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# *The Experiences and Coping Strategies of United Kingdom-Based African Women Following an HIV Diagnosis During Pregnancy*

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*A qualitative investigation was conducted to explore the experience of African women living in the United Kingdom after being diagnosed with HIV during pregnancy. Participants (N = 12) completed a demographic questionnaire and participated in one-to-one semi-structured interviews. The interview addressed multiple personal, interpersonal, and systemic issues related to HIV, as well as HIV in the context of motherhood. Data were analyzed using interpretative phenomenological analysis. Themes that emerged included: (a) HIV being part of one's wider tapestry, (b) community and systemic influences and responses to HIV, (c) experiencing a different story of HIV, and (d) the mother-child relationship. Strikingly, the aspect of HIV these women reported finding most distressing was their inability to breast-feed, which seemed central to their cultural identity as mothers. Clinical recommendations and implications are made.*

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**I**n 1999, the United Kingdom introduced an opt-out antenatal testing policy resulting in many new HIV diagnoses being detected during pregnancy. As suggested in the literature, motherhood requires constant change, redefinitions of self, relationships, and goals. Pregnant HIV-infected women have additional

challenges to cope with; they have to move toward a new normality, achieve a maternal identity (Mercer, 2004), and may experience personal, social, and biological transitions (Smith, Flowers, & Larkin, 2009). Furthermore, they may contend with uncertainty and fear about transmitting HIV to their children (Schuster, Beckett, Corona, & Zhou, 2005), unpredictable infection, stigma, isolation, and relational difficulties, such as sero-discordance, abandonment, blame, and loss of economic support.

Mothers living with HIV (MLWH) are often the primary caregivers in a family constellation and may experience guilt about the impact of HIV on their families (Goggin et al., 2001). The accumulation of environmental and emotional stress can lead to high levels of distress and depression (Murphy, Marelich, Dello Stritto, Swendeman, & Witkin, 2002), which can interfere with effective parenting, maternal well-being, the mother-child relationship, and the child's cognitive, emotional, and social development.

To date, most research on MLWH has focused on populations based within the United States; on

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drug-using women; and on the behavioral, risk, and biomedical aspects of HIV (Onwumere, Holttum, & Hirst, 2002). Studies have predominately explored three areas in relation to MLWH: (a) disclosure issues, such as whether disclosure hinders or benefits a child's development or what factors influence disclosure decisions for MLWH (Murphy, 2008); (b) childcare provisions, with studies exploring the experiences for MLWH of being unable to care for their children, missed parenting opportunities, or for making plans for their possible death (Murphy, Johnston-Roberts, & Herbeck, 2011); and (c) the reproductive decisions of HIV-infected women (e.g., Bedimo-Rung, Clark, Dumestre, Rice, & Kissinger, 2005). The extant literature highlights several influencing factors regarding reproductive decisions for MLWH. These include the perceived risk of vertical transmission; beliefs about vertical transmission risk-reduction strategies; desire for motherhood, stigma, religious and spiritual beliefs; cultural perceptions of HIV; confidence in antiretroviral medications; attitudes of partners and health care providers; and the impact of the mother's health on the child (Bedimo-Rung et al., 2005).

Few studies have examined motherhood in the context of maternal illness or considered the relationship between illness and identity in the context of HIV. Additionally, most studies have focused on problem-saturated discourses, as opposed to exploring this population's capacity for resilience. People of African origin are another underrepresented group in the literature, despite evidence that, in the United Kingdom, they are the second largest group of HIV-infected service users in the National Health Service (Kesby, Fenton, Boyle, & Power, 2003).

Although the term "African" will be used here, it is acknowledged that this implies homogeneity within a heterogeneous group of individuals comprised of numerous cultures, languages, tribes, religions, nationalities, and ethnicities. This group may include asylum-seeking or refugee people whose needs are multi-dimensional. They may have to justify their presence whilst living in legal limbo and under the omnipresent threat of being repatriated and whilst contending with myriad psychosocial difficulties, including language barriers, housing, and unemployment. Moreover, many have experi-

enced traumas, losses, and political uncertainty. For example, the female HIV prevalence in Rwanda prior to the 1994 conflict was 1%, and it rose to 11% by 1997, when an estimated 3% of all Rwandan women had been raped (Joint United Nations Programme on HIV/AIDS, 2010).

For some, HIV is viewed as being coupled with social and religiously proscribed behaviors, such as promiscuity, homosexuality, prostitution, and sexual relations with foreigners, or as a result of punishment, sorcery, or witchcraft (Okpako, 2006). Moreover, HIV has been strongly associated with death and dying. Koku (2010) illustrated this in his discussion of some of the linguistic labels used to describe HIV in various African countries, such as *maiti inayotembea* (walking corpse) used in Tanzania, *makizi yaku mochari* (keys to the mortuary) used in Zambia, and *menfese mute* (ghost) used in Ethiopia. Therefore, it is important to consider an individual's influences and beliefs, particularly as people from different cultural backgrounds may have varying illness scripts, illness narratives, and illness representations (Leventhal, Leventhal, & Cameron, 2001).

In summary, both MLWH and United Kingdom-based African people with HIV are underrepresented in the literature and can face significant additional challenges. Arguably, this is likely to be particularly the case for United Kingdom-based African women who are diagnosed with HIV during pregnancy. Surprisingly, however, there is a dearth of literature exploring the needs and experiences of these women, despite the increasingly high proportions of African MLWH in the United Kingdom and the UK Department of Health's focus on delivering culturally competent care. Therefore, this population will be the focus for the current paper.

Taking into account the re-conceptualization of HIV as a chronic illness, the improvement in life expectancy due to medical advancements (National Center for Health Statistics, 2011), and the increase in HIV diagnoses being detected during pregnancy (Health Protection Agency, 2010), more exploration of these women's quality-of-life issues, coping styles, and lived experiences would be helpful. This is also a research priority because of the significance of maternal well-being on child outcomes, the mother-child relationship, and early intervention opportunities.

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