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Testing HIV positive in pregnancy: A phenomenological study of women's experiences

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ABSTRACT

Objective: globally women receive HIV testing in pregnancy; however, limited information is available on their experiences of this potentially life-changing event. This study aims to explore women's experiences of receiving a positive HIV test result following antenatal screening.
Design: a qualitative, phenomenological approach.
Setting: two public National Health Service (NHS) hospitals and HIV support organisations.
Participants: a purposive sampling strategy was used. Thirteen black African women with a positive HIV result, in England, participated.
Methods: data were collected using in-depth semi-structured interviews. An interpretive phenomenological approach to data analysis was used.
Findings: the emergent phenomenon was transition and transformation of 'being,' as women accepted HIV as part of their lives. Paired themes support the phenomenon: shock and disbelief; anger and turmoil; stigma and confidentiality issues; acceptance and resilience. Women had extreme reactions to their positive HIV diagnosis, compounded by the cultural belief that they would die. Initial disbelief of the unexpected result developed into sadness at the loss of their old self. Turmoil was evident, as women considered termination of pregnancy, self-harm and suicide. Women felt isolated from others and relationship breakdowns often occurred. Most reported the pervasiveness of stigma, and how this was managed alongside living with HIV. Coping strategies included keeping HIV 'secret' and making their child(ren) the prime focus of life. Growing resilience was apparent with time.
Key conclusions: this study gives midwives unique understanding of the complexities and major implications for women who tested positive for HIV. Women's experiences resonated with processes of bereavement, providing useful insight into a transitional and transformational period, during which appropriate support can be targeted.
Implications: midwives are crucial in improving the experience of women when they test HIV positive and to do this they need to be appropriately trained. Midwives need to acknowledge the social and psychological impact of HIV and pathways should be developed to support early referral for appropriate support.

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Introduction

Worldwide, there are approximately 36.9 million individuals infected with HIV (UNAID, 2015); 70% of those infected reside in sub-Saharan Africa (UNAID, 2015). In the UK, an estimated 107,800 individuals live with HIV (Public Health England, 2014).

In the UK, during 2013, uptake rates of routine antenatal HIV testing were 98% ($n=700,000$ pregnant women) (Public Health England, 2014). The majority of women with HIV ($>80\%$) had been diagnosed prior to pregnancy (Public Health England, 2014) and Black African migrants represent the largest group of women being diagnosed during pregnancy (Southgate et al., 2008; Giravdon et al., 2009; HPA Report, 2011).

A positive HIV diagnosis impacts women's childbirth experiences and treatment options (BHIVA, 2012). Vertical transmission of the HIV virus from an infected childbearing woman to her

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[1] AL was a postgraduate research student at the University of Manchester when conducting his research. Andrew passed away suddenly. This paper stems from Andrew's empirical PhD work, an overarching aim of which was to give a voice to the women in his study.

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fetus or infant during pregnancy, childbirth or postnatally (through breastfeeding) is a major cause of concern (Landesman et al., 1996; Kuhn et al., 1997; Lyall et al., 2001; BHIVA, 2012). However, reducing vertical transmission relies on the pregnant women agreeing to test for HIV (Kennedy, 2003; NAM, 2011).

HIV diagnosis, is pivotal to women receiving appropriate care (Jones et al., 1998; Adler, 2001a, 2001b; Kennedy, 2003; Giravdon et al., 2009; NAM, 2011). Antiretroviral drug therapy has had a major impact on HIV disease management; HIV positive pregnant women have benefited from drug treatments leading to a decrease in transmission rates to their unborn infant (HPA Report, 2011; NAM, 2011). Of all children born to HIV positive women in the UK between 2006 and 2012, less than 2% were diagnosed with HIV (Public Health England, 2014). The potential health benefits of HIV testing have led to the support for routine screening being integrated within antenatal care (Mercey, 1998; Mercey and Nichol, 1998; Boyd et al., 1999a, 1999b; Baxter and Bennett, 2000).

Despite studies investigating women's views of the acceptability of the antenatal HIV test in pregnancy (Duffy et al., 1998a, 1998b; Simpson et al., 1998; Boyd et al., 1999b; Simpson et al., 1999), and pre-test information giving (Sherr et al., 2001), there are limited in-depth explorations of pregnant women's experiences. Existing literature tends to focus on mothering (Sandelowski and Barroso, 2003), decision-making (Kirshenbaum et al., 2004) and psychological impact (Nancy et al., 2004). Previous qualitative research has mainly focussed on women being pregnant knowing that they were HIV positive. Sanders, 2008, for example, presented powerful narratives of nine HIV positive women's experiences of losing temporary parental rights and how mothering positively impacted their recovery.

We are only aware of one other relevant study that has explored women's experiences of diagnosis during pregnancy. Kelly et al. (2012) conducted two interviews (antenatal and postnatal period) with four women who took part in another study that explored reproductive decision-making (Kelly et al., 2011), and reported that HIV disrupted health, relationships and social identity, but the baby became a metaphor for hope and orientation towards the future. Kelly's focus was less on the testing and more on the subsequent experience.

Although routine pregnancy screening is generally accepted (NAM, 2011), women's experiences of receiving a positive HIV result have not been adequately explored; given the likely impact of a positive HIV result this area needs further investigation. Thus the aim of this study was to gain an understanding of the personal experiences and the emergent phenomenon of women testing HIV positive in pregnancy within an antenatal testing programme in England. Thus the research question was: ‘what is the lived experience, for women, of testing HIV positive in England?’

Methods

The study used a qualitative approach, underpinned by a naturalistic paradigm and using the human science discipline of phenomenology. Heidegger's (1962) hermeneutic phenomenology suited the purpose and interpretive philosophical aims of the study; the study explored the lived experience of receiving a positive HIV result with antenatal testing. Phenomenology attempts to understand the holistic nature of the phenomenon rather than focusing on one aspect or concept (Van Manen, 1990, 2006); an HIV positive result in not an isolated event as its impact is life changing (Kennedy, 2003).

Ethical approval was gained from the North West Ethics Committee, reference 10/H1010/60, December 2010. Written approval from each hospital site was also obtained.

Sampling

Women who had undergone the experience of an HIV diagnosis in a UK antenatal testing programme were accessed using purposive sampling strategies (Polit et al., 2005; Bowling, 2009). The study aimed to obtain the views of women from different races, ethnicity and social groups; however, most women affected by HIV in the UK are Black African in origin (HPA, 2011), and this was reflected in the sample.

Sample size

This study explored the phenomenon of HIV testing as a unique experience; each story had a personal meaning (Van Manen, 1990). The sample size was thus influenced by its ability to provide rich in-depth data portraying individual women's accounts of the impact of HIV. A minimum sample of six women and a maximum of twenty were sought, in keeping with the phenomenological approach (Bowling, 2009).

Inclusion and exclusion criteria

Women who had received a positive HIV diagnosis in an antenatal HIV testing programme as routine UK testing was introduced in 1999 (DOH, 1999, 2003), irrespective of parity or pregnancy outcome, were included. Women were excluded if diagnosed in any other testing programme or prior to pregnancy. Women under the age of 18 and those with a severe mental disorder or who were unable to consent for themselves, were also excluded.

Access and recruitment

Two recruitment routes were used: a hospital route and a community route.

Hospital route

Two inner city public hospitals (situated in South and North-West England) were selected which serve populations from diverse ethnic and socio-economic backgrounds. These hospitals have high levels of HIV diagnosed in the pregnant population. In both hospitals, it was the midwives' responsibility to undertake the HIV testing and to inform women of the results. Both hospitals had the support of HIV specialist midwives who supported women following a positive diagnosis.

In the South, all eligible women were contacted by an experienced HIV specialist midwife; an initial meeting was held during hospital appointments, where interested women were fully informed of the study. Following this, women were given several options: to be given researcher's contact details, to self-refer, to allow for the midwife to pass on the women's contact details to the researcher or to be introduced directly to the researcher. It was made clear at this point that the interviewer was a male midwife; it was believed that some women may be more reluctant to discuss personal issues with a man. Most women were directly introduced to the researcher, in person, by the HIV specialist midwives. No direct contact was made by the researcher, thus reducing coercion. All women were given time to consider participation before meeting the researcher; for some women, this was several months.

In the North-West, recruitment was not successful despite the same access strategy.

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