CLINICAL ETHICS

Routine antenatal HIV testing: the responses and perceptions of pregnant women and the viability of informed consent. A qualitative study

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This qualitative cross-sectional survey, undertaken in the antenatal booking clinics of a hospital in central London, explores pregnant women's responses to routine HIV testing, examines their reasons for declining or accepting the test, and assesses how far their responses fulfil standard criteria for informed consent. Of the 32 women interviewed, only 10 participants were prepared for HIV testing at their booking interview. None of the women viewed themselves as being particularly at risk for HIV infection. The minority ($n=6$) of the participants who declined testing differed from those who accepted, by interpreting test acceptance as risky behaviour, privileging the negative outcomes of HIV positivity and expressing an inability to cope with these, should they occur. Troublingly, only a minority of women ($n=9$) had a broad understanding of the rationale for the test, and none fulfilled the standard criteria for informed consent. This study suggests that, although routine screening combined with professional recommendation may be successful in increasing uptake, this may be at the cost of eroding informed consent. Protecting third parties (notably fetuses) from a preventable disease may outweigh the moral duty of respecting autonomy, enshrined in Western bioethical tradition. Nevertheless, such a policy should be made transparent, debated in the public domain and negotiated with women seeking antenatal care.

and integral part of their antenatal care.⁸ Targets were set to increase the uptake of HIV testing to 90% and antenatal diagnosis to 80% by the end of 2002.⁹ In 2001, the number of babies born to infected mothers had considerably increased ($n=561$), but the maternal diagnosis and treatment rate also increased, such that the proportion of exposed infants becoming infected fell significantly.¹⁰ Extrapolating from the figures,^{11–12} around 100 infants were saved from HIV infection. This statistic provides a powerful incentive for continuing with a screening programme that can prevent a significant emotional, physical and practical burden for HIV-infected children and their families,¹³ and a drain on medical, economic and social resources.

Despite improved figures, it was noted at the end of 2002 that the targets had not been fully met.¹⁴ In response to this, in 2003, the Department of Health reinforced the existing policy that all pregnant women should be offered screening for infectious diseases, including HIV, as an integral part of their antenatal care.¹⁵ The department's document makes scant reference to consent, apart from stipulating that screening is performed with "documented consent" which does not require a patient signature, and that women have a right to decline screening.¹⁶

From the utilitarian public health perspective, the residual concern is that a small, but significant proportion of women are declining screening, allowing more babies to be infected. From another ethical perspective, based on respecting people and not treating them instrumentally, there is a real concern that such a powerful target-driven imperative to increase the uptake of HIV testing may erode respect for autonomy, with women not acting as consensual partners in the process. Previous research has suggested that the main reason why pregnant women decline routine HIV testing is the perception of low risk to HIV infection.^{17–18} In this paper, we explore in greater detail the way women respond to routine antenatal HIV testing in order to better understand what shapes their decisions and whether they meet the criteria of informed consent.

Setting

This study was conducted in a large teaching hospital in central London serving a multiethnic population, at two clinic sites where antenatal care was provided. The local National Health Service research ethics committee gave ethics approval. At the time of this study, the hospital had a

In 1994, a landmark trial established that perinatal antiretroviral treatment with zidovudine reduced mother-to-child (vertical) transmission of HIV from around 25% to 8%.¹ Further measures, including selective caesarean section,² avoidance of breast feeding,³ careful obstetric management and combination antiretroviral treatment were shown to reduce transmission to around 2%.⁴ In other words, vertically acquired HIV infection can be a near-preventable condition. Women also stand to gain through earlier treatment and control of symptoms.⁵ Unsurprisingly, antenatal screening for HIV became a public health priority in the UK and elsewhere.

In 1999, an estimated 380 babies were born to HIV-infected mothers in the UK,⁶ with over 70% unaware of their status.⁷ In this context, the British Government advised that all pregnant women should be offered an HIV test as a routine

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well-established policy for routine antenatal HIV testing. Midwives at the booking clinic offered blood tests for a checklist of conditions and infections involving mother and baby, including HIV infection, and stamped a tick box in the medical notes to record the refusal or acceptance of a HIV test. All midwives received education and training for discussing the antenatal HIV test, and were expected to recommend testing. Information leaflets were sent to the women before attendance at the clinic. There was a specialist team, including a midwife and obstetrician, responsible for the care of HIV-positive pregnant women and their families. The uptake of testing was 75–80% and the prevalence of HIV among women attending the antenatal clinics was around 0.5%.

Participants, methods and theoretical framework

Participants were women attending antenatal booking clinics at the hospital. Purposive sampling was used to ensure a wide diversity among study participants in terms of parity, country of origin, religion and refugee status. PdeZ identified and recruited potential interviewees before booking their consultation with the midwife. Participants were offered the choice of an interview in a private room at the clinic or at their home. All participants gave written informed consent before the interview and all were assured confidentiality. In all, 16 invited participants were not interviewed: 1 required an interpreter (unavailable), 11 declined stating lack of time, 2 declined without stating a reason and 2 were not interviewed for administrative reasons. Demographic variables were not significantly different from those interviewed.

A total of 32 women attending the antenatal booking clinics participated in interviews. Their mean age was 29.66 (SD 5.12, range 18–38) years. Their mean gestation was 14.9 (SD 5.46, range 11–36) weeks; 16 were nulliparous (first baby) and 16 multiparous (having had already one or more children). Five women required an interpreter and four described themselves as refugees or asylum seekers; their other social characteristics are described in table 1.

Semistructured interviews were conducted with the help of an interview guideline (see appendix). Women were encouraged to give their own perceptions and accounts. These lasted for 20–45 min and were audiotaped, anonymised and transcribed verbatim. Two interviews were conducted in Spanish, and transcribed and translated by PdeZ.

The content of the transcripts was analysed for emergent themes and coded/categorised using the matrix-based thematic method of the National Centre for Social Research, London, UK. These codes/categories were systematically compared for similarities and differences, and themes were developed methodically.¹⁹ MB also analysed a random selection of interviews to incorporate a different perspective and add to the validity of the analysis. Prospect theory, a psychological decision-making theory, provided an additional tool for analysing and making sense of the women's interpretations of risk and their subsequent decisions.²⁰ This theory, developed by Tversky and Kahneman, provides an account of how perceptions and experiences can affect decisions. These include previous experience of such an intervention, the framing of information in guiding action, the relative salience of desirable or undesirable outcomes, and the capacity to respond to the information given. Rothman and Salovey²¹ distinguish three types of framing: health promoting, disease detecting and recuperative. The first two are of relevance here. Testing for HIV can be interpreted as risk-reducing behaviour if framed as health promoting ("making sure that my baby is healthy") or as risk-seeking behaviour if framed as disease detecting ("finding out if I and/or my baby have a life-threatening disease"). In a study of prenatal (α -fetoprotein) testing, researchers developed another useful formulation.²² The

researchers found that both refusers and acceptors applied notions of risk to account for their decisions, but the difference between the two lay in how they perceived this risk. Both groups believed in the power of biomedical information to affect their lives but differed in their acceptance of medical authority.

The General Medical Council²³ and the Department of Health²⁴ guidelines were used as a framework in assessing informed consent.

The General Medical Council guidelines state:

You must ensure that anyone considering whether to consent to screening can make a properly informed decision. ...You should be careful to explain clearly: the purpose of the screening; the likelihood of positive/negative findings and possibility of false positive/negative results; the uncertainties and risks attached to the screening process; any significant medical, social or financial implications of screening for the particular condition or predisposition; follow up plans, including availability of counselling and support services.²⁵

Findings

Responses to the offer of an HIV test as a routine part of antenatal care

Prior consideration of HIV testing

Most women (22/32) came to the booking interview unprepared for the offer of an HIV test. These women had not anticipated that they would be asked to make a decision on HIV testing and showed little or no evidence of prior deliberation. Few ($n = 5$) women recalled reading the hospital's information leaflet.

... "But coming here I did not think that I would be confronted with this, and be asked about my understanding of AIDS. I come this time, thinking they would be doing a scan, check the baby, and that's it, all done". Acceptor [3254237]

Ten women who were more prepared had read the literature or discussed HIV testing beforehand, either with their partner or friends, or in the context of a previous test offer.

"I must say I read a lot, I mean as soon as I found out that I was pregnant, I bought a lot of books (laughs) and you do find so much information in those, that once you come here you more or less know what they are doing and why they are doing it." Acceptor [621192R]

Acceptance and refusal of HIV testing

Twenty-seven women were tested for HIV at the time it was offered in the booking clinic. However, three of these women did not realise that they had been tested, one of whom thought that she had declined testing. Overall, 26 of 32 women were classified as "accepting" testing and 6 of 32 women as "declining" testing.

Among those who accepted testing, 13 described their acceptance as of their own personal choice. These women espoused the value of individual autonomy:

"I believe that everyone must be responsible for his or her actions. And it is good if every person follows their own conscience, and are aware of what they are doing". Acceptor (Colombian) [3254237]

"But it is the woman's decision whatever she agree with, because it's her body – she is the one carrying the baby". Decliner (Somalian) [3169006]

Nine women (including the two who did not realise they were tested) deferred their decision to another person (usually their partner or the midwife) and three felt pressured into accepting against their will.

"And I am thinking, I go home, and ask first my husband." Acceptor [3070217]
 ... "a very good friend of mine is just a few weeks ahead of me and she has already been here, so she is guinea-pigging for me, and so when she has choices, I choose what she chooses, because she is very fair (laughs)." Decliner [3259586].

Among those who declined testing, four presented the decision to decline as their own personal choice, one (who was nevertheless tested) had deferred to another person and one rejected, on religious grounds, the legitimacy of testing.

"You are tampering with something that is a gift from God". Decliner [30698717]

How testing was offered: the power of recommendation and routinisation

The way testing was offered, and in particular the midwives' recommendation, heavily influenced women's responses. As HIV testing was offered alongside a number of other tests, it was perceived as easier to accept the job lot than to start selecting among the different tests. "Routine" was often equated with lack of choice, a formality to go through.

"I'd actually assumed that they might even...that it would have been one of the routine tests that they did rather than you being given a choice...Acceptor [3282211X]
 "If it had involved something more complicated than just the blood she was already taking I probably would have said 'no', because I am convinced I'm not HIV positive." Acceptor [3157977]

Twenty-eight participants found it difficult to recall what other tests had been discussed, but indicated that they had accepted all those on offer (these included hepatitis, rubella and syphilis, blood group and blood sugar). Four of those who declined HIV testing specifically mentioned that they would also decline serum screening for Down's syndrome.

What shapes decisions? A comparison of acceptors and decliners

Participant characteristics

From this small sample, those who declined testing could not be clearly distinguished from those who accepted testing in terms of their religion, country of origin, refugee status, age, gestation or parity (table 1). However, two women who declined testing were of African origin, one Colombian and one of British African Caribbean ethnicity.

Self-perception of risk for HIV infection

None of the women attending the clinics perceived themselves to be at high risk, although virtually all acknowledged that the possibility could not be ruled out altogether, acknowledging the risk from sexual contact.

Table 1 Characteristics of participants

	n (decliners)
Country of origin	
Sub-Saharan Africa	4 (2)
Middle East	2
Indian subcontinent	1
Europe	16 (3)
South East Asia	2
South America	4 (1)
Australia	3
Religion	
Roman Catholic	8 (1)
Other Christian faiths	8 (1)
Muslim	6 (2)
Buddhist	1 (1)
Jewish	2
None stated	7 (1)

"Maybe I can't say 100%, I am sure, I don't have this disease - I can't. I can say only if 90% I am sure, I am safe." Decliner [3169006]

... "however much people have protected sex, people usually stop at some point having protected sex and that's the risk, and if neither of you have an HIV test, it's a risk. You know that most people have slept with several people before they end up with their final partner"....Acceptor [3282211X]

Prior experience of HIV tests and antenatal screening

Eight women had been tested for HIV infection previously (antenatal, premarital or blood donation). All agreed to testing, although one questioned its necessity. Two women described distressing experiences of false positive prenatal tests (one a serum screening test for Down's, and one an ultrasound scan with a potential diagnosis of hydrocephalus). Both of these declined HIV testing.

Framing and interpretation of risk; the power of knowledge

Acceptors and decliners alike expressed a profound sense of maternal responsibility, and the agenda to benefit their unborn baby dominated the way they framed testing. However, acceptors and decliners differed in the way they assessed the risk involved with HIV testing. Twenty-three of the women who had accepted testing viewed it as risk reducing and providing confirmation that their unborn baby was healthy. "It's good to know" was a frequent refrain. These perceived knowledge as empowering. In addition, ten identified specific benefits for their babies, and/or themselves or their partners.

"Well, I think as much information as you can get to ensure that you have a healthy pregnancy and healthy birth and a healthy baby afterwards. I think that it's handy, so yes, I thought well, yes, if it's going to change the way we do things, then it's good to know, and it does take that 2% doubt out of your mind, like 'what if?'. Acceptor [3282230H]
 ... "and if you can prevent the child from getting it [HIV] from you, well then you owe it to that child to do just that. So it's just knowledge is very powerful". Acceptor [6247877B]

Anticipatory regret was also expressed:

"I just thought it would be irresponsible and also I would feel terribly guilty to find out at a later date that I could have

saved the child from having the infection. Acceptor [3244148X]

Five acceptors additionally viewed testing as a disease-detecting activity—that is, identifying them (and their unborn baby) as HIV infected. Of these five, four volunteered that they would have a termination if found to be HIV positive. Three acceptors did not show clear evidence of framing.

All the decliners viewed testing as risk seeking and primarily disease detecting. For these women, framing the test in this way made them focus more on the adverse outcomes of a positive test result and on their low capacity to cope with such information. “Ignorance is bliss” was a frequent comment. Knowledge was threatening, disempowering. Three of these volunteered that they would not wish to terminate the pregnancy if found to be HIV positive.

Risk assessment: the relative salience of desirable or undesirable outcomes

Women did not appear to weigh up formally the burdens and benefits of learning their HIV status, but did carry out a broad risk assessment. With one exception, both acceptors and decliners from diverse backgrounds and ethnicity, viewed a positive test result as devastating—leading to a number of negative consequences including reduced life expectancy, stigma and discrimination, loss of job, difficulties with insurance, adverse effects on relationships and the potential for termination of pregnancy. There was also a widespread belief of an adverse effect of maternal stress and anxiety on fetal health (brought on by having the test, or being found to be HIV positive). Confidentiality was another concern.

“Well, it affects the length of your life, number one, and then also your quality of life, and I’ve seen people dying of AIDS, and it’s not very nice...Um, I just think I’ve seen people sort of segregate people who are HIV positive, and treat them not very nicely, treat them like they’re sub-human. So I wouldn’t want to be treated that way.” Acceptor (nurse) [328227V]
 “...I mean I work on a trade floor, so I mean I don’t think that I would have been allowed to work, to be honest with you. I don’t know - it would have been very, very difficult.” Acceptor [6211921R]

“What strain is that going to put onto our relationship? How will it affect, you know, our sex life in the future. Will I feel like a pariah?” Acceptor [32144148K]

For five of the six decliners, the fear and stigma of HIV eclipsed or discounted potential benefits (if they believed there were any) of knowing they were infected.

“Basically it would cause me stress, if I am positive I’ve got another extra thing to deal with. Basically if you have something like that, you’re like a leper, aren’t you, in society? And that would be too much for me to deal with, to handle, and plus my partner might leave me as well, leave the baby, he might not want to handle the pressure (laughs). Then plus if you do find out if you are or not, your insurance, everything, you are reckoned... so forget about fitting in society again, and basically I think that’s just too much for me to deal with.” Decliner [M069878R].

For some individuals, the idea of being placed into an “at risk” category by having the test is in itself a threatening prospect:

“But for someone who is always careful, and doesn’t use drugs or doesn’t have multiple partners, then it’s frightening to be confronted with the whole idea that you’re gonna need the test...it’s not the same as other diseases...” Decliner [6629035]

Capacity to cope with a positive HIV test result

Although acceptors and decliners shared a common perception of HIV as stigmatising, they differed in how far they thought they had the internal resources (self efficacy) and external resources (response efficacy) to cope with a positive test result.²⁶ Thirteen of the eighteen acceptors who talked about this in the interview believed that they would be in a position to take positive action, acquiring the benefits of medical treatment. They looked to their own social network and healthcare professionals to provide support.

“Yes, I have a lot of support around me, and I know that I’d be able to talk to people about it, and people would be supportive”. Acceptor [3282230H]

By contrast, five of the six decliners expressed a low confidence in their personal capacity to cope with a positive result and four of these also felt a lack of external support.

“I’ve never heard of anything supportive in reference to HIV anywhere. You’ve got no support, I don’t hear any support”. Decliner [M069878R]

Do these decisions meet the criteria of informed consent?

The Department of Health’s guidelines for named antenatal HIV testing indicate the requirement for informed consent and set out the relevant criteria.¹⁵ Information:

The purpose of the test

Nine participants (6/26 acceptors and 3/6 decliners) broadly understood that the purpose of antenatal HIV testing was to reduce vertical transmission, and that, if they tested positive, measures were available to prevent transmission of HIV to their baby. Only one thought that there would be benefits for her. None of the women knew the risk of transmission with or without treatment.

What the test determines

Only two participants understood that a positive result does not necessarily indicate an infected fetus; the rest assumed a 100% transmission rate. Similarly, few understood that a positive HIV test does not necessarily mean that they have AIDS.

Negative consequences of testing for women

Twenty-four women (6/6 decliners and 18/26 acceptors) addressed these issues at the interview, although it is unclear whether they were discussed with the midwife.

How they would be informed of result

None of the women had a clear idea of how they would be informed of the result or of how confidentiality would be maintained.

Voluntariness

The process of obtaining and recording consent revealed problems. As noted above, three women did not realise that

the midwife had assumed consent, three women had felt pressured to accept testing against their will and one participant was recorded as having consented despite a very poor understanding of English and had no interpreter. In addition, one of the decliners who had stuck to her decision to refuse had felt under considerable pressure to accept. She said that she was made to feel uncomfortable with her decision and the midwife asked her to consider not only her own and her baby's health, but also her lack of consideration for exposing the health professionals to risk. "I still felt under pressure to make a decision there and then".^[6229035] One acceptor believed that she would have the test whatever her decision:

"I said 'yes' because they may not tell you if you refuse. I am convinced they'd do it anyway. So if you say 'yes', then you know". Acceptor [3180293]

DISCUSSION

The study presented in this paper has given an insight into how women respond to routine antenatal HIV testing. Although the sample is small, it includes individuals from a wide variety of backgrounds. This has enabled us to explore a wide range of viewpoints which, rather than statistical generalisability, is one of the aims of qualitative research. The use of semistructured personal interviews made it possible to explore sensitive issues and gave participants the opportunity to explain their views and concerns in their own terms.

The small scale of the study also gives rise to several limitations. It was carried out in only one hospital in London and may not reflect what happens in antenatal clinics in other hospitals. The number of women who declined testing is also small, although it indicates the proportion of women (20–25%) who declined testing in the clinics studied.

All the women in this study considered themselves at low risk of HIV infection but only six declined testing. This contrasts with previous studies that reported perceived low risk of HIV infection as the main reason for declining testing.^{17, 18} This low-risk perception and the routinisation of the test may have resulted in women downplaying the significance of testing, and reduced their attention and processing of the information given.²⁰ In fact, routine testing has been proposed as a method of taking decision-making out of women's hands.²⁷

Those who accepted testing perceived it as risk reducing, providing further reassurance of their unborn babies' well being, in much the same way as they viewed any other antenatal testing.²⁸ Even when acceptors either it as disease detecting, this was viewed as an opportunity either to opt for a termination or seek treatment and prevention of transmission.

The minority of participants who declined testing viewed the test primarily as risk seeking, highlighting the negative outcomes and their inability to cope with them. Framing^{29, 30} and perceptions of control, or lack of it, are relevant in this context.²⁶ Some pregnant women may feel threatened by a system that explores intimate facts of their sexuality over which they may have little control.³¹ Normalising HIV infection and emphasising the availability of maintenance treatment may counteract these negative perceptions. But cultural attitudes take time to change, and HIV is still perceived as a highly stigmatising infection and a taboo subject in many cultures.³²

Consent

The process of seeking consent for a healthcare intervention demonstrates respect for people and an assumption that autonomous individuals are best placed to evaluate their best interests. There should be a rolling dialogue to establish

understanding and to explore beliefs and concerns. A health professional may experience conflict between the duty to respect the pregnant woman's autonomy and the duty to safeguard the interests of the vulnerable fetus, if the woman's behaviour seems to threaten these. We shall not explore this here, but suffice to say that the welfare of the fetus undoubtedly underpins the policy to increase maternal test uptake.

For an agreement to constitute consent, four elements need to be in place: voluntariness, competence, information and decision making.

Voluntariness

Voluntariness requires freedom from deception as well as from coercion. In this context, coercion can be subtle and indirect, often transmitted through non-verbal and verbal signals. The Department of Health's leaflet for HIV testing in pregnancy, "Better for baby" suggests that all babies will benefit.³³ The underlying message is that not having the test may be worse for the baby. In addition, the power imbalance between professionals and patients facilitates high status coercion.³⁴ If a health professional recommends a procedure, the pregnant woman is burdened with having to justify her refusal. A significant proportion of women may believe they cannot refuse,³⁵ and women from ethnic minorities may find it especially hard to refuse testing and cope with a positive result³⁶—emphasising the need for culturally sensitive approaches to prenatal testing.

Competence

Although it is reasonable to assume that all women attending antenatal clinics are competent, some of them may be rendered incompetent by a lack of understanding of what is being said to them, owing to poor communication skills of the informant or to language barriers, as appeared to be the case with one potential participant.

Information

As Onora O'Neill³⁷ has argued, fully informed consent may be neither definable nor achievable but adequately informed consent as outlined by Raanan Gillon³⁸ should still be expected. As a minimum, the woman should understand the rationale for the test—notably the reduction in vertical transmission, the broad implications of a positive test (including vertical transmission rates with and without treatment) and the treatment available. This was found not to be the case among most participants. Similar findings were reported in a study of attitudes to HIV screening among predominantly white, well educated, middle-class women.³⁹

Decision making

Draper⁴⁰ points out that there is a significant difference between decision making and acquiescing. Decision making, the final stage in the process of giving consent, is viewed as a conscious reflective process, whereas acquiescing is agreement without reflection—an automatic assent. A striking aspect of the acceptors' responses was the lack of deliberation displayed by most women, as found elsewhere.³⁰

Why did consent so rarely meet the professionally-set standards? The answer may lie in the context in which decisions are made. Booking appointments, according to the participants' accounts and the first author's observations, are encounters laden with complex information, involving multiple agendas and requiring making difficult decisions within tight time constraints. The pivotal role of the midwives undoubtedly influenced consent and uptake, as has been demonstrated in other studies.⁴¹ Multiple tests and lack of time can strain communication and contribute to the erosion of valid consent.⁴² Routine HIV testing and the imposition of targets may create

further pressures on both midwives and the women they are caring for to conform to clinic procedures. Empirical studies have shown that making professional procedures routine can reduce awareness of ethical issues and reduce reflexivity in decision making.⁴³ Indeed, there is debate as to whether a routine testing policy aiming for high uptake is compatible with authentic informed consent.^{44–45} As Lantos⁴⁶ points out, habitual, automatic actions may indicate just as much about our moral nature as do deliberative actions, and should also be the proper concern of ethics. Time for reflection is also relevant: the nine women who broadly understood the rationale for testing gave evidence of being primed before attending the clinic. Although the current rhetoric is of patient-centred consent⁴⁷ and patients as partners,⁴⁸ another story emerges when we look at what is actually happening on the ground. Other studies have reported a similar erosion of consent.³¹ As prophylactic treatment for the fetus need not start until the third trimester, deciding to have the test could be deferred until a later appointment, allowing more time for reflection and gathering of information, thereby increasing the opportunity for valid consent.

Utilitarian calculus: risks and benefits

Arguably the benefits to HIV-infected women and their unborn babies outweigh any harm that may result from failing to respect women's autonomy. But this ethical position should be made explicit and form the subject of an inclusive, public, democratic and formal debate, rather than lie buried beneath epidemiological data. Not all women may comply with the recommended risk-reducing treatments and procedures,⁴⁹ some of which can cause undesirable or dangerous side effects⁵⁰ or may cause an increased rate of prematurity.⁵¹ In the UK, HIV-positive pregnant women can legally refuse prenatal treatment, but would undoubtedly find themselves under considerable pressure to comply. After birth, breast feeding or refusal to allow the child to be tested for HIV may result in referral to social services with the child being made a ward of court.⁵² Avoiding breast feeding may be difficult in cultures where breast feeding is the norm. In addition, there are risks to women of stigmatisation and discrimination from their partners, families and communities. Violence or abandonment from partners may be a real threat for some women.^{32–53} Albeit these reports have largely been from African countries, can we be confident that the behaviour of partners and families (particularly recent immigrants) will be significantly different in the UK? Women who are found to be HIV positive but have not given consent may well lose trust in healthcare professionals. In addition, since <25% of babies risk being infected¹¹ Most are given treatment that they do not need. Antiretroviral treatment seems to be reasonably safe for uninfected infants,⁵⁴ but there are concerns regarding long-term sequelae.⁵⁵

CONCLUSION

Even though HIV testing need not be awarded a special status above that of any other test with serious implications, we would question whether this implies avoiding a free and frank dialogue. Pretest counselling need not be laborious and exhaustive, but should contain the solid elements of information sharing, as outlined in the professional guidelines. We submit that routine antenatal HIV testing can rarely be compatible with valid consent. The potential benefits to unborn children and their mothers need to be carefully balanced with the fundamental principle of respecting autonomous individuals—enabling them to make voluntary, adequately informed and imedecisions.

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APPENDIX

INTERVIEW GUIDE ROUTINE HIV TESTING IN THE BOOKING CLINIC

Communication with the midwife

Understanding and voluntariness (informed consent)

1. Have you had any blood taken as part of your antenatal care during this pregnancy?

IF NO – Has anyone told you that you will have blood tests as part of your antenatal care?

2. Have you been told the reasons for taking blood when you are expecting a baby? Do you understand what the doctors want to look at in the blood?

PROBE for her understanding of what they test blood for:

Her health in pregnancy—eg, anaemia

Health of the baby—eg, spina bifida, Downs

Any infections she may pass on to the baby—eg, syphilis, HIV

Anything else

3. Before coming to the clinic, did you think that you might be offered a blood test for HIV?

IF NO – Was it a surprise to be asked?

If YES – Did you know before? How did you find out?

PROBE: Had you made up your mind whether you would accept or not?

4. Did the midwife ask you if you would agree to have your blood tested for HIV infection?

PROBE: What did she say?

5. Did she explain to you why they wanted to test your blood now, when you are expecting a baby?

PROBE: What did she say?

Did the midwife explain to you who were being tested for HIV infection?

PROBE: Did you feel that you were being singled out?

What did you think about being asked to agree to a blood test for HIV infection?

PROBE: Did you think it was a good idea?

If YES, Why do you say that?

Would you rather she hadn't asked?

Why do you say that?

Did you agree to have a blood test for HIV?

If YES - Did you feel that you could say no?

If not, PROBE: Why not?

If NO - did you feel that it was hard to refuse?

If Yes, PROBE: Why?

9. Did you feel at ease during the interview?

If NO – why not?

10. Did you learn anything new about HIV in pregnancy from the midwife?

If YES – Can you tell me what that was?

11. Do you think that there for you any advantages of having a blood test for HIV?

(Which are the most important?)

PROBE: Are there any advantages for the baby? For you?

12. Do you think there are any disadvantages to having the test?

For the baby? For you?

13. Do you have any worries or concerns about having a blood test for HIV?

(Which are the most important?)

PROBE: What would a positive result mean to you?

14. What about the timing of the test? Do you think that this is a good time to ask women to be tested for HIV?

If NO, why do say that. Do you think that there is a better time?

If YES, Why do you say that?

Decision making

15. In the end, what made you decide whether or not to have the blood test?

16. Did you change your mind during the interview?
If YES - In what way?
17. Now how do you feel about the decision you have made?
(If refused, do you think you may change your mind?)
18. Do you think partners should be involved in the decision making?

Follow up

19. Would you advise other people to have the test?
20. Did they tell you how you will be told the result of your test?

21. [Optional] What do you think about mandatory testing for HIV? In some countries women are given no choice. What do think about that ?

22. Is there anything else you would like to tell me?

Closure of interview

Thank interviewee. Make sure she has contact number if she has follow-up queries.

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