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Spotlight on Heather O’Connor: My Journey with Breastfeeding and HIV

In this edition of our "Spotlight: Women Making a Difference" series, The Well Project asked A Girl Like Me blogger Heather O’Connor about breastfeeding as a woman living with HIV in the United States. In this candid, in-depth interview, Heather shares how she found The Well Project after her HIV diagnosis; making the joyful but stigmatized decision to breastfeed her daughter, and her advocacy throughout the process; how factors like white privilege, a support system, and the threat of HIV criminalization affected her experience; advice she received while breastfeeding; why she is sharing; and what she believes must be done so that more women living with HIV can have their providers’ support in making informed infant feeding choices.

September 9, 2020 By The Well Project

This post originally appeared on and can be read in its entirety at The Well Project.

Heather, thanks so much sharing your story with us! To begin, how did you find The Well Project and what prompted you to reach out?

I’m so thankful for the opportunity to share! Thank you all so much for having me. I discovered The Well Project in June of 2016 following my HIV diagnosis. Overwhelmed with the weight of my diagnosis, my personal lack of knowledge regarding the virus (which, in my opinion, is something that should be addressed through sexual education both in the school systems, as well as with guardians at home), and need for support, I began browsing the internet and discovered blogs from A Girl Like Me, as well as other helpful resources for women living with HIV on The Well Project website. I frequented the website after discovering it. It was helpful for me to obtain information and firsthand accounts coming from women who were also living with the virus. Following my diagnosis, I received support from my partner, immediate family, and a few of my closest friends with whom I’d shared my diagnosis; however, I was thankful to have access to resources coming from other women who had also received an HIV diagnosis and were able to share their own personal coping experiences.

It wasn’t until March of 2017 that I made the personal decision to publicly post a video on my Instagram account (I am a trained dancer) of myself improvising movement to an excerpt from the documentary How to Survive a Plague (available to stream on Amazon Video and other services – I highly recommend watching), along with a blurb regarding my HIV diagnosis. The response I received from family and friends was an overwhelming amount of sadness and support. With time, my confidence to openly share details regarding my diagnosis grew and I became very interested in exploring my identity as an advocate for other individuals, specifically women living with HIV. During this time, I wrote an email to The Well Project inquiring about available advocacy work and eventually was given the opportunity to begin blogging for A Girl Like Me. I have continued blogging for A Girl Like Me throughout this pandemic and have made connections with other wonderful women, allowing my network of support to grow and strengthen. I am happy to share my story with others in an effort to raise awareness about the virus and to be an active part of a support system for other women living with/affected by the virus.

What have been some of the results of writing about your experiences? What kinds of responses have you gotten?

Since beginning to blog for A Girl Like Me, I've been given the opportunity to revisit and share the story of receiving my diagnosis, my life and health leading up to the diagnosis, and my journey after the diagnosis. I have been able to consider and shed light on the difficulties that come with navigating obtaining HIV medication, the importance of medication adherence to achieve and maintain viral suppression, and the dire need of support from others to manage life with HIV. Blogging has allowed me time for self-reflection, as well as given me opportunities to share my experiences with others while simultaneously raising awareness. I have become connected with other women active in the HIV community and have had the privilege of hearing their stories as well. It has been enlightening to have made these connections and to become involved in a network of such strong, powerful women. I feel proud to stand with and by them.

Overall, the response I have received from others has been largely positive and inquisitive. I have had several friends reach out to me with questions regarding HIV. My husband has had this experience with his friends, as well. Mostly I find that others are interested to learn about U=U (Undetectable Equals Untransmittable) and how that allows for my husband and me to have a healthy sex life without any risk of transmission and how we navigate day-to-day life as a serodiscordant couple. I have also received multiple questions regarding pregnancy and HIV, and I am always more than happy to share my experiences with others.

Breastfeeding while living with HIV is not common here in the US, but you breastfed your first child. Can you tell us how you made that decision?

When I became pregnant and started receiving prenatal care, my initial intention was to use formula to feed my baby because of my HIV diagnosis. All of the research I had done regarding infant feeding in the United States, including the CDC (US Centers for Disease Control and Prevention) recommendation, stated that the safest way to feed your infant as a mother living with HIV (in the United States) was with formula in order to prevent any risk of transmission from mother to child. I recall reading that breastfeeding was encouraged for mothers living with HIV in Africa, due to lack of access to formula and clean water. Statistically speaking, the risk of infant death due to factors such as diarrhea (from unclean water sources) is higher than the risk of HIV transmission to a child through breastfeeding from a mother who has achieved viral suppression (undetectable viral load). Further recommendations suggest that antiretroviral therapy for the child, such as AZT, should be administered to the child during the exclusive breastfeeding period, which should range from (at least) six months to two years to further prevent transmission of the virus to the child.

It wasn't until I had an initial appointment with a new infectious disease doctor that I even began considering the concept that I could breastfeed my child. Before being diagnosed with HIV, I had big plans of being a mother someday. Within those plans, I envisioned myself breastfeeding my child. Following my diagnosis, I was prepared to follow recommendations from my medical health care professionals to ensure the absolute safety of my child, and this included giving up my dreams of breastfeeding and choosing to use formula instead, if that's what I was instructed to do by professionals to reduce any risk of transmission. It's even written on the bottle of my HIV medication in all capital letters: "BREAST MILK CAN TRANSMIT YOUR INFECTION TO YOUR INFANT; THEREFORE DO NOT BREASTFEED." (A further conversation regarding the offensiveness of that language to women living with HIV is definitely one to be had, as well.)

However, while at my appointment with my newly assigned infectious disease doctor (my previous doctor had left the practice), he asked me what my intentions were for feeding my child. I immediately answered by saying "Oh, formula, of course. I know." He responded by asking me whether or not I wanted to breastfeed, to which I responded by saying, "Well, yes, of course. I always imagined I would breastfeed my child before being diagnosed with HIV, but now I know that's just not possible. Is it?"

The doctor then began to inform me about the PROMISE studies conducted in Africa, which were intended to investigate whether an exclusive breastfeeding relationship between a child and a mother with an undetectable viral load posed any risk for transmission of the virus. The findings from the studies, at the time my infectious disease doctor was informing me of them, were that the risk of transmission from mother to child (when mother obtained and maintained an undetectable viral load and child was treated with antiretrovirals as a preventative during the breastfeeding period) was less than 1 percent.

That being said, while we can now assert with significant scientific research that a person living with an undetectable viral load CANNOT transmit the virus through sexual contact (U=U), under any circumstance, the same is not true for breastfeeding. Further research is still needed in order to discover exactly what being undetectable means for a mother living with HIV who wishes to breastfeed her child. In the US, it is assumed that formula and clean water are generally accessible (although this is not the case for everyone); therefore there have been no studies conducted to further explore this topic, as it is easier to eliminate any risk of transmission by strongly encouraging the use of formula and discouraging breastfeeding, hence the strongly-worded warnings on HIV medication bottles.

After receiving this information from the infectious disease doctor, it sent my head spinning. I was excited about the possibility of being able to breastfeed (I had been undetectable for two years), but I was also afraid of the potential risk of transmission to my child, no matter how small. I was aware that the risk of transmission was negligible and had even been told by my infectious disease doctor that the benefits of breastfeeding far outweighed the risk of transmission. However, there were so many sources (and people) discouraging me from breastfeeding and encouraging me to "not take the chance" and use formula instead. I was very confused about what decision I would make, and all the way up to the day of my induction I'd decided I would use formula instead of breastfeeding. While I was in labor, I had a conversation with one of my nurses regarding the internal conflict I was experiencing wanting to breastfeed my child, wanting to make the best decision possible for my child, and the pressure I felt to use formula due to the stigma of living with HIV and breastfeeding (not to mention the pressure society puts on mothers to breastfeed, in general!). There was so much going on in my mind along with the fact that my body was actively in the process of delivering a human.

I ultimately began feeding my daughter formula after her arrival, a formula suggested to me by a nurse to be “the closest thing to breast milk.” As I fed my daughter the formula, I couldn’t help but acknowledge the strong feeling that this wasn’t the path I was meant to choose for my daughter (every path a mother chooses for her child is valid and unique to them). I kept telling my husband that I felt as though I was supposed to be breastfeeding. I felt my milk starting to come in and finally, late on the first night of my daughter’s life, I decided to ask my nurse if I could speak with a lactation consultant as soon as possible. She stated that she would put in the request and I eagerly awaited to hear back, but it wasn’t until the next day that I was able to meet with her.

How did you gain the support of your health care providers to breastfeed when women living with HIV in the US are so routinely discouraged from doing so?

I think one of the biggest factors in my decision to breastfeed was the encouragement coming from my infectious disease doctor to do so. He stated that, should I choose to breastfeed, he would follow both my and my child’s health throughout the breastfeeding period and would test my child’s blood every two months to ensure that there had been no transmission. He would also continue to test my blood to ensure that my viral load remained undetectable. When my daughter was born, he visited us at the hospital (the hospital was part of the same practice as the infectious disease clinic and essentially across the street). He congratulated me on the arrival of my daughter and asked whether or not I was breastfeeding. When I replied that I had decided to feed with formula due to fear of stigma, he was supportive of my decision. However, as I’d mentioned before, I eventually decided to acknowledge my maternal instincts and request a consultation with a lactation specialist.

When meeting with the lactation specialist, I explained that I was living with HIV and undetectable (since 2016) and that I wished to receive support with breastfeeding my daughter. I explained the PROMISE studies to the specialist and requested that she consult with my infectious disease doctor, as he would be able to provide her with additional information regarding the negligible risk of transmission through breastfeeding if mother was undetectable/baby was taking AZT. The lactation consultant and head nurse returned from consulting my infectious disease doctor via phone call. I held my breath as I awaited their response. My mother, mother-in-law, and husband were also present and I could feel the tension in the room. Then, to my surprise, the nurse said “Well, after speaking with your doctor I have learned so much that I did not know before. I am COMPLETELY ON BOARD! I agree that the benefits of breastfeeding far outweigh the risk of transmission to your baby, which is nearly zero, and I will make sure we get you a pump as soon as possible so that we can encourage your milk to come in.” The lactation consultant also stated that she had told the student shadowing her for the day that she was witnessing history in the making: the beginning of a future for women living with HIV who wish to safely breastfeed their children. I was completely overwhelmed with happiness. I was so glad that I chose to follow my maternal instinct and advocate for myself and my child. I was also extremely nervous, but very determined.

You've acknowledged that your experience of advocating for yourself and gaining the support of your health care providers to breastfeed as a woman living with HIV may have been very different if you were a Black woman or a woman of color. Can you speak to that?
Absolutely. The rate of maternal mortality in the United States for Black women and women of color is historically and currently significantly higher than the rate of maternal mortality for white women. This has nothing to do with differences in biological or anatomical make-up due to race or ethnicity. This is due to systemic racism. This is due to Black women and women of color not being heard and not being cared for appropriately by their medical health care professionals. This is not me asserting that this is the case for ALL practices and ALL health care professionals, but it is me asserting that this problem exists in our country and that the lives of women and mothers are being lost at an unforgivable rate due to it.

When I say that my experiences as a white woman advocating for myself and my child may have had a different outcome if my race were different, it is because in no way did me being white make the process any more difficult. In recalling all of the events that occurred from the moment I gave birth to my daughter to the moment we received the final test confirming that she was HIV-negative, I experienced bias due to the stigma associated with HIV from many individuals with loaded, uneducated opinions. Never once did I also have to navigate dealing with racial bias on top of that. If I did, I imagine that the journey for myself and my daughter would have been significantly more difficult. That is neither fair nor acceptable. Advocacy is so important to ensure that all mothers living with HIV are receiving appropriate, substantial health care, but most of all it is extremely important for our Black sisters and sisters of color. Our system was built to work against them and it's imperative that white women who are advocates do our part to speak up against the injustices that exist within the system (and with family, friends, and strangers). We must make it our work to uplift the voices of Black women and women of color on a daily basis.

Outside of working with your providers, what kind of personal support system did you have?

Honestly, my biggest source of support came from my husband, as he's my biggest ally. I wanted and needed him on board, most of all, as my daughter's father. That included having the very difficult, but necessary "what if" conversations. We knew the risk of transmission was very, very low, but we still understood that the risk could not be technically asserted as zero. There was SOME risk involved, no matter how small – so we were forced to consider every potential outcome of our decision. My husband is pretty well-known for being extremely honest about his opinions. I've never had to pry information from him in regards to his position on a given subject. One conversation I remember very clearly having with him is one where he admitted that he was scared, but that he was prepared to support whatever decision I wanted to make as my daughter's mother. He stated that if the dreaded "what if" were to become a reality, should our daughter acquire HIV, she would be "just as strong as her mother," she would be loved, she would be cared for, and she would always be our beautiful miracle.

In the beginning of our journey breastfeeding our daughter, she did not latch immediately and I had to pump her milk and feed it to her in a bottle. My husband did some (a lot of) research on HIV and breastfeeding and came across "flash heating" as a method used commonly in Africa to kill any existing virus in breast milk. This method is achieved by exposing the breast milk to boiling temperatures for a short period of time before offering it to baby. We put my expressed milk into an uncovered glass mason jar, set it in a pan of water (the water surrounding the jar of milk, but not entering it) and brought that water to a boil on the stove. We then removed the jar of milk from the boiling water, allowed it to cool, and served it to our daughter in a bottle. We did this for approximately the first two months of my daughter's life FOR EVERY FEED. Continue reading...

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The Well Project is a non-profit organization whose mission is to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls. Visit their website, www.thewellproject.org, to access fact sheets (English and Spanish), blogs, and advocacy tools, and to join a global community of women living with HIV.
