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4. The psychosocial care of women living with HIV during and after pregnancy

4.1 Psychosocial issues around HIV and pregnancy

4.1.1	Antenatal HIV care should be delivered by a multidisciplinary team (MDT).	1D
4.1.2	We recommend that pregnant women living with HIV are offered peer support where available.	1B

First, it is important to acknowledge that the majority of women living with HIV engage well in care during pregnancy, resulting in the low rates of vertical transmission outlined in section 3. This is to be celebrated. Furthermore, for many women pregnancy and early motherhood is a joyful time. However, some women may experience psychosocial challenges during and/or after pregnancy. Trans women and non-binary individuals may experience challenges as a result of stigma and discrimination (including within healthcare services), and the lack of trans-inclusive antenatal and obstetric services [1]. Therefore they may require particular support.

HIV is associated with a higher risk of poor mental health [2]. Data from the UK-based ASTRA study reveal that the prevalence of depressive symptoms among women living with HIV is nearly 30% [3]. Furthermore, women may experience significant psychosocial barriers to accessing HIV care such as HIV-related stigma, unemployment and lack of financial resources. It is therefore important to be aware that pregnancy and the postpartum period may precipitate new psychosocial issues, or indeed exacerbate existing issues, among women living with HIV [4]. A recent national review of vertical transmissions has identified psychosocial issues such as immigration and HIV-related stigma as key contributing factors [5].

According to a systematic review of HIV and perinatal mental health, the prevalence of postnatal depression (PND) among women living with HIV in high-income settings is reported to be between 30% and 53% [6]. In the studies that include an HIV-negative comparison group, there was no evidence of an association between HIV status and PND [6]. Factors associated with PND in women living with HIV include past history of mental health issues, financial, immigration and housing concerns, lack of social support, HIV-related stigma, intimate partner violence, substance misuse and lack of support from a partner [6-8]. However there remains an absence of data on perinatal mental health among women living with HIV within a UK setting. Trial data on interventions targeting psychiatric and psychosocial outcomes in pregnant women living with HIV are also currently lacking [6].

The link between gender-based violence and HIV is well established [9]. As in the general population, women living with HIV may be at risk of intimate partner violence during pregnancy, with a lifetime prevalence rate of intimate partner violence in pregnancy estimated to be 14% in women living with HIV in the UK [10]. We therefore fully endorse NICE antenatal guidelines recommending that *all* pregnant women be asked about domestic violence [11].

4.1.1 Social issues

Many women living with HIV will have issues relating to social support and/or immigration. In both situations, it is important to identify the issues as early as possible so that women can be referred for appropriate specialist advice and support. We therefore suggest that all pregnant women living with HIV are routinely asked about their social situation as early as possible during their pregnancy.

Dispersal is an issue that may arise and is generally felt to be inappropriate in pregnant women, especially in late pregnancy or soon after delivery [12-14]. Some short-term visitors to the UK and undocumented migrants are not eligible for free secondary care on the NHS; however, since 1 October 2012, individuals living with HIV have not had to meet any residency requirement in order to access treatment. Treatment for HIV is freely available to anyone regardless of immigration status, and no hospital should refuse HIV treatment to anyone living with HIV.

Since October 2017, all antenatal, intrapartum and postnatal services are required by law to be considered 'immediately necessary'. Any service deemed 'immediately necessary' or 'urgent' cannot be denied to an individual regardless of ability to pay. However, people who are not eligible for free care on the NHS can be billed afterwards for these services.

Advice should be sought from colleagues, the General Medical Council (GMC), British Medical Association and Medical Defence Organisations in difficult cases. Advice can also be sought from organisations such as the Terrence Higgins Trust (www.tht.org.uk) or the National AIDS Trust (www.nat.org.uk). You can also contact the Doctors of the World advice line (0207 515 7534) for advice on access to healthcare in the UK.

4.1.2 Psychosocial care

A critical component in the prevention of vertical transmission of HIV is to facilitate a woman's engagement in care from an MDT that can employ medical interventions and provide appropriate holistic support. Clinicians should be mindful that clinical experience indicates that the management of issues such as adjusting to an HIV diagnosis and uncertainty during pregnancy, and robust confidentiality processes, have an impact on adherence to ART and acceptance of recommended interventions. Adherence to medication is of vital importance for the success of ART. Pregnant women may require extra support and planning in this area, especially if there are practical or psychosocial issues that may impact adversely on adherence. Referral to peer support workers, psychology support and telephone contact may all be considered [15]. Adherence can sometimes be suboptimal postpartum, resulting in viral load rebound [16]; early engagement in HIV care in the postpartum period has been shown to improve adherence [8].

Reassurance about confidentiality is extremely important, especially regarding family members and friends, who may not know the woman is living with HIV, but who are intimately involved with the pregnancy. Women from communities in which HIV is more common may be concerned about HIV 'disclosure-by-association' when discussing certain interventions, including taking medication during pregnancy, having a CS, and avoiding breastfeeding. Possible reasons such as the need to 'take vitamins', or having 'obstetric complications' and 'mastitis' may help the women feel more confident in explaining the need for certain procedures to persistent enquirers [17]. For couples where a male partner is HIV negative, advice should be provided on condom use and PEP following sexual exposure if a woman does not have an undetectable viral load [18].

The importance of informing appropriate healthcare workers about HIV status should be emphasised to women as well as the need for HIV status to be included in the birth plan wherever possible. This includes midwives, GPs, health visitors and paediatricians. The process of inpatient care should be explained clearly so that women can be supported in informing ward staff explicitly about maintaining confidentiality about HIV status, especially around visitors.

4.1.3 The antenatal HIV MDT

The minimum team should comprise an HIV specialist, obstetrician, specialist midwife and paediatrician, with the recommendation of peer and voluntary-sector support. All efforts should be made to involve the woman's GP and health visitor, with her permission. It may be necessary to involve some of the following: patient advocates, social workers, legal advocates, clinical psychologists, psychiatrists, counsellors, health advisors, Citizens Advice Bureau workers, interpreters, community midwives, pharmacists, adult and paediatric clinical nurse specialists and health visitors [19].

In settings with relatively few women living with HIV, it is still important to develop robust pathways of care with identified members of an MDT. Regular links, formal or informal, can also be established with a larger unit to provide advice and support as necessary. Good communication is vital in view of the complexity of the issues involved. An early assessment of the social circumstances of a woman given a new diagnosis of HIV is important. Patients who initially decline interventions or disengage from follow-up need to be identified and actively followed up.

Support by trained peer support workers is a valuable component of the care of a woman living with HIV and should continue into the postpartum period. Peer Mentor Mother programmes to support women living with HIV during pregnancy are well established in the UK and internationally, with positive multidimensional impacts on vulnerable women and improvements in clinical outcomes (such as adherence, prevention of vertical transmission

interventions and lower rates of depression) in randomised controlled trials [20,21]. Many newly diagnosed pregnant women are initially reluctant to engage with peer support because of fears around confidentiality; however, the great majority of women who do engage find that it becomes one of the most highly valued interventions [22,23]. We therefore strongly recommend that pregnant women are offered peer support. More information on Mentor Mothers is available at positivelyuk.org and salamandertrust.net.

4.1.4 The psychosocial care of women newly diagnosed with HIV during pregnancy

Women diagnosed with HIV for the first time during pregnancy may experience significant psychosocial stress and trauma as a result of the diagnosis in the context of pregnancy, and will therefore require the support of an MDT of experienced carers. A new HIV diagnosis may precipitate a complex mix of emotional, psychosocial, relationship, economic and, sometimes, legal issues. The newly diagnosed pregnant woman also has a relatively brief time in which to develop trust in her medical carers and attain sufficient medical knowledge of her situation to be able to make informed decisions that will affect her long-term health, as well as that of her baby and her partner. In the case of newly diagnosed HIV in pregnancy, prompt linkage to HIV care is beneficial [24], as is the offer of psychological support soon after an antenatal HIV diagnosis [25].

Confidence in telling others about an HIV diagnosis will vary from woman to woman, and there may be cultural factors that influence the patterns of telling partners and other social network members [19,26]. Talking about HIV should be encouraged in all women but should be viewed as a process that may take some time [27,28]. Talking about HIV to a family member, other than a sexual partner, should be encouraged as this has been demonstrated to reduce levels of postnatal depression [29]. There are situations in which a woman given a new diagnosis of HIV may be reluctant to share this with a current sexual partner, or appears to want to delay telling indefinitely. This can give rise to complex professional, ethical, moral and, potentially, legal situations. There is a conflict between the duty of confidentiality to the index patient and a duty to prevent harm to others. Breaking confidentiality in order to inform a sexual partner of the index patient's positive HIV status is sanctioned as a 'last resort' by the World Health Organization (WHO) [30] and GMC [31]. However, it is not to be taken lightly as it could have the negative impact of deterring others from testing because of the fear of forced imparting of HIV status and loss of trust by patients in the confidential doctor–patient relationship. Cases with challenging issues around sharing of HIV status should be managed by the MDT. It is important to accurately record discussions and management strategy in these cases. Timely partner testing during the pregnancy should be encouraged where possible and support given.

HIV testing of existing children should be raised with all women. In practice, if the children are asymptomatic the testing is often most easily done when the newborn is attending paediatric follow-up for HIV diagnostic tests [32].

4.2 Perinatal mental health assessment

4.2	Assessment of antenatal and postnatal depression should be undertaken at booking, and 4–6 weeks postpartum and 3–4 months postpartum in accordance with National Institute for Care and Health Excellence (NICE) guidelines.	1D

We advise that HIV MDTs follow existing NICE guidance on the detection of antenatal and postnatal depression [33]. This includes identifying women with past or present severe mental health illness including previous history of postnatal psychosis. These women should be managed in conjunction with a perinatal mental health team. Assessment of mental health should occur at antenatal booking, postnatally at 4–6 weeks, and then again at 3–4 months. This should include asking the following questions:

1. During the past month, have you often been bothered by feeling down, depressed, or hopeless?
2. During the past month, have you often been bothered by having little interest or pleasure in doing things?

If a woman answers 'yes' to either of the initial questions, consider asking a third question:

3. Is this something you feel you need or want help with?

As per the general antenatal population, if a mental health problem is suspected as a result of answers to these questions, we advise further assessment in accordance with NICE guidance, and prompt liaison with perinatal

mental health services, or the patient's GP, and/or voluntary groups as appropriate.

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