group Prenatal Care, GPC) at the University Hospital adapted its approach to prenatal care by including testing for ZIKV and monitoring the results. Consequently, the model was adapted to include women who were infected with ZIKV or at risk of being infected. The group model enabled the pregnant women who were infected with ZIKV to establish a support system that helped them make decisions in a non-judgmental environment. In addition, both groups of women provided testimonies and information in their group sessions that has been valuable to improve their care as the ZIKV epidemic continues to evolve.

Centering Group Prenatal Care is a model of group healthcare, which incorporates three major components: clinical assessment, patient-centered education, and emotional support and empowerment. Numerous published studies show that GPC mothers have healthier babies and that GPC nearly eliminates social disparities in preterm birth (16). Expectant mothers actively engage in their healthcare and learn to manage their health information. Participating women are better prepared for labor, delivery, and to care for their infants. Practices report fewer after-hours calls and emergency visits from GPC mothers because they have a better understanding of what is normal during pregnancy and what are the causes for concern (16, 17).

Implementing this model in the Puerto Rico public system of care for at risk pregnancy was challenging, however, the positive effects in our cultural and healthcare context have been documented. This model has resulted in a decrease in preterm birth rates in at risk population nationally and in Puerto Rico (18, 19). The model was adopted for its clinical benefits and it provided the platform and framework to introduce innovative

care in the context of an evolving epidemic. Furthermore, since the model was already in place at the University Hospital, we could channel the resources that were becoming available for addressing ZIKV without needing to create or administratively implement a new program.

In the Centering model, the support of the community and membership feelings are very important. The sessions include topics such as: overview of pregnancy, guidelines, nutrition, healthy lifestyles; common complaints of pregnancy; relaxation; stress management; breastfeeding; relationship issues; contraception; preterm labor; signs of labor; births procedures; new baby care; emotional adjustment; birth concerns; post-partum issues; and others. Typically, eight to twelve women with similar gestational ages meet in group and participate in facilitated discussions to learn health care strategies and develop a support network with other group members. The women bring their husbands, partner or a close relative to the session. Each group of pregnant patients meets for a total of 10 sessions during prenatal care. Students from a doctoral program in clinical psychology were also included in each of the groups to provide mental health support. Group sessions last 90 to 120 minutes, which is much more than the usual time spent in an individual visit. Expectant mothers enrolled in GPC spend 10x more time with their provider than women in traditional care (18-19).

By December 2016, fourteen of the women evaluated at the University Hospital had a diagnosis of Congenital Zika Syndrome (CZS), with fetal microcephaly and other brain abnormalities, consistent with the ZIKV embryopathy. Within this group, mothers of the pregnant women were identified as the main support person. Counseling included options for pregnancy termination and brief description of the potential neonatal outcomes. Only seven had the option of pregnancy termination due to advanced gestational age at the time of diagnosis of intrauterine abnormalities, consistent with the CZS. Of the remaining seven, three opted to continue with the pregnancy. Their age was between 18 and 22, only one of them was currently living with her partner. The three that opted for continuation of pregnancy, reported that their decision followed religious beliefs and considerations of fate: "This is my destiny." They agreed with allowing nature take its course in case of decreasing fetal heart tones during labor. The women were offered to be followed in a special group of three, or to continue their group prenatal care (Centering). They expressed more comfort while in group care with other ZIKV infected women without microcephaly. Experts on the care of children with disabilities were part of the group sessions and will provide continuing assistance (15). Based on the needs of the women participating in the sessions and following emerging practice guidelines, group prenatal care was modified to cover for conversations and participatory discussions regarding decisions during labor such as fetal monitoring, need for emergency cesarean section due to fetal compromise, need for maternal and family psychologic

support, antidepressants, contraceptive advice, need for neonatal subspecialty consultations, infant special care needs and economic burden. Women have been empowered to make decisions about sharing via photos and media exposure. They discuss how to deal with curiosity of people in public places. Concerns with stigma, feelings of fear and isolation are examined with the participation of mental health professionals (20). Because of the association of ZIKV with microcephaly, pregnant women become susceptible to anxiety and stress. Clearly, these mothers would greatly benefit from the emotional support and reassurance offered by a prenatal program that will empower them with the proper tools and access to healthcare needed in the coming years (3, 21, 22).

The Transformación Prenatal (Centering Group Prenatal Care, GPC), reached a cohort of women who are already pregnant. It became evident to the women served and to the health professionals that the delivery of reproductive health services is fragmented, the flow of services and choices encounter policy and legal barriers, and there are many assumptions and misunderstandings about the multiple dimensions that go into the decision of bearing and caring for a child with potential life lasting disabilities. The experiences gathered during these group encounters, at the onset of an epidemic that causes disproportionate anxiety to women of reproductive age, signal the need for a comprehensive approach to sexual and reproductive decision-making regardless of pregnancy status. While providing prenatal services to this group of women, we became increasingly aware that we need to renew the discussion to encompass the overt and subtle messages that women are sharing. The current messages provided and advice to carefully plan or postpone pregnancies, use contraception or abstinence, and to guard against mosquito bites seem limited and exclude those for whom these measures are not feasible (12, 23, 24). In a resource-constrained environment the potential physical, emotional and social liability of ZIKV should not be ignored. As follows, we discuss a framework to guide the discussion and the advancement of reproductive decision-making among women affected by ZIKV.

A framework for reproductive decision-making: The quest for justice

The emergence of the ZIKV epidemic as a public health emergency with significant implications to women of reproductive age and infants, has drawn attention to the ethical and moral implications associated to recommendations regarding reproduction, child bearing, and caring for children. In response to the ZIKV outbreak in Puerto Rico, Latin America and in other parts of the World affected by the epidemic, there has been official advisory statements cautioning women to avoid pregnancy until the ZIKV epidemic is under control (23). Concurrent to these recommendations, issues and positions regarding family planning, contraception, and abortion have been debated in the press and in professional settings. There has also been an emergence of publications in scientific journals,

mainly in the form of commentaries, which signal some of the dilemmas associated to intervening with reproductive decision-making (11, 12, 22-24). At the same time, health professionals are expected to advocate for more resources and for the accessibility to contraceptive measures, family planning, and abortion (23, 25). Debates and recommendations that lack clear implementation pathways or that do not match the resources that are available within the women's health care system are conducive to fear, stress, and anxiety (22). Pregnant women, even those that are not infected by ZIKV, participating at University Hospital High Risk Clinic echo and share this anxiety and uncertainty. They have articulated many of the issues raised in lay and scientific publication including the feeling of lack of control over their body and of being in the spotlight. The intersection of religion, perceived duties, fate, and the desire to have a child are forces and values that permeate decisions. As we consider empowering women and their families to make decisions in a comprehensive way, we need to go beyond reproductive health and incorporate actions to promote reproductive rights and reproductive justice.

Reproductive health mainly focuses on the delivery of services and accessibility to care earmarked to men and women of reproductive age. It recognizes that people should be "able to have responsible, satisfying, and safe sex lives." Services offered should acknowledge the choice of, if, and when to reproduce. It includes "access to safe effective, affordable and acceptable methods of fertility regulation, based on choice." Reproductive health emphasizes in those services and strategies that would enable women to have a healthy pregnancy and child birth, for a better chance to having a healthy infant (26, p. 1). Health care systems, especially the primary health care clinics, have lead the family planning efforts, and Puerto Rico is not an exception. Many could argue that these services should be expanded to community settings so that they could be more accessible and respond better to the population and community needs. However, in time of ZIKV and due to the clinical implications for mother and the child, the health care sector needs to remain as a strong partner in offering reproductive health services integrating adolescent, women, family and child care. Figure 1 illustrates key actions and elements to further support and strengthen the reproductive health during the ZIKV epidemic. Central to these actions is the improvement of the testing and monitoring process for the ZIKV.

Figure 1. Key actions for reproductive health during the ZIKV epidemic

Guaranteeing access to comprehensive sexual education and counseling.
Screening for sexually transmitted infections.
Eliminating barriers to effective forms of modern and emergency contraception.
Testing for the Zika virus during pregnancy and monitoring for those who tested positive.
Guaranteeing access to safe pregnancy termination.
Guaranteeing access to continuation of pregnancy without coercion.

Reproductive rights encompasses a set of actions and assurances that complement reproductive health by addressing legal and policy issues. Sexual and reproductive rights encompasses and are an inherent component of universal human rights, including: equality and non-discrimination under the law; body integrity and privacy, freedom of choice and expression, safety and security, and the highest attainable standard of health (26, 27). Governments have the opportunity and the responsibility of closing the gaps in reproductive rights by formulating policies. These policies should respect sexual and reproductive rights and should amend, enact or repeal laws, if necessary. The reproductive rights of women living in high risk areas for ZIKV need to be addressed in order to avoid injustices and decrease stigma. Personal choices become a matter of public policy when these choices cannot be legally exercised or there are social coercions and imbalances of power (12). In addition, due to the lack of scientific knowledge and treatment options, the funding of research is an integral element of achieving evidence-based policies (12). Figure 2 provides a set of key actions that should be considered during the ZIKV epidemic to promote reproductive rights. The importance of linking policies to resources and to the reduction of financial barriers should be highlighted as an essential element of reproductive rights.

Figure 2. Key actions to promote reproductive rights during the ZIKV epidemic

Authorize family planning programs that provide non-judgmental information on human sexuality.
Support community mobilization and public discussions on human, sexual and reproductive rights.
Reduce legal and financial barriers to effective forms of modern and emergency contraception.
Reduce financial barriers to legal and safe abortions.
Decriminalize abortions in Zika-endemic regions.
Improve guidelines and affordability of testing for the Zika virus.
Invest in surveillance, documentation and communication of the evolution of the epidemic.
Approve funding for clinical studies researching the pathophysiology, prevention, and treatment of Zika infection during pregnancy, including vaccines.

Reproductive Justice "entails a complete physical, mental, spiritual, political, social and economic well-being of women and girls based on full achievement and protection of women's human rights." Reproductive justice mainly focuses on "movement building", integrating and consolidating reproductive health and rights, while expanding the scope of services and program to address the social determinants of health, the culture and the environment. When we refer to reproductive justice, we have to be careful not to single out the focus on access to contraception and abortion as the main issues of concern. Reproductive justice is based on the tenets of "the right to have a child; the right not to have a child; and the right to parent their children under

the best of circumstances” (6, p. 6). We should highlight that it has been the experience at the University Hospital Clinics that some women are choosing to have a child with congenital deficiencies. These children will require specialized, coordinated and costly care. Under the framework of reproductive justice, these women should have access to information and services to raise their child. As with other epidemics, the ZIKV epidemic affects women and their families who suffer other health care disparities due to compromised environments, constrained access to resources, and asymmetrical social power that reflects on overall health. The challenges cannot be simplified and the responses need to go beyond physical health and legal considerations. Figure 3 provide examples of key actions that can enhance the movement towards reproductive justice. These actions promote that reproductive life decisions occur under the best scientific and moral circumstances.

Figure 3. Key actions for supporting the movement towards reproductive justice during the ZIKV epidemic

Ensure that all people of reproductive age are screened for potential ZIKV exposures.
Integrate reproductive health services to economic development.
Offer reproductive health services with inter-sectorial collaborations.
Formulate family planning programs and policies based on the social determinants of health.
Promote accurate information regarding ZIKV transmission and prevention to the public at large.
Integrate mental health services throughout the reproductive cycle.
Acknowledge culture, religion and traditions in the decision-making process.
Destigmatize reproductive choices and eliminate coercion towards specific decisions.
Link services aimed to family planning, prenatal care and child care to avoid fragmentation.
Provide access to medical and social services to women with children with congenital ZIKV syndrome.

Conclusions

Since the onset of the ZIKV epidemic, women of reproductive age and their families are faced with making decision about sexuality and family planning under uncertainty and limited information. Moreover, pregnant women with ZIKV infection, or at risk of ZIKV, do not only face the risk of fetal complications, but are also faced with ethical dilemmas regarding prenatal care, reproductive option, and maternal and infant care needs. Actions are needed to prepare for the expected increase in congenital defects, CZS; microcephaly cases, and a wide range of developmental disabilities, which will strain existing resources for families of affected infants. The ZIKV epidemic provides the opportunity to integrate different stakeholders to advance reproductive justice in the contest of Puerto Rico. Biomedical and behavioral scientists, clinicians, public

health and population policy advocates, government, and the communities should continue to work in leveraging and coordinating the response. Clinics like CEMI and the Puerto Rico University High Risk Clinics should continue to document their response, challenges and accomplishments. Service-based research, integrating the experiences of health care providers and the patients can make valuable contribution and complement epidemiological, clinical and basic research.

To this date, no national or global organization has issued a comprehensive guideline on the reproductive options, reproductive decision-making or reproductive justice. The framework presented will contribute to the debate in the medical, legal and social contexts.

Resumen

El 1 de febrero del 2016, La Organización Mundial de la Salud (OMS) declaró el brote de ZIKV como una Emergencia de Salud Pública de envergadura internacional. Las mujeres embarazadas y sus hijos fueron identificados como el sector más vulnerable a ser impactado. La incertidumbre asociada al desarrollo de defectos congénitos, producto de la infección con ZIKV durante el embarazo, ha renovado el debate sobre derechos reproductivos. Las estrategias, recursos y servicios dirigidos a la prevención del virus han sido insuficientes cuando se trata de salud, derechos y justicia reproductiva de la mujer. Programas dirigidos a la reproducción, en tiempos de Zika, son necesarios para capacitar a mujeres y sus familias en la toma de decisiones reproductivas.

Este escrito presenta las contribuciones del Centro de Estudios Materno Infantiles (CEMI), en colaboración con el Departamento de Ginecología y Obstetricia de la Escuela de Medicina de la Universidad de Puerto Rico y el Hospital Universitario, para proveer un cuidado integrado de salud a mujeres embarazadas con ZIKV o a riesgo de contraer ZIKV, al comienzo de la epidemia. CEMI ofrece servicio prenatal sobre las base de justicia reproductiva, integrando cuidado clínico, educación, investigación y abogacía. Transformación Prenatal (Centering Group Prenatal Care, GPC) ha sido esencial para lograr este objetivo. La experiencia de los profesionales y los testimonios de mujeres se utilizan para formular un conjunto de principios y acciones claves a considerarse para lograr que las mujeres en edad reproductiva, sus hijos y familiares reciban cuidado en un marco de justicia.

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