

Frozen in a Moment in Time: The Experiences of Mothers Being Diagnosed With HIV Infection

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The HIV pandemic persists despite advances in treatment options and access to care. Currently, the life expectancy of people living with HIV (PLWH) who are receiving antiretroviral therapy (ART) is comparable to that of the general population, and HIV is increasingly considered to be a chronic health condition. Despite the normalization of HIV, the psychological and social impact of HIV remains (Bravo, Edwards, Rollnick, & Elwyn, 2010; Flowers, 2010; Mazanderani & Papparini, 2015; Perrson, 2012). Globally, HIV testing is the cornerstone of HIV prevention, as it is only by establishing who is infected that further infections can be stopped. However, receiving this diagnosis can be an emotionally challenging time for newly diagnosed individuals, especially for mothers and pregnant women, who must assimilate HIV into their identities (Reichert, 2010). Despite the fact that the chances of vertical transmission occurring during pregnancy is minimal with antiretroviral prophylaxis, an HIV diagnosis remains life-changing and can bring uncertainty (Walsh, Horvath, Fisher, & Courtenay-Quirk, 2012).

The predominant discourse with mothers living with HIV infection is about avoiding vertical transmission (Loutfy, Sonnenberg-Schwan, Margolese, & Sherr, 2013). Worldwide, perinatal HIV infections have decreased significantly (Joint United Nations Programme on HIV/AIDS, 2016) due to prioritization of ART during pregnancy to prevent vertical transmission. Having children is important to many women with HIV (Logan-Kennedy et al., 2014),

and many opt to have children following an HIV diagnosis. French, Cortina-Borja, Thorne, and Tookey (2012) drew attention to the continued increase of HIV repeat pregnancies in the United Kingdom and Ireland. The most recent Irish figures revealed that, in 2016, 22% ($n = 508$) of newly diagnosed individuals were women of childbearing age (Health Protection Surveillance Centre, 2017). Recently, Willcocks, Evangeli, Anderson, Zetler, and Scourse (2016) highlighted the emotional and psychological impact of an antenatal diagnosis, as preventing vertical transmission often takes priority over the mother's well-being (Kelly, Alderdice, & Lohan, 2009; Kelly, Alderdice, Lohan, & Spence, 2012). This study explored the experiences of women who were diagnosed with HIV when pregnant or as mothers. Gaining an understanding of the HIV diagnosis experience at different points on the mothering trajectory allowed the emotional impact of the news of an HIV infection to be considered so that care provision could be more mother centered.

Methods

A narrative approach, which focused on storied accounts (Casey, Proudfoot, & Corbally, 2016), was adopted for the study. Narrative health research studies can be useful in the exploration of how

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meaning is given to disruptive health experiences (Stephens, 2011; Stephens & Breheny, 2013). Using purposive sampling, 11 in-depth interviews were conducted by the author in an Irish HIV support center. The study sample of mothers included women from Africa, Europe, and Ireland. Ethical approval for this doctorate study was granted by the Ethics Committee at Bath University, UK prior to the commencement of data collection. All participants signed a study consent form before being interviewed and each interview began with an opening question about mothering experiences. All participants were allocated a pseudonym to protect confidentiality.

Themes from the literature and research objectives were incorporated into the development of the interview guide. Interview transcripts were transferred to the software package NVivo8 (QSR International, Doncaster, Victoria, Australia), which was used to manage study data and supported the identification of significant narratives. Analysis focused on an iterative process of identifying personal diagnostic narratives to present a synthesis of different experiences while drawing on selected theoretical perspectives. These included feminist mothering theory (O'Reilly, 2008), HIV stigma frameworks (Campbell, Nair, Maimane, & Nicholson, 2007; Herek, 2002), and Social Capital Theory (Putnam, 1995). Murray's narrative framework (Murray 2000; 2008) was used during data analysis. Murray's narrative framework examines four specific elements within narratives: personal, interpersonal, positional, and ideological (Murray, 2000, 2008; Proudfoot, 2014; Shelton & Johnson, 2006). The narrative analysis approach facilitated the integration of levels of analysis to establish a more detailed appreciation of the maternal HIV diagnostic experience with women at different stages of the childbearing years.

Results

Eleven mothers with HIV infection were interviewed; among them, they had 21 children, ranging in age from preschool children to adults. Five participants were migrant African-origin women, five were Irish born, and one was from Eastern Europe. The time since diagnosis ranged

Table 1. Participant Demographic Information ($n = 11$)

Demographic Information	Participants
Place of birth	
Africa	5
Ireland	5
Europe	1
Age range	
20-30	4
31-40	3
41-50	2
51-60	2
Years since diagnosis	
1-3	3
4-10	4
11-15	2
16+	2
Number of children	
1	4
2	4
3	3

from 1 to 22 years. Two were diagnosed before they had children, seven were mothers (1 was pregnant) when diagnosed, and two were pregnant for the first time. A summary of participants' characteristics is provided here in Table 1. Analysis of the diagnostic narratives of both mothers and pregnant women revealed that (a) the HIV test result was unanticipated, (b) preventing vertical transmission dominated a woman's response to an antenatal diagnosis, and (c) on diagnosis, mothers were more troubled about the possible repercussions of the diagnosis for their children.

The Unforeseen HIV Diagnosis

A variety of reasons led the women to have an HIV test, including antenatal testing and health screening for newly arrived asylum seekers. In this study, prior to the HIV diagnosis, most of the women did not perceive themselves to be at high risk for contracting HIV infection. This was due to (a) a shared belief that they did not fit the stereotypical profile of those who contract HIV or (b) a belief that they were in a low-risk category. This was notwithstanding that some of the women were from countries with a high HIV incidence, others had previous or current partners who had HIV, and some had been treated for a sexually transmitted infection (STI).

Suzi, a mother of one, who received her diagnosis in the late 2000s, described what led to her having an HIV test: “I got herpes and I went to the hospital, at the same time they told me I am HIV. It was a shock, you know, I was in shock, I could never think, you know, I could get it.” It was clear that Suzi did not anticipate her diagnosis, although having an STI can increase risk of infection with HIV. In Ireland, 13% of newly diagnosed individuals also had a history of another STI ([Health Protection Surveillance Centre, 2017](#)).

Ann, an Irish mother of two, whose partner was infected with HIV, described how she became aware of her infection status:

1999. That’s when I found out, ah that was a disaster. Me partner, I was with him for years, he was an ex-drug user and he had it (HIV). We used condoms, we were safe. I ended up getting a cold, chest infection, and I couldn’t breathe, and just went down to about 6 stone (84 pounds), didn’t know what was wrong with me, hadn’t got a clue. Then I went up to the hospital, some doctor transferred me to another hospital, they told me there that I was HIV. I nearly died. I couldn’t believe it because I didn’t know what was wrong with me.

Ann’s account exemplified the unexpectedness of the diagnosis; although she knew her partner had HIV and practiced safe sex, on some level she did not believe that she was at risk of contracting HIV. Upon diagnosis, her immediate concern was for her child’s future should anything happen to her. For some in this study, HIV meant little to them prior to the diagnosis, implying a reluctance to confront their own vulnerability to HIV or that they appeared to be unaware of the risks of close relationships with known PLWH. On diagnosis, participants who were pregnant were concerned about the possibility that their unborn children could become infected with HIV.

Preventing HIV

For women diagnosed antenatally, an emphasis on preventing further HIV infections meant they had to simultaneously adjust to the diagnosis while dealing with interventions to prevent vertical transmission.

Rose, an African-origin mother of two, spoke about her diagnosis in the late 2000s when she had not been in Ireland for very long:

When I was 8 months pregnant, then I found out I was HIV positive. It was a shock and I was on my own, no family, and my ex-husband just neglected me, so it was a nightmare, a nightmare. My fear was what if the baby had HIV. When I had my daughter, thank God, she was HIV negative.

The unexpectedness of Rose’s antenatal diagnosis was apparent, and her response was affected by her belief that her unborn baby could also have HIV. For Rose, who was preparing to bring a new life into the world, the diagnosis meant she had to deal with the possible consequences of HIV for her unborn child. Her relief at her daughter’s negative test was apparent. The heightened sense of responsibility toward an unborn child on diagnosis was also evident in another narrative. Joanne, an Irish mother of one son, knew her boyfriend had HIV when she became pregnant. She spoke about her worries while newly diagnosed and pregnant.

I knew as soon as I was pregnant, I was always worried about the baby catching the disease. That’s what my most concerns were about and I had to get a drip into my arm throughout the labor, just to make sure the baby still didn’t get it. After he was born every time he got a snuffle or a cold it was terrifying thinking he had it, but I never thought (of) myself, it was just him I was worried about.

In Joanne’s account, her primary concern was for her child, the impact of her own diagnosis was secondary. An antenatal HIV diagnosis brings the possibility for pregnant women that their baby could also have HIV and strategies to avert vertical transmission took precedence.

Implications for Their Children

Another significant finding was how child-centered the participants were. Most of the women in the study were anxious to find out their child’s HIV status. Few of the participants talked about personal responses following the diagnosis because

their immediate worries were that they could have infected their children with HIV. This signified a “moment of being frozen in time,” which could not be overcome until the HIV status of their children was known.

For example, Ethel, an African-origin migrant mother of one, who was diagnosed in 2010 shortly after she arrived in Ireland, said:

Yes. I was very worried, obviously I thought I was going to die, you know, I was just thinking about her (her daughter) and what would happen to her and I was worried as well, “Has she got it (HIV)?” They sent me to the children’s hospital and carried out some tests on her and she was negative.

It is possible that Ethel’s previous knowledge of HIV in Africa affected her response to her diagnosis, as one initial fear she expressed was whether she would die. On diagnosis, she wanted to find out if she had infected her daughter during her pregnancy, suggesting that her reaction was dominated by the possibility that vertical transmission had occurred. Ann, an Irish mother of two, reacted in a similar manner upon diagnosis: “When I was first diagnosed, I was worried about my daughter having it.”

The shared concern from some participants was that their children could also be infected. Few studies have examined how mothers deal with HIV testing of their older children. In this study, the immediate worry of newly diagnosed mothers was that they had unwittingly infected their children. One Irish mother spoke about testing her teenage daughter shortly after her own diagnosis in the late 1990s: “She was only 13. I had to bring her for tests, and she wasn’t impressed, and she kept asking me what are they doing, and I think I just told her they were blood tests.” This woman spoke about trying to protect her daughter from the real reason for the blood test. Importantly, the HIV risk is minimal for older children if their mothers were infected after they were born. Regardless of the low likelihood of their older children being infected with HIV, the possibility did concern mothers following diagnosis, and most prioritized viral testing of their children. When their children’s status was known, the mothers could focus on how the diagnosis would personally affect them, demonstrating how the response to their

own diagnosis was child-centered. This response was intensified by a heightened sense of responsibility toward their children.

Discussion

The dominant driver in how the participants dealt with an HIV diagnosis was associated with maternal responsibilities. From this study, three main conclusions were drawn: (a) for most participants, the HIV diagnosis was unforeseen; (b) following diagnosis, most mothers focused on how the diagnosis would affect their children rather than their own postdiagnosis needs; and (c) the possibility of vertical transmission was a concern at the time of diagnosis irrespective of interventions during pregnancy and the point of infection (Proudfoot, 2014). The denial of risk prior to diagnosis for these participants suggested that prior to the diagnosis, HIV had not been a concern. This finding echoed research with women with HIV infection in other countries (Anderson & Doyal, 2004; Doyal & Anderson, 2005; Ndirangu & Evans, 2009; Stevens & Hildebrandt, 2006; Walsh et al., 2012). Four of the African-origin mothers in this study were diagnosed in Ireland, and prior to the diagnosis, may have felt that they had left the risk of HIV infection behind in their home countries. The participants were unprepared for an HIV diagnosis, and most believed they were not at risk of HIV infection despite the presence of known risk factors. This, in turn, resulted in serious consequences for their health.

This study’s accounts resonated with other research about mothers’ HIV diagnosis experiences, which have reported that the possibility of having infected their children was an immediate concern on diagnosis (Walulu & Gill, 2011). Importantly, the study uncovered the accounts of mothers with both younger and older children, allowing for insights about experiences at different mothering life points. After learning about the HIV diagnosis, most mothers prioritized having their children tested for HIV. Importantly, British HIV Association (2009) guidelines recommend that “... all the children of HIV positive parents are tested for HIV” (p. 19). In this study, women diagnosed after they had children

overemphasized the possibility of their children being infected, which may have been associated with the medical advice they received after the diagnosis, suggesting that even when the likelihood of vertical transmission was low, the possibility that it could occur was a postdiagnosis concern for mothers. Lessening of the importance of their own health by mothers living with HIV and emphasizing the health of their children echoed previous work (Walsh et al., 2012; Walulu & Gill, 2011). This study asserts and extends the notion of child-centeredness upon diagnosis, and for these mothers, finding out their children's HIV status took priority over their own personal concerns.

Interestingly, there were similarities between participants who were already mothers and women diagnosed in pregnancy, insofar as the women with children shared concerns about the possibility that their children had HIV even if the risk was minimal. A shared perception was evident in the narratives even though the risks were different between those who were diagnosed when pregnant and those diagnosed as mothers. During pregnancy, the women were prescribed ARTs to decrease the possibility of vertical transmission and they did not know the infant's HIV status until after their babies were born. This quandary was resolved sooner for women with children, typically within the weeks after diagnosis. Studies in different contexts have documented that the main worry after an antenatal diagnosis was the deterrence of vertical transmission (Fletcher et al., 2016; Kelly et al., 2009; Kelly et al., 2012; Long 2009; McDonald, 2008; Willcocks et al., 2016). This study found that despite medical reassurance, the possibility of vertical transmission was a concern for both newly diagnosed mothers and pregnant women irrespective of the risk, suggesting that there was an exaggerated sense of the threat of potential infection in their children.

In this study, establishing their children's HIV status was a significant concern for all participants. The use of a narrative approach allowed the women to tell their stories and make meaning of the experiences of being diagnosed with HIV. The study involved a small but diverse group of participants, reflecting individual experiences and the author's interpretation of those accounts, and may, therefore, not reflect the diagnosis experiences of women living

in other countries or in other settings. Nonetheless, it does offer understanding into how mothers respond to an HIV diagnosis.

Recommendations for Health Care Providers

The narratives of postdiagnosis experiences of mothers with HIV highlight that, upon diagnosis, mothers and pregnant women have to deal with unique challenges. For these mothers, personal needs were secondary to those of their children; on diagnosis, they tended to concentrate on the ramifications of the diagnosis for their children or unborn babies. Notably, health care providers seldom acknowledged how being a mother affected the health experience (Vallido, Wilkes, Carter, & Jackson, 2010). The onus on health professionals is to respond to the unique situations that newly diagnosed mothers and mothers-to-be face. Significantly, mothers living with HIV invest heavily in their mothering roles (Fletcher et al., 2016; Logan-Kennedy et al., 2014) and, consequently, health professionals need to be aware of this and to ensure they espouse a mother-centered care approach, particularly upon and beyond diagnosis.

Conclusion

This study explored the meaning of an HIV diagnosis for women at different times during their childbearing years, drawing attention to what some argue is the growing lack of interest in the psychosocial effect of an HIV diagnosis (Greene, Ion, Kwaramba, Smith, & Loutfy, 2015; Perrson, 2012). The HIV pandemic has had a multifaceted effect on women and their maternal experiences, notwithstanding advances in HIV treatments. Mothers' stories of diagnosis show that their responses to having HIV are child-centered; their own needs are secondary. The transition to being pregnant and becoming a mother creates distinctive challenges for women with HIV. Given the significance these participants gave to the HIV diagnosis, it is imperative to recognize women's concerns on diagnosis, while taking account of how they fulfill their mothering responsibilities. The HIV diagnostic experience is distinctive for mothers.

Disclosures

The author reports no real or perceived vested interests that relate to this article that could be construed as a conflict of interest.

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