**“I owe her so much; without her I would be dead”: Developing a model of mother-infant bonding following a maternal antenatal HIV diagnosis**

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**Abstract**

Women can face a period of psychological vulnerability following antenatal HIV diagnosis, affecting feelings about both the pregnancy and motherhood. Our study explored the impact of being diagnosed with HIV during pregnancy on mother-infant bonding. Grounded Theory was used to assess perceived challenges and facilitating factors for mother-infant bonding for 10 mothers given an HIV diagnosis during pregnancy. Data analysis led to a model of mother-infant bonding composed of four theoretical codes: (a) facing barriers to bonding, (b) feeling disconnected from the baby, (c) developing a special bond, and (d) strengthening and moving on. Challenges with bonding emerged primarily during early stages after diagnosis and birth, with maternal resilience and positivity about the future developing as the infant HIV testing process progressed. Study recommendations include more timely information regarding vertical transmission and more targeted psychological support along with greater promotion of services to support women diagnosed with HIV antenatally.

*Keywords*. antenatal HIV diagnosis, grounded theory, HIV testing, maternal HIV, mother-infant bonding, pregnancy

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Maternal HIV testing has become a routine component of antenatal care in the United Kingdom, bringing with it a significant reduction in the vertical transmission of HIV from mother to child (Townsend et al., 2014). Antenatal HIV testing has also become more prevalent on a global scale, with 70% of countries (*n* = 118) participating in a global study (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2013) reporting widespread integrated HIV testing within antenatal care services.

Women can face a period of psychological vulnerability following a diagnosis of HIV during pregnancy, impacting feelings about pregnancy and motherhood (Alder, Fink, Bitzer, Hösli, & Holzgreve, 2007), and functioning as a mother (Psaros, Geller, & Aaron, 2009). A diagnosis of HIV during pregnancy can also be associated with the presence of suicidal thoughts (Kelly, Alderdice, Lohan, & Spence, 2012). In recent years, the antenatal care provided to women with HIV has been overwhelmingly focused on physical health and reducing the risk of transmitting HIV to the baby, for example through guidance to avoid breastfeeding (Sanders, 2008). Much less is known about the ways in which a diagnosis of HIV in pregnancy impacts the development of early mother-infant relationships.

**Challenges Faced by Mothers Living with HIV**

Motherhood, in the context of a chronic and stigmatizing illness, such as HIV, brings with it many unique challenges (Nelms, 2005). Qualitative studies have reported that mothers experience HIV-related discrimination, a fear of transmitting HIV to their unborn children, restrictions related to breastfeeding (Treisman, Jones, & Shaw, 2014), and the dual challenges of caring simultaneously for themselves and their children (Murphy, Marelich, Herbeck, & Payne, 2009).

An additional factor impacting women diagnosed with HIV prior to, or during, pregnancy is the infant screening process following birth. Studies interviewing mothers living with HIV and diagnosed postnatally reported that levels of maternal anxiety were notably increased prior to confirmation of their infant’s HIV status, suggesting that this could impact women’s mental health and maternal role during this period (Lazarus, Struthers, & Violari, 2009).

Mothers with HIV have also been shown to have a tendency to internalize stigma, experiencing feelings of guilt, shame, and worthlessness as mothers because of their HIV status (Lazarus et al., 2009). Qualitative research has provided personal accounts of the burden that HIV-associated stigma can place on pregnant women and their relationships. A heightened sense of shame and fears of negative disclosure outcomes, such as discrimination or rejection by family and friends, has been documented as a factor leading women to distance themselves from family and friends (Green & Smith, 2004).

**Mother-Infant Bonding**

Much research in the general population has focused on the impact of early mother-child relationships on subsequent child outcomes across different cultures and socio-economic levels. Mother-infant bonding, defined as, “the feelings of a mother towards her infant” (Myers, 1984, p. 243), is highly predictive of later attachment security, quality of the mother-child relationship, and resulting child outcomes (Pawlby, Hay, Sharp, Waters, & O’Keane, 2009).

Two of the most widely documented risk factors for disrupted mother-infant bonding are social isolation and maternal post-natal depression (Moehler, Brunner, Wiebel, Reck, & Resch, 2006) with a strong relationship between the two (Crouch, 2002).Additional factors associated with disrupted bonding include a lack of physical contact between mother and infant after birth, previous maternal negative life events, and restricted opportunities for infant breastfeeding (Triesman et al., 2014).

A steadily growing literature has demonstrated the high prevalence of poor long-term outcomes for children of mothers living with HIV, who are shown to be at risk of behavioral, developmental, and emotional difficulties (Bauman, Silver, Draimin, & Hudis, 2007). In an attempt to explain these behavioral and developmental difficulties, a number of authors have suggested that maternal HIV may impact negatively on mother-infant relationships after birth (Oswalt & Biasini, 2010). However, to our knowledge, no studies to date have explored maternal perceptions of mother-child bonding following a diagnosis of HIV during pregnancy.

**Unique Characteristics of HIV Diagnosis During Pregnancy**

Receiving an HIV diagnosis can be challenging at any time, bringing with it the potential for depression, denial, and fears surrounding unintended disclosure (Anderson, Riesch, Pridham, Lutz, & Becker, 2010). A small number of studies have explored the specific experiences of women diagnosed with HIV during pregnancy, suggesting that the news of HIV infection during this period can be particularly devastating (Kelly et al., 2012). These studies suggest a number of ways in which women diagnosed during pregnancy may have different experiences from those diagnosed prior to pregnancy or after birth (Simpson & Forsyth, 2007). These differences include a disrupted adjustment to diagnosis whilst preparing for the birth of a child (Kelly et al., 2012), a heightened level of shock associated with diagnoses from routine screening in pregnancy (Blaney et al., 2004), greater experiences of stigma for mother and baby (Kelly et al., 2012), greater urgency for decision making related to medication due to the potential for vertical transmission (Sanders, 2008), and complexities related to onward disclosure decisions (Earnshaw & Chaudoir, 2009).

The literature has highlighted the unique period of maternal vulnerability following an HIV diagnosis during pregnancy. Taken together, these studies introduce the possibility that stressors related to a maternal antenatal HIV diagnosis may influence the development of the mother-infant bond.

**Research Aims and Questions**

Our exploratory study aimed to develop a theoretical model of mother-infant bonding following an antenatal HIV diagnosis. The research questions were:

1. What are the experiences of mothers diagnosed with HIV during pregnancy when bonding with their babies?
2. What are the main challenges for bonding and what helps to facilitate bonding during pregnancy and the first 18 months after birth?

**Method**

**Research Design**

A cross sectional qualitative design was used. The data gathered from 10 semi-structured interviews with mothers diagnosed with HIV during pregnancy were analyzed using Grounded Theory (Charmaz, 2006).

**Participants**

Women were sampled systematically from a sexual health clinic situated in central London. All eligible women were provided with information about the study by their clinicians at regular clinic appointments. Women were eligible to participate if they had been older than 18 years of age when they gave birth and had received an HIV diagnosis during pregnancy. Women who were documented as suffering from Post Traumatic Stress Disorder (PTSD) following a traumatic childbirth experience were excluded from this study, due to the likely effect on the mothers’ recollection of experiences following the birth. In line with the service research policy, patients were also excluded if they had been treated under the Community Mental Health Team (CMHT) during this period for severe and enduring mental health problems.

Twenty-five eligible women were approached by clinicians at routine clinic appointments. Fourteen women agreed to take part in the study and be interviewed, but 4 women did not attend the scheduled interview and were subsequently unreachable. Of the 10 participants interviewed, the age of their first post-HIV-diagnosis children varied from 18 months to 4 years. Eight participants came from sub-Saharan Africa, one from the United Kingdom, and one from Jamaica. Participants ranged in age from 25 to 41 years. All 10 infants following maternal antenatal HIV diagnosis had subsequently been found to be uninfected with HIV.

**Data Collection and Ethical Approval**

Semi-structured interviews were undertaken, allowing mothers’ experiences to be explored in depth. Information about the semi-structured interview has been added. The interview guide covered HIV diagnosis and pregnancy, the birth, and experiences until the child was 18 months of age. The guide consisted of lead questions (e.g., *What were the first few days like after your child was born?*) and probes (e.g., *Who was with you when you first brought your baby home?*).

Interviews were carried out face-to-face at a specialist National Health Service HIV outpatient service within an inner-London hospital. All interviews were audio recorded, and observations about the setting and the interview itself were recorded in a reflective journal at the end of each interview to enrich the data set (Pidgeon & Henwood, 1997). The first author completed all 10 interviews in private consultation rooms in the clinic. Interviews lasted between 60 and 91 minutes, with a mean interview length of 72 minutes.

Our study was granted ethical approval from the London Bloomsbury National Health Service Research Ethics Committee and from Royal Holloway University of London Ethics Committee.

**Data Analysis**

Interviews were transcribed verbatim, and guidelines were followed to ensure a systematic procedure was applied to all transcripts (McLellan, MacQueen, & Neiding, 2003). The approach to transcription incorporated verbatim elements of participants’ speech including pauses, emphasis, and utterances (Davidson, 2009). Data coding consisted of three distinct stages of coding: initial coding, focused coding and theoretical coding, and diagramming (Charmaz, 2006). All three stages were linked and supported by on-going memo-writing.

Initial sentence-by-sentence coding was conducted on each of the transcripts, assigning each sentence a label that “categorizes, summarizes, and accounts for” that piece of data (Charmaz, 2006, p. 43). As data collection and analysis occur concurrently in Grounded Theory, the initial codes applied to each interview were explored for ideas and analytic concepts that could be pursued with subsequent interviewees.

The second stage of focused coding involved developing codes to describe larger sections of the data, which were more abstract and conceptual. The most significant and frequently adopted codes during the initial coding stage formed the basis of focused coding. The first author applied Charmaz’s (2006) methods of challenging preconceptions, being sure to avoid over interpreting, and being mindful of the tendency to force the data into preconceived categories.

The final stage of coding aimed to describe how the initial categories related to each other and could be integrated into a theory (Charmaz, 2006). Memos were central to this process and were employed to establish theoretical links and relationships between the codes, leading to the development of an analytical framework. A diagram was used to assist in this process and to help explain some of the categories, their properties, and the relationships between them (Charmaz, 2006).

**Data Credibility**

Validation and triangulation methods were incorporated into the design to allow for independent verification of the categories and the emerging theory and to enhance the credibility of the study. This involved checking the coding of interview transcripts and resulting themes with other researchers familiar with Grounded Theory techniques and the specialist HIV midwife at the service. The latter provided a credibility check of the analyses and supporting data to confirm that it resonated with her clinical experiences. This ensured that the first author did not miss any important themes, that data were considered from multiple perspectives, and that the labels and interpretations fit the data well. It also helped ensure coherence of the results and that the findings were presented in a way that made coherent sense to others.

**Results**

The analysis produced four theoretical codes composed of 19 focused codes, each containing a number of specific properties developed during the initial stage of coding. The main themes emerging from the four overarching theoretical codes are discussed below.

**Facing Barriers to Bonding**

The mothers in our study reported initial barriers to bonding with their babies following the HIV diagnosis during pregnancy. On learning of the diagnosis, maternal thoughts were dominated by anxiety about fetal death, with powerful negative images of their babies’ futures living with HIV. The majority of the women experienced this anxiety as first-time mothers, and perceived it as having a detrimental impact on the antenatal and postnatal periods. Fears about HIV transmission were most pronounced for women prior to learning of the extent to which vertical transmission could be avoided by following appropriate prevention of mother-to-child transmission (PMTCT) guidelines (e.g., avoiding breastfeeding). “So I thought ‘Well I’ve got it, so my baby’s going to have it, and … then … it’s too late to have an abortion, ‘cos I’m so far gone, so my baby is going to die’” (Participant [P]5).

Central to the women’s experiences of being diagnosed with HIV during pregnancy was a feeling of being overwhelmed by a number of different stressors simultaneously. These stressors included the urgency of starting medication immediately after diagnosis, with a lack of time to consider her feelings about it. The diagnosis disrupted the focus on becoming a mother for some participants, transforming pregnancy from a period of excitement to one of anxiety.

So it was a really tough angle. Everything just came together at the same time. If it was one at a time, the pregnancy, and then the HIV, then yes – maybe I would have been able to cope better. But this time it was, “How do I cope?” (P6)

A key emotional burden for women following the diagnosis was the battle with pervasive negative feelings about themselves and the HIV infection. Feelings of guilt and shame were reported by nearly all mothers, and these were perceived to interfere with the new mother role in some cases. For some women, negative feelings about themselves detracted significantly from the ability to enjoy the experience of pregnancy and the first few months with the new baby. This may have been exacerbated by more general feelings of shame related to the diagnosis, which seemed to have impacted participants’ feelings about being a mother. “I didn’t feel joyful about the pregnancy after I'm diagnosed. I wondered what I was doing having a child in my situation. It was stupid. I felt stupid”(P4).

**Feeling Disconnected From the Baby**

The mothers described a range of emotional stressors following the HIV diagnosis, in many cases leading to a perceived distancing from their babies’ needs and the parenting role. The mothers talked about being distracted, stressed, and distanced from the baby in the first months, making clear links between these problems and the recent HIV diagnosis.

After first hearing of the HIV diagnosis, many mothers experienced uncertainty about continuing the pregnancy. Most considered termination and adoption, only abandoning these thoughts after professional reassurance about the low risk of mother-infant transmission in the context of PMTCT interventions. The main triggers for these thoughts were the ideas that the baby might suffer and maternal uncertainty as to whether she would be around to care for the child in the long term.

I said to the nurse, “I don’t want to die and leave the baby on its own,” and so I asked if we could terminate so that the baby wouldn’t suffer… I thought that I didn’t want it because of the HIV. (P10)

For some women, status as a single woman living with HIV seemed both incompatible with motherhood and inadequate for bringing up a child. Whilst all mothers were retrospectively pleased to have continued the pregnancy, a sense of uncertainty over the suitability for motherhood continued to dominate during the first year after birth.

I went to the social services people, and I said, “I want you to take my son away,” because I couldn’t cope with the situation and I wanted him to be moved to a better place without my problems. I wanted to protect him … I don’t have my place, I don’t have any money, people are getting to know about our business. I thought at the time if I give him up to care for a while perhaps I can sleep on the streets and save money to rent our own house, and get him back again. It is better for the baby that way. (P8)

Several mothers saw breastfeeding as a central part of the maternal role, and the inability to do so for fear of HIV transmission led to self-doubt and feelings of maternal inadequacy. For mothers struggling emotionally with bottle-feeding, restrictions related to breastfeeding also led to a perception of interrupted maternal-infant bonding. The bonding disruption was characterized as maternal distancing from the baby, and a delay in connecting initially as the participants thought a mother and new baby should. “Don’t get me wrong, I love her unconditionally and whatever, but I felt like if I’d breastfed, the attachment between herself and me would have been a bit more stronger. A little bit more from me to her” (P1).

The majority of mothers struggled to feel hopeful about the next stage of a child’s life prior to receiving an uninfected result from the infant-testing process after 18 months. The mothers described the period of infant testing as putting the relationship with the child “on hold,” with some mothers seeming reluctant to start developing a “full” relationship with the baby until they had greater certainty about the baby’s future health and survival. This may have acted as a form of emotional protection as mothers prepared for the possibility of bad news. “Before the results I was living but I wasn’t really living ... And after that it was like ‘OK, thank God. Now let’s be mummy and daughter, and nobody is going to take you away’”(P2). The fear that the baby might die left mothers and babies in a state of limbo, living one day at a time, and unable to think optimistically about a future together.

Mothers expressed concerns about the potential for transmitting HIV to their babies after birth, which, in some cases, affected the level of physical contact some felt comfortable having with their newborns. A number of mothers were initially wary of any saliva contact with the baby, which led to restricted displays of physical affection, such as kissing and cuddling. Sensitivity to cuts or open wounds on their own bodies also led mothers to limit physical contact with babies to minimize risk of HIV transmission.

At first I don’t kiss my baby… I would try to keep her away from me as much as possible if I thought I had a scratch or a cut or something … I don’t want to sneeze, I don’t want to kiss her, I don’t want to touch*.* (P4)

Before that I was worried about kissing and cuddling my daughter – I did cuddle her, but did less kissing until I’d been reassured by the doctor. I’m glad I asked because it’s not nice holding back. It feels all wrong.(P6)

**Developing a Special Bond**

The majority of mothers described moving on from the initial challenges to develop a strong maternal-infant relationship, achieving a special and heightened bond despite the notable barriers to bonding. One reason for strengthened bonding seemed to be a maternal awareness of early distancing from the baby. This led to subsequent concerted efforts to compensate for these shortcomings as the baby developed and anxiety started to decrease over the first 18 months.

The special bond described between mothers and their babies was influenced to a large extent by the infant medication and testing process after birth. Whilst this period was emotionally draining for mothers, it was also perceived to have created a rare connection between mother and child, which may otherwise never have developed. Having been through HIV blood tests and taking medications themselves, the mothers felt able to empathize during treatment and testing, feeling closer to their babies through this shared experience.

I used to look at her sometimes and I think, “You and me, we are the same - you know how I feel. You know my secret” - when nobody else does. It was just us two in our little world.(P4)

The mothers also related the HIV diagnosis to a perceived heightened sensitivity to their babies, monitoring infants closely for any signs of discomfort or illness. Whilst this level of sensitivity was initially prompted by HIV-related anxiety, it brought with it a closer connection between mother and child.

It has made us closer because I make sure anything she does, I never cause her illness or anything. So I make sure that I watch her, her movements, the way she plays … In fact it brought me closer to her to monitor her movements and to make sure that she doesn’t fall ill unnecessarily, you understand?(P7)

The mothers drew comfort from physical proximity to their babies when they were feeling low in mood, frightened, or alone, with physical closeness bringing reassurance and contentment during the later stages of pregnancy and after birth. Within these maternal narratives was a sense of the baby understanding the mother’s pain, and providing comfort in a way that nobody else could at that time. “So it was very emotional … Because I had brought him into the world, and I needed to take care of him …. That was the only thing that mattered to me, and that made us feel tight together” (P8).

Maternal responsibility to protect a baby from harm was characterized not only in terms of protection from HIV, but also in protecting the child emotionally against any HIV-related stigma. The mothers felt there was significant potential for their babies to be discriminated against by family, friends, and professionals as a result of the maternal HIV diagnosis. Most mothers who described a desire to protect felt it brought them closer to their babies and supported the bonding process.

The mothers also described a sense of gratitude and mutual life giving between themselves and their babies following the antenatal diagnosis. This was characterized by the baby giving life to the mother, by triggering the early antenatal diagnosis of HIV and subsequent treatment and the mother then giving life back to the baby, by protecting the infant’s health during pregnancy and after birth. This reciprocity in life giving led to a unique bond between mother and baby, with each reliant on the other for survival, and it appeared to contribute to a perception of equality within the mother-infant relationship. “I owe her so much. Without her I would be dead now. For sure. I freed her, she freed me” (P4).

Mothers described their babies as bringing happiness and meaning back into their lives after the traumatic experience of being diagnosed with HIV. A well-defined connection existed for mothers between the birth of their babies and the start of new beginnings for themselves. For many mothers, the birth of the baby seemed to bring with it a shift in self-identity, from that associated with disease and ill health toward a more positive identity associated with motherhood and new life.

**Strengthening and Moving On**

Central to the women’s experiences of motherhood following antenatal HIV diagnosis was a deep feeling of relief upon hearing that the baby had been found to be free from HIV following the infant testing process. The news appeared to prompt a notable shift in how the mothers felt about themselves and their relationships with their children. The phase of moving on started in the latter part of the first year for most mothers, following good news from the second round of infant testing up to 6 months after birth.

Almost all of the mothers shared a strong faith in a Christian God; prayer and trust in God’s protection provided comfort and support following the diagnosis. For many women, faith enabled them to look back on their experiences since diagnosis and to find some purpose and meaning in their personal journeys. For mothers reflecting on their experiences, a bond with the baby emerged as the most notable positive outcome. This helped to boost a sense of maternal wellbeing and strengthen the women’s positive feelings about themselves and their infants’ futures. Mothers were able to talk in a more positive way about their relationships with their children in the future, freed from uncertainty surrounding their own life expectancies and the health of their babies.

There’s a light at the end of the tunnel, you know? The child is a blessing – some people are diagnosed and they are unable to have children – so, be grateful and just live your life as if it’s your last, every day, you know?(P1)

The mothers viewed their lives from this point on as defined by a need to survive HIV and continue living for their children. The responsibility to mother and look after a baby was central in helping overcome anxieties about their own future health. The sense of obligation to remain healthy was expressed most clearly amongst single mothers, who felt there was no option but to carry on living.

Sometimes I feel that I wouldn’t live that long because of the HIV. But then I remember I have to live for him, you know? ... I’m just looking after myself because he won’t have anyone if I’m not here. ­(P8)

The final theme to emerge for mothers considering on-going relationships with their children was related to accepting the HIV diagnosis and the resulting negative implications for motherhood. The mothers described a steady growth in self-assurance in the role of the mother following results from infant testing, and were able to let go of some of the associated feelings of guilt and shame. A sense of living every day as it came was supported by a wish to appreciate the time they had with their children.

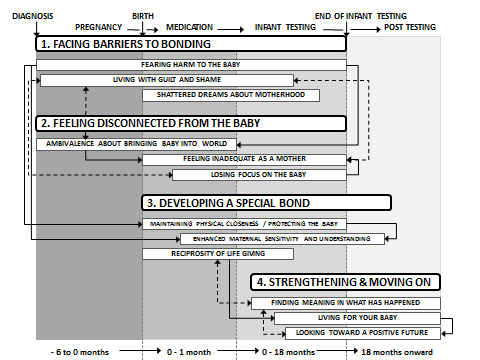
Let your child be your child and enjoy every moment of having them around … You’ve got it [HIV], but live on the fact that it doesn’t have you … And crucially, it does not have my child. My child is so free.(P2)

**Model of Mother-Infant Bonding**

A model of mother-infant bonding was developed to show how the main themes interacted in relation to mother-infant bonding following an antenatal HIV diagnosis (Figure 1). The model uses a chronological and developmental structure, with themes plotted across a timeline from antenatal diagnosis to the completion of infant testing 18 months after birth and the time after testing.

The model shows that barriers to bonding and feelings of maternal disconnection from the baby begin during pregnancy, before the birth of the infant. It shows how women move developmentally through different stages from diagnosis to after the end of infant HIV testing. Challenges with bonding are primarily experienced in the first 18 months, before the completion of the infant testing process. Maternal strengthening and positivity about the future develop toward the end of infant testing, and particularly following the confirmation of an HIV-uninfected infant status.

The arrows in the model show how one factor may feed into and influence another. The solid arrows indicate a one-way relationship between themes, whilst the dotted arrows indicate a circular relationship, in which both themes feed into and influence each other. *Living with guilt and shame* is an example of a circular relationship that fuels *ambivalence about bringing a child into the world*. Many women reported further feelings of guilt and shame as directly resulting from ambivalence about the pregnancy, leading to a circular relationship between the two processes.



*Figure 1.* Model of mother-infant bonding after an antenatal HIV diagnosis.

There are also examples in which a theme is shown to lead to both positive and negative implications for mother-infant bonding. For example, *fearing harm to self and baby* leads to both an initial ambivalence about continuing the pregnancy (and consequent disconnection from the baby) and a later enhanced maternal sensitivity and desire to protect the baby from harm (fuelling the development of a special mother-infant bond). Some themes in the model were, therefore, shown to have both a positive and a negative impact on mother-infant bonding. The positive and negative bonding processes can occur at the same time for some mothers, such as *feeling disconnected from the baby* and *developing a special bond*.

**Discussion**

Our study suggests that a number of mutually interacting processes influence a woman’s experience of bonding with her baby after being diagnosed with HIV during pregnancy. The themes we found were consistent with research reporting antenatal maternal anxiety related to the health of an unborn baby following an antenatal HIV diagnosis (Oswalt & Biasini, 2010). The fear of infant ill health seems to have been heightened for the mothers in our study during the period immediately following HIV diagnosis during pregnancy, with little time to adjust and process information about the risk for mother-to-child HIV transmission. Whilst this anxiety provided early challenges to bonding for some mothers, it also contributed to enhanced maternal monitoring, and a strong desire for infant protection contributing to stronger subsequent bonding.

For women in the study, the realization of their own health vulnerabilities appeared to clash with images of being a mother, a role that has traditionally invoked images of strength and stability (Walzer, 2007). The perceived incompatibility of HIV with motherhood was consistent with research with women diagnosed with HIV prior to pregnancy (Wilson, 2007). Participants in Wilson’s study reported HIV to be irreconcilable with good mothering, threatening the self-concept of mothers with HIV. Becker’s (1997) Theory of Disruptionprovided a useful framework for understanding the distress experienced at the point of antenatal diagnosis. Becker’s theory asserted that distress occurred when people experienced disparity between a cultural ideal of how life was supposed to be lived and the reality of actual experiences. The women in our study, who had grown up with positive images of motherhood and negative images of HIV, may have been particularly challenged to reconcile the two. The fact that most participants had grown up in Sub-Saharan Africa, where HIV was associated with high mortality rates (UNAIDS, 2013), may have further fuelled negative views about HIV.

Participants reported pervasive feelings of guilt and shame following antenatal HIV diagnosis, which were closely related to a perception of personal responsibility for their infants’ suffering. This type of shame has been described as internalized stigma(Earnshaw & Chaudoir, 2009)*,* characterized by the endorsement of negative beliefs and feelings associated with HIV. The maternal experience of guilt and shame can also be considered in terms of Jackson’s (2000) concept of Disrupted Mothering*,* which proposed that mothers experienced significant guilt and distress when plans for mothering were disrupted. The concept helps to explain the circular relationships between maternal guilt and shattered dreams about motherhood, in which the inability to breastfeed led to increased feelings of self-blame and responsibility for harm to the baby.

The majority of mothers in our study described feelings of ambivalence about pregnancy following the antenatal HIV diagnosis, with many temporarily considering terminating the pregnancy. These findings concurred with studies exploring decision making related to termination amongst pregnant women with HIV diagnosed prior to pregnancy, which reported maternal fear of inflicting suffering on the baby after birth (Orner, de Bruyn, Harries, & Cooper, 2010). The findings of our study suggest that this period of maternal ambivalence may have affected the women’s perceptions of the path toward motherhood, thus affecting the sense of bonding with the unborn baby during pregnancy.

The infant HIV testing process provided an additional set of anxieties for mothers in our study, many of whom were unable to think about a future with the baby until they received a negative result from the infant testing process. This period of uncertainty was perceived by the majority of mothers to prevent fully entering into a relationship with their babies until they gained clarity about the child’s future health and survival. These findings were consistent with other studies with mothers living with HIV (Shannon, 2015) and with literature showing that threats to infant ill health (e.g., through premature delivery) might be associated with disruptions in effective and timely mother-infant bonding (Hoke, 2001). Whilst some researchers have attributed bonding difficulties in the context of threatened infant ill health to an overly controlling and insensitive maternal style (Muller-Nix et al., 2004), the findings in our study suggest an element of maternal self-protection in preparing for the possibility of her baby being infected with HIV.

One of the key concerns for mothers in our study focused on the potential for HIV transmission to the infant through physical contact or the passing of saliva after birth. Lazarus et al. (2009) reported that many mothers with HIV held incorrect beliefs about the ease with which HIV could be passed from mother to child. A further study reported that maternal misconceptions about HIV transmission could limit behaviors such as kissing and sharing utensils between mother and child (Schuster, Beckett, Corona, & Zhou, 2005).

**Strengths and Limitations of the Study**

One of the key strengths of our study was the recruitment of a group of women diagnosed with HIV during pregnancy, whose experiences have rarely been explored in isolation from mothers diagnosed at different times. Participants were broadly representative of the study hospital population in terms of age, ethnicity, and country of origin. Another strength of our study was the incorporation of credibility checks and triangulation methods to maintain quality and allow validation of categories in the emerging theory (Madill, Jordan, & Shirley, 2000). We sought service-user feedback on the interview format prior to data collection to ensure clarity and sensitivity for the questions and validation of the initial coding table for sense and clarity (Charmaz, 2006).

One of the main limitations of the study was the recruitment of participants from a single site, potentially limiting the external validity of findings. The majority of the sample (8 of 10) were first-time mothers, suggesting that the emergent model might not be relevant to all mothers diagnosed with HIV during pregnancy. It is also worth noting that all participants reported eventually bonding well with their babies despite early challenges, which may support the idea that our sample was not representative of some other populations. The retrospective design of the study led to reliance on the women’s recollections of bonding experiences. It is possible the data may have been subject to recall bias (Kazdin, 1998), which may have compromised the reliability of the study. We attempted to limit the potential for such bias by narrowing inclusion criteria to include only those with a post-HIV-diagnosis child younger than 4 years of age.

It should also be noted that most of the babies discussed in our study were born prior to the advent of routine post-partum antigen testing of infants born to women with HIV infection. Because of this, the mothers in our study could not be sure of their infants’ HIV status until the completion of 18 months’ worth of antibody testing. Changes in testing practices may make a difference in the future experiences of women diagnosed with HIV in the antenatal period and their infants.

**Implications for Future Research**

A valuable area of future research would be to explore the perceptions and experiences of partners who are in relationships with women diagnosed with HIV during pregnancy and to explore what enables fathers to adjust and support their partners through this difficult process. Women in our study whose partners remained present following an antenatal HIV diagnosis reported feeling more able to manage the demands of new motherhood than newly single mothers (6 of 10 study participants). Quantitative research has shown that single mothers in the general population showed poorer emotional involvement and bonding with their newborn infants than new mothers who were married or cohabiting (Figueiredo, Costa, Pacheco, & Pais, 2009).

Secondly, our findings suggest that recently diagnosed mothers feel the potential for HIV-related stigma most acutely on behalf of their children, rather than themselves, with mothers avoiding disclosure of their own HIV status to protect children from future discrimination. It may, therefore, be useful to conduct a longitudinal study exploring how anticipated stigma changes over time for new mothers following an antenatal diagnosis. Such research could lead to a consideration of ways to better help newly diagnosed women to manage disclosure and cope with HIV-related stigma and discrimination, as set out in the British HIV Association guidelines (Taylor et al., 2012) for HIV in pregnant women and as recently called for in a systematic review (Tam, Amzel, & Phelps, 2015).

**Conclusions and Implications for Clinical Practice**

Our findings highlight the importance of providing effective and timely psychological, social, and practical support to women following a diagnosis of HIV during pregnancy. As outlined by UNAIDS (2013), routine antenatal HIV testing continues to increase internationally, leading to a steady rise in the numbers of women diagnosed antenatally with HIV each year, which has been accompanied by an increase in the number of children placed in PMTCT programs across the developing world. Our study findings may, therefore, be relevant for practitioners supporting women antenatally diagnosed with HIV both within the United Kingdom and globally.

**Timely Information and Psycho-Education**

Our findings suggest that mother-infant bonding may be disrupted in some situations due to maternal misunderstandings about mother-to-infant HIV transmission after birth, which stresses the importance of timely education for women diagnosed antenatally across all contexts, to avoid maternal misunderstandings impacting negatively upon mother-infant bonding. The findings suggest that such information may need to be communicated through different formats at various points in a mother’s adjustment to her diagnosis.

In the context of the National Health Service in the United Kingdom, our study provided support for protection of the role of the specialist HIV midwife to provide continuity of support and reassurance to women diagnosed antenatally. In African countries where resources may be more limited, the findings would suggest more targeted information and practical support provided by health care professionals or lay workers operating in health care settings. This could be specifically designed to aid women’s decision making related to breastfeeding to enhance bonding opportunities and adherence to antiretroviral medication under the 2013 World Health Organization (2013) Guidelines, specifically Option B/B+ for all women diagnosed during pregnancy.

**Psychological Support**

Whilst the British HIV Association guidelines (Taylor et al., 2012) for working with women living with HIV recognize the importance of psychological support during the antenatal period, our study provided greater detail about aspects of adjustment with which this group may need support. Findings suggest the need for an intervention that focuses specifically on women’s emotional and psychological transition to motherhood and on developing a maternal-infant relationship in the context of adjusting to a recent HIV diagnosis. Targeted psychological support could include Compassion Focused Therapy (Gilbert, 2010) to address the pervasive experience of maternal guilt and shame, Cognitive Behavioral Therapy (Beck, 1995) to help manage maternal anxiety related to infant health and support positive cognitive reframing, and Acceptance and Commitment therapy (Hayes, Kirk, & Kelly, 2011) to help with adjustment to and acceptance of the diagnosis. In resource-limited countries where psychological care may be lacking, workers in health care settings could effectively communicate key aspects of these approaches, including managing HIV transmission anxiety, coping with feelings of distance from the baby, and engaging in behaviors to enhance effective mother-infant bonding.

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**Key Considerations**

* Women may face a period of psychological vulnerability following antenatal HIV diagnosis, affecting feelings about both the pregnancy and motherhood.
* Maternal resilience and positivity about the future develop as the infant HIV testing process progresses.
* It would help to provide more timely information about vertical transmission to women diagnosed with HIV during the antenatal period.
* More targeted psychological support should be offered to counter maternal feelings of anxiety, guilt, and shame.