

Men's Attitudes to Intimate Life (MAIL)

Exploring Views about Parenthood among
HIV-Positive Gay and Bisexual Men in London

An Interview Study of Patients and Healthcare Practitioners in HIV Clinics

KEY FINDINGS

March 2018

The **Men's Attitudes to Intimate Life (MAIL)** study is a research project, supported by the British HIV Association and the Wellcome Trust, aiming to explore views about parenthood and intimate relationships among gay and bisexual men living with HIV in London. The study is a collaboration between the Reproductive Sociology Research Group (ReproSoc) at the University of Cambridge, Chelsea and Westminster Hospital NHS Foundation Trust, Homerton University Hospital NHS Foundation Trust and Royal Free London NHS Foundation Trust.

This report draws on qualitative interviews with patients and healthcare practitioners conducted in HIV clinics across London in 2016. Findings presented in the report offer a snapshot of some of the most pertinent themes identified in the analysis of interview extracts. This selection illuminates contexts in which considering parenthood might be relevant in working with HIV-positive gay and bisexual men. We hope that our report will offer useful insights to clinicians, researchers, community organisations as well as people living with HIV.

Contents

Summary	3
Why did we conduct this study?	4
What did we do?	5
Who did we speak to?	6
What did we find?	7
Talking about parenthood in HIV clinics	7
Biogenetic parenthood	12
Adoption and fostering	16
Recommendations and directions for future research	18
MAIL Study Team	19
Acknowledgements and contact	19

Summary

- The majority of healthcare practitioners working in HIV clinics had at least some gay fathers among their patients, but they had little awareness of what younger men who have sex with men thought about having children.
- Practitioners were unlikely to ask gay men if they wanted or planned to become parents. Conversely, gay men were unlikely to ask HIV clinicians about reproductive health. The lack of discussion about parenthood left most practitioners under the impression that having children was of little interest to their gay male patients.
- Of the 25 patients interviewed, only four men could recall discussing the possibility of having children with HIV clinicians. Two men asked if having children was an option for them and the other two were told that this was the case. Some men noted that taking part in the study was their first opportunity to talk about parenthood in relation to HIV.
- Patients overwhelmingly identified HIV diagnosis as the most appropriate context for raising the issue of parenthood. Whether or not they were interested in having children themselves, the men highlighted the importance of reassuring newly diagnosed patients that it is possible for people living with HIV to become parents.
- Many men commented on how being diagnosed HIV-positive had affected their views about parenthood, with some excluding the possibility of having children in the future. This was reflected in the experiences of practitioners who often encountered relief when telling patients that they could still become parents.
- When asked about the possibility of having children, some patients said that they did not fully understand the mechanics of HIV transmission and if there was anything that could be done to minimise or eliminate the risk of infection.
- Even though they were never asked about it directly, patients frequently mentioned sperm washing, which they saw as the go-to-method for HIV-positive men to become parents. Whereas patients regarded sperm washing as a present or even future possibility, practitioners universally described it as a procedure that was used in the past. Sperm washing was described as redundant and unnecessary in cases where the patient's viral load is undetectable.
- Patients often commented on how important being undetectable is for their intimate relationships – in that they no longer have to worry about transmitting HIV through sex – but they rarely mentioned undetectability as something that might be relevant to parenthood. Knowledge about sexual relationships did not seem to translate to reproductive relationships, which revealed a complexity in patients' understandings of undetectability and HIV transmission.
- Some patients were unsure whether surrogacy was an option for HIV-positive men and implied that their HIV status was one complication too many for considering what was already a complex procedure.
- A number of men had female friends who had asked them in the past – to various degrees of seriousness – about being a sperm donor. The men assumed that being HIV-positive made them no longer suitable to provide friends with their sperm, which sometimes posed dilemmas about HIV disclosure.
- Partly because of the perceived inability to pursue biogenetic parenthood, patients were more likely to consider adoption. However, the men were also uncertain whether HIV-positive people could be considered as adoptive parents, how adoption agencies would approach their HIV status, and whether there was a need to disclose it as part of the adoption process.

Why did we conduct this study?

We observed four concurrent trends highlighting the need for evidence on views about parenthood among gay and bisexual men living with HIV.

■ More gay men are having children

Increasing numbers of gay men and same-sex couples are choosing to become parents through adoption and surrogacy. In 2017, there were 430 adoptions by same-sex couples in England, with 240 children adopted by gay male partners. Compared to only 30 adoptions by gay male couples in 2007, this represents a 700% increase in just ten years.¹

While there are no official statistics, available evidence indicates that growing numbers of gay men pursue parenthood via surrogacy. It is estimated that about one fifth of surrogacy in the UK is undertaken for gay male couples,² while the number of patients registered at UK fertility clinics as surrogates has more than doubled in the past ten years.³ Increasing numbers of gay men also pursue surrogacy abroad.

■ The number of HIV-positive gay men is growing and they expect to live long and healthy lives

Based on available estimates, 1 in 25 sexually active gay and bisexual men in the UK – and 1 in 7 in London – are living with HIV. A total of 47,000 gay and bisexual men were estimated to be living with HIV in the UK in 2015, which constituted almost half of all people living with HIV.⁴

As a result of significant advancements in highly active antiretroviral therapy (HAART), people living with HIV now have near-normal life expectancy.⁵ Over the past decade, the proportion of people accessing HIV care who were aged 50 years has more than doubled.⁶ What was once considered a terminal disease is now seen as a manageable condition, and HIV-positive people are increasingly living longer and healthier lives.

■ HIV is less of a barrier to parenthood than it used to be

Growing evidence shows that effective treatment reduces the risk of HIV transmission possibly to zero.⁷ Rates of 'vertical' HIV transmission from mother to baby have dropped to just 0.27%,⁸ while heterosexual couples where the man is HIV-positive are increasingly advised to conceive 'naturally'.

■ More women are becoming mothers with donor sperm, often with gay men as donors

Increasing numbers of women undergo fertility treatment, including lesbians and women who are single. Over the past ten years, the number of women registering at UK fertility clinics with a female partner to undergo donor insemination has more than tripled.³ Although the prevalence of non-clinical donor conceptions is impossible to determine, it is widely recognised that gay men frequently donate sperm to their female friends, sometimes also becoming involved in parenting.

1. Department for Education (2017), *National statistics on children looked after in England including adoption*
2. Surrogacy UK Working Group on Surrogacy Law Reform (2015), *Surrogacy in the UK: Myth busting and reform*
3. Human Fertilisation and Embryology Authority (2018), *Fertility treatment 2014-2016: Trends and figures*
4. Public Health England (2016), *HIV in the UK: 2016 report*
5. The Antiretroviral Therapy Cohort Collaboration (2017), 'Survival of HIV-positive patients starting antiretroviral therapy between 1996 and 2013: A collaborative analysis of cohort studies', *Lancet HIV*, 4:e349-e356
6. Public Health England (2017), *Towards elimination of HIV transmission, AIDS and HIV-related deaths in the UK*
7. Rodger AJ et al for the PARTNER study group (2016), 'Sexual activity without condoms and risk of HIV transmission in serodifferent couples when the HIV-positive partner is using suppressive antiretroviral therapy', *JAMA*, 316(2):1-11
8. Peters H et al (2017), 'UK mother-to-child HIV transmission rates continue to decline: 2012-2014', *Clinical Infectious Diseases*, 64:527-528

What did we do?

Between May and December 2016, we interviewed 25 patients and 16 healthcare practitioners in four London HIV clinics across three NHS Foundation Trusts: Chelsea and Westminster Hospital (56 Dean Street and Kobler Outpatient Clinic), Homerton University Hospital (Clifden Centre) and Royal Free London (Ian Charleson Day Centre).

We sought to speak with HIV-positive men who were gay or bisexual, 20-45 years old and without children, as well as clinical staff working with this patient group. The key aim of the study was to better understand views about parenthood among non-heterosexual men living with HIV. However, the study was not advertised as research on parenthood. We called it Men's Attitudes to Intimate Life (MAIL) because it was important for us to reach men with a variety of views (including those not interested in having children) and understand creating families (or remaining child-free) as one aspect of personal and intimate relationships. Recruitment for the study was facilitated by local clinical research teams.

Men's Attitudes to Intimate Life

We are recruiting for interviews!

ARE YOU:
A GAY or BISEXUAL MAN?
20-45 YEARS OLD?
HIV-POSITIVE?
WITHOUT CHILDREN?

IF SO, WE WOULD LOVE TO HEAR FROM YOU

A new study seeks to find out how young non-heterosexual men living with HIV approach their personal life and what they think about the future.

We want to learn about your views on issues such as sexuality and fertility to know what matters in your life and how healthcare can address your needs.

The study is conducted by the Reproductive Sociology Research Group (ReproSoc) at the University of Cambridge. It is funded by the British HIV Association and the Wellcome Trust.

To find out more about the study, ask the clinic's staff for more information or visit our website:
www.sociology.cam.ac.uk/mail

repr@soc UNIVERSITY OF CAMBRIDGE British HIV Association BETA wellcome trust

Interviews were semi-structured and followed a similar format.

Patients were first asked about what had made them want to take part in the study. Initial answers led to subsequent questions, which covered, in no specific order: views about parenthood; experiences of intimate and personal relationships, including partners, family of origin and friends; views about the 'gay community'; and thoughts about the future. HIV was addressed in relation to these topics based on information interviewees volunteered, usually unprompted. Patients were asked about how (and why) their approach to living with HIV had changed over time. Towards the end of the interview, they were asked if they had ever discussed parenthood or reproductive health with HIV clinicians; whether they would like, or would have liked, to discuss this topic as part of HIV care; and whether they thought there were any needs for support or information.

Practitioners were first asked about what their job involved and what patient groups they worked with. They were then asked, in no specific order, about contexts in which parenthood or reproductive health was addressed in their work with patients as part of HIV care; their experiences of discussing reproduction with men who have sex with men; and their perceptions of how men's intimate relationships had changed over time and what role HIV had played in these changes. Towards the end of the interview, practitioners were asked about needs for support or information.

All interviews were conducted by the study's chief investigator. The average length of patient interview recordings was just over an hour and a half and practitioner interview recordings were, on average, just under an hour. Overall, the study produced 56 hours of audio recordings and over 1000 pages of interview transcripts. All data were analysed by the study's chief investigator.

Who did we speak to?

This section offers a brief description of the patients and healthcare practitioners who took part in the study. This qualitative research did not aim to provide a statistically representative account. However, every effort was made to capture a variety of views from diverse perspectives.

Patient interviewees were born between 1970 and 1995, with the youngest aged 20 and the oldest 45 (the median age was 35). All but two identified as gay men. One man identified as bisexual and another man as neither gay nor bisexual nor heterosexual. None of the men identified as transgender.

The age at HIV diagnosis ranged from 20 to 34 (the median age was 29) and the time since diagnosis from one month to 15 years (the men were diagnosed between 2001 and 2016). All men were on antiretroviral treatment at the time of the interview.

Just over half of the men were UK-born, four came from another European country and eight from outside Europe, including countries in Asia, Oceania, South America and the Caribbean. Overall, including the UK, the men came from 11 different countries. Using the ethnic group categories from the UK census, 17 men were White, five Asian, two Mixed and one Black.

Only four men were originally from, or just outside of, London. The remaining 21 moved to London between 1996 and 2015 aged from 14 to 33 (the median age at the time of moving to London was 23).

The men were well-educated, with all but two having, or studying for, a university degree. Of those university-educated some came from relatively disadvantaged socio-economic backgrounds. Two men were unemployed at the time of the interview, one was a full-time student and the rest worked in a variety of sectors.

It proved more difficult to recruit men who self-identified as bisexual, men in their early 20s, men from Black ethnic backgrounds and men without university education.

Of the 25 men, 13 were single, 11 had a partner and one man was dating. Of the 11 men in a relationship, all had male partners (four were married or in a civil partnership). The length of the men's relationships ranged from two months to ten years. Three men had a partner who was also HIV-positive and eight were in a serodiscordant relationship.

The men had generally positive relationships with their parents and families of origin; only one man described his family relationships in mainly negative terms. Almost all men had come out to their parents as gay or bisexual (most of them had received positive or mixed reactions to coming out). In contrast, only five men had told their parents about their HIV status. Overwhelmingly, the main reason for not telling parents about being HIV-positive was not to worry them about something that had relatively little influence on one's life.

For the majority of men, their HIV status was a very private issue; five men had no friends who knew about their HIV status. Just over half of the men knew or were friends with other people living with HIV. About half of the men also knew at least one gay father.

The men expressed a range of parenting desires, which had been shaped in complex ways, had usually changed over time and often seemed contingent or flexible. Overall, twelve men could be described as wanting to become parents in the future, nine were more inclined towards not having children and four were undecided or could not be placed in either category.

Practitioner interviewees

included five physicians, five health advisors, three nurses and three psychologists. For some practitioners, men who have sex with men constituted more than 90% of their patients; for others, less than a half. Many practitioners had previously worked in clinics with different patient demographics. Some had worked in HIV medicine since the first AIDS cases were identified in the 1980s; others had begun working in this area much more recently.

What did we find?

Talking about parenthood in HIV clinics

Practitioners who took part in the study knew if their patients had children but they had little awareness of views about parenthood among men who have sex with men (MSM).

The majority of practitioners had a small number of gay or bisexual fathers among their patients. Most common were older men with children from previous heterosexual relationships who came out as gay later in life. Some practitioners mentioned younger men, usually from ethnic minorities, who had children with female partners having been involved in sexual relationships with other men. Practitioners also mentioned individual cases of gay men who had pursued surrogacy or adoption.

As one physician noted, asking new patients whether they already had children was crucial “because you need to make sure that any children who are at risk are also tested for HIV”. But this initial question was where conversations about parenthood with MSM usually ended. Another physician explained:

“I do ask everybody if they have kids. Because even if they are, you know, a 20-year-old MSM, you don't know what's happened in their teens. So I always ask if they have kids. And sometimes they're like, oh god no! And you're like, okay, well, I don't need to have that conversation.”

Questions about parenthood could be met with bafflement. A health advisor commented:

“I've seen older guys who have looked at me like I was literally from outer space – like, what are you talking about? As in it's never occurred to them, it's just so impossible.”

Some practitioners said that they would not ask gay men about their parenting intentions.

“I suppose I don't seek such conversations with many of my patients, I wouldn't ask them that. You know, I'd respond if I was asked, but I wouldn't give them information, perhaps in the way I would if it was with a straight man or a woman. Which may be wrong.”

Practitioners often questioned their own approach and openly reflected on their clinical practice, recognising the role that gender and sexual identity played in their interactions with patients. A nurse observed:

“I would automatically ask women about fertility. I'd probably ask heterosexual men if they're in a relationship – you know, have you got plans to have children? And I suppose because it's a different mechanical process for MSM and how you go about that. . . potentially I am doing a disservice because I'm not asking about it.”

At the same time, some practitioners were conscious about not ‘pushing an agenda’ by addressing issues that patients did not raise themselves. A psychologist pondered:

“I haven't had that much of an opportunity to have that conversation with men. And I think because, you know, we are patient-led in the work that we do, I would never presume something unless it's raised with me. So if somebody's referred to me for something and we're working on it, I feel I would be presumptuous to say, oh, and have you thought about having kids? But then, again, might there be reasons why men haven't necessarily been raising this issue with me?”

The possibility of having children was an issue that some practitioners could not recall discussing with their MSM patients.

“I can't think of any gay men with whom I've had a conversation about planning to have kids. And I don't know whether that's because they're not planning to or just because I haven't asked them. We haven't had those conversations.”

At the same time, other practitioners noticed that these conversations had been happening more frequently, alluding to a possible generational shift.

“I would say it tends to be much younger gay men, probably those under 30, that would think about this. I would say it's not a question that I hear older gay men ask.”

Sometimes practitioners' personal circumstances made it more likely for conversations about parenthood to come up.

“I might have said in just general chit chat, oh, do you want kids? And I think it's something that came up with patients when I was pregnant.”

“My daughter's adopted and a lot of [my patients] know that. So I think that kind of makes it easier for them to talk about it in a way.”

Some practitioners were surprised how little they knew about their patients' views about parenthood considering how familiar they were with the men's personal lives.

“I do think I'm used to talking to gay guys about sex and intimacy and the things which get in the way of that, and all the painful feelings which sometimes could be brought up, and helping them work through those feelings in terms of, you know, having enjoyable sex and an enjoyable sex life. But I haven't. . . I think there was something within me which wasn't allowing the possibility that an HIV-positive guy could be a . . . could be a dad. And that's bonkers.”

A number of practitioners commented how participating in the study made them more aware of potential barriers to addressing the issue of parenthood with their MSM patients.

“I suppose this whole [interview] has made me reflect on my practice and what happens here and what doesn't get talked about and why that may be. So I suppose it's been a thoughtful process for me in that sense. Yes, maybe there's a lot of unspoken assumptions. I suppose we've probably moved on from the idea of gay men don't have children. But being able to move further forward in terms of talking about it more. . . maybe there's still kind of stumbling blocks around there.”

“No matter how open-minded clinicians feel, I think that if you've got a woman of a certain age who's heterosexual in front of you, there's sort of an automatic thing the doctors will say – oh, you can still have children! There's something about making that assumption – that that's important to that person because of her gender. And because of her age. I can't imagine, I don't know if [others] do that, but my experience of the people that come to me is that's not done with men – probably not even that much with straight men either, I don't know. I think it might be more of a gender thing than it is a sexuality thing. And the difference, I think, is that the men probably have to take an active role in asking. Whereas my experience with women is it tends to be kind of thrown at them. And it's not that, I wouldn't say that people working here are particularly prejudiced – they're not. I think it's just the assumptions that we make about, you know, certain people – we think, okay, they might want children, so I'm going to reassure them that's okay. But we wouldn't necessarily do it to everybody that we meet.”

Out of the 25 patients, only four men could recall discussing the possibility of parenthood with HIV clinicians. Two men had been told that despite being HIV-positive they were still able to become parents and two men had asked if this was an option.

Interestingly, both men who did recall being told about the possibility of parenthood received care at the Homerton HIV clinic where the majority of patients are women. The two men who asked about parenthood themselves, both Asian, raised the topic at different points: one during HIV diagnosis and the other one when he had already received HIV treatment.

The man who had inquired about parenthood when he was diagnosed HIV-positive said “that was the first question I asked them, will I be able to have children?” The other man, who wanted to adopt a child with his partner, had asked his HIV consultant if it was an option. He had been told that “it should be alright”.

Some men were not sure if they had ever discussed parenthood with HIV clinicians.

“It’s hard to know entirely because I’ve, A, been told so much and, B, searched so much, so the two kind of cross over. It’s something which I’m almost certain has been mentioned to me in no great depth whatsoever.”

“I must admit there have been a lot of things and places and professionals and blah, blah, blah, that it’s so hard to... I just lose track, even of the dates and stuff. But I do not remember really, and I don’t think so.”

Some men noted that taking part in the study was their first opportunity to talk about parenthood in the context of HIV.

“You were the first encounter I’ve had in relation to my health – like, HIV – and children.”

“Other than the discussion with you, I don’t think that it ever has been discussed with me before.”

The men highlighted, to various degrees, that it was important to discuss parenthood as part of HIV care.

“I think I had a lot of questions that came out of [this interview] that I didn’t realise were there, so I think that alone is justification for there being some kind of provision for discussing parenting.”

“I think that, even though I don’t have any intention, you know, [to become a parent], it’s something I would be curious about – in case, you know, I decide to do it.”

“I don’t think there would be a need for that much detail unless someone asked for it. But if someone were to sit you down and go, here are your fertility options, it would be very useful – just to know that that door is still open.”

Some men suggested that it was not necessary for HIV clinicians to initiate conversations about parenthood with their male patients.

“If a person is actually wanting to explore that fatherhood avenue, I think then that person should be really wanting to open that avenue with their consultant. I don’t really think it should be a rule for every gay man that comes into the clinic. But you could put some signs out that say, well, if there ever is such a need then you know who to actually speak to.”

This linked to the recognition by some men of the limited time clinicians had to see their patients and the perception of parenthood as a relatively low-priority topic.

“They don’t have the luxury of time to give that much information. So I don’t think that this needs to be sort of included in the healthcare, you know, like part of your routine check-up. I think what should be provided is a little bit of, look, if you have questions about this, you can search this webpage.”

Patients overwhelmingly identified **HIV diagnosis** as the most appropriate context for raising the issue of parenthood. They seemed to agree it was important to highlight that being HIV-positive did not in itself prevent people from having children. This was regarded as a valuable – and usually sufficient – message, which they would have appreciated (or did appreciate) receiving at the time of being told about their HIV status.

“I could be wrong, but I don’t recall being diagnosed and then being asked, does this bother you about parenthood? I don’t think that’s ever been discussed with me. And I do think that it should be discussed with those that are interested. I don’t know if it’s even possible for me to have a child, because I don’t know if I’m going to transmit HIV to the child or to the mother. So even if that was just very briefly explained to me – that it is possible to have a child and not have them be HIV-positive, so if you ever did want children, you can go about seeking it, and we’ve got this support group or this organisation that you can go to... And at that point, I would go, thanks very much, but it’s not of interest to me. But someone else might be interested. I definitely think having that option or that information there would be a good thing.”

Many men commented on how being diagnosed HIV-positive had affected their views about having children. For some, HIV diagnosis had signalled that they were no longer able to become parents.

“Before I was diagnosed, a family with children – that’s kind of what I wanted to have, you know. And since being diagnosed I’ve kind of... it doesn’t even cross my mind anymore. It’s not something that I’ve been very kind of traumatised by. But I guess before I was diagnosed I had always grown up thinking, you know, just because I’m gay doesn’t mean that I will never have children. But since the diagnosis I’ve just kind of thought, well, that’s just not going to be possible now.”

“At the time [I was diagnosed] I thought, well, long-term partnerships are done – you know, nobody will want to be with me, unless it’s out of pity. Having children, well, whatever ideas I might have had, that’s done now, that’s not going to happen.”

Whether or not they wanted to become parents in the future, the men recognised the importance of being reassured that having children was an option for people living with HIV.

“I just think [parenthood] is not something that can be addressed in a sort of, like, you know, in your update sort of appointment. Maybe it could just become part of a, you know, sort of general diagnosis, just part of that sort of general checklist of things – like, you know, these are the things you need to be aware of, these are the things you need to look after. Oh, and, you know, if you’re considering having a family or, you know, want to have kids, then there is... you know, there are options.”

“It was never really a big consideration for me but I know it is for a lot of men. And I think that a diagnosis could really stress them when it comes to children, especially if they want to have their own children. It’s that whole thing when you’re diagnosed, you do question the future.”

Some men alluded to potential implications of knowing that being HIV-positive did not preclude parenthood beyond the actual awareness of the ability to have children.

“Even if I wasn’t interested [in having children], the very fact that someone could come and tell you that, well, you can still be a parent, means that you actually then think, oh, well, then I can live much longer if you think I can be a parent, do you know what I mean? The two come hand in hand.”

“Actually [being told that I was able to have children when I was diagnosed] could [have been] one of the factors that made me want to, you know, not go to the dark side as well, you know. It was that hope that, yes, it's not the end, everything's possible.”

Some practitioners also described the effects being told about the ability to have children had had on some of their patients.

“I had a patient and the one thing that he found most upsetting when he was diagnosed was – you know, he could deal with all the health stuff and he knew a lot about, you know, if I'm on my meds I'll be fine, you know, it's a long-term path, he knew that kind of narrative – but what he hadn't realised is that it may be possible for him to have children. He was a gay man and he was likely to probably have children with a straight female friend who wanted to have a child but didn't have a partner. And he just assumed that it would no longer be possible. And then I sort of said, well, it's not impossible – you know, there are ways in which these things can be done. And he sort of burst into tears. And he was like, oh, I had no idea that, you know, that that could happen.”

“Certainly in my experience, definitely, a new diagnosis is often – this is over now. And then there's the relief when you say, well, it can still happen, it just... you know, you just have to think about it in a different way and, you know, there are ways and we can talk about that later – I don't tend to go into detail about things like that at that time. But it's about sort of saying, you know, the avenues are not completely shut.”

Recognising that at the time of HIV diagnosis patients may not have the capacity to ask about things that matter to them led some practitioners to adopt a more proactive approach.

“They have so much stuff going on that sometimes I think it's just good to say it for them, you know. They're thinking about lots of things and then sometimes I think they're a little bit overwhelmed. What's the best way to say it? You just try to demonstrate for them that they still have all the options that they would have had otherwise. Those options might just take a little bit more of a work around.”

Thinking about his work with newly diagnosed patients, one health advisor explained how proactively raising the issue of parenthood made the patients more future-oriented:

“Throwing that into the conversation, you know, these are things that could happen in your future – that is something that allows [patients] to almost, like, see – alright, if I'm thinking about children or the possibility of having children at some time in the future, then I'm actually directing my focus ahead as opposed to here and now. So it's almost like throwing that in is an opportunity to explain more about how the virus works and how it can be managed. It gives possibilities of sharing more information, because it's almost like you've sown a seed that instantly germinates because they will kind of respond, is that possible? And that is another opportunity for education. So I use it as a teaser, as it were – yes, to tease out and get people to engage in thinking.”

“I guess [when I was diagnosed] I just thought, well, that means that if I wanted to have a child it would mean that child would have HIV. And I guess I don't really understand it that much. I don't understand how people get around that – or if you can even get around that. I don't really know anything about it. But in my mind, I had kind of made up my mind that it's just something that wouldn't be possible.”

“I think if you've just been told at the beginning of your journey, as it were, that [parenthood] is a possibility and if you do want to talk to us about it we can put you in contact with people, for me personally that would be enough. Just to go, okay, cool, it's an option, you know, it's not impossible. Because having a child is a very practical thing, in a sense. So if that had been explained to me, that actually, in a practical sense, it is possible, here are your options kind of thing – you know, so you're positive now, what next? They told me, listen, you'll have boyfriends, you'll be fine, blah, blah, blah. But at that point, you can't really hear that. The idea of having kids was... just in a practical sense, like, well, this cannot happen. You know, like my sperm is now sullied, it cannot be used by anyone.”

Biogenetic parenthood

When asked about the possibility of becoming parents, some patients said that they did not fully understand the risks of **HIV transmission**.

“It's not something that I actually understand 100%. I believe that a mother can be HIV-positive and carry a child and the child not be positive. But if they used my sperm in surrogacy to get a woman pregnant, I don't know if that woman could catch HIV or if the baby could be HIV-positive. I don't know.”

“I remember thinking [when I was diagnosed] that I didn't actually understand how exactly the transmission worked. So I knew a mother can pass it to a daughter – sorry, a mother can pass it to a child – but I didn't know whether or not the father could pass it to a child. So I just wasn't sure whether or not it would be possible for me to have my own child, through surrogacy or whatever else.”

Other men, while assuming that it *was* possible for HIV-positive men to become fathers without transmitting the virus, were unsure about how to eliminate or minimise the risk of transmission.

“I don't know whether that's possible if you're HIV-positive to actually inseminate someone with your own sperm – whether they can remove the HIV from it, I don't know. I never looked into it, but I'm sure that there are some ways of doing it.”

“I don't know if there's an HIV scrubbing that you can sort of do, I don't know. I certainly don't know what options are available for HIV-positive people trying to have kids.”

“I'm trying to think of how you do it... I think there's the option of doing something to the sperm and then the sperm being given to whoever is having the baby.”

Even though they were never asked about it directly, patients often mentioned **sperm washing** as the go-to method for HIV-positive men who want to have biogenetically related children. The men were only vaguely aware of this technique and they had found out about it in a variety of ways.

“I know that if you have HIV – I read somewhere, I don’t know if I’m wrong, it’s just something that comes to my mind – now they know how to, like, clean the sperm from HIV and inseminate. Yes, I’m aware of that. But no more than that. I can’t remember. I read somewhere... I’m not sure.”

“It might even have been at the first INSTI result. I know someone mentioned, don’t worry, you can still have children – there’s this thing called sperm washing. Someone mentioned just about everything I may have had an issue with, so I was at least aware. And then they brought it up again at the [HIV support] group. So I knew it was an option.”

“I saw someone on Facebook – a friend of a friend of a friend had a child through sperm washing. I think it’s a lesbian couple, not sure. And... yes, so, I just really didn’t know about that at all. It just seemed impossible, something like science fiction. If I’d known about that, I could have imagined it.”

Two men, both over 35, recalled finding out about sperm washing from the soap opera *EastEnders* (which was the only reference to any kind of media portrayal of HIV-positive parenthood).

“I haven’t watched it for years, but in *EastEnders* there was this guy, Mark Fowler. He had HIV and then he wanted to have a baby. And they sort of came up with this storyline of how you could kind of, sort of, basically clean up the sperm and, you know, get her pregnant. I’ll be honest, that’s more or less when I stopped watching. But my understanding is that, if I want to father a child, that in itself can be accomplished these days without passing HIV onto the child.”

“I remember quite vividly the whole storyline with Mark Fowler in *EastEnders*. And they kept on talking about how he was going to have a kid with his wife or girlfriend or whoever she was. And they talked about sperm washing, which just sounded utterly ridiculous but it sort of made me think that they can do something about it.”

Not knowing about sperm washing did not stop one man from imagining this technique as a future possibility.

“Is it that one day we’ll be advanced enough to remove the virus from your sperm so that you can actually still be a parent and use it with a surrogate to have a kid? I think one day that might become a reality, very soon. Maybe they have successfully done that but whether they have commercialised it – maybe in the labs it’s possible now. It would be interesting to know actually – you know what, actually we can remove the HIV from the sperm and you can have a kid. That would be awesome.”

There was a stark contrast between patients and practitioners in how they talked about sperm washing. Like patients, practitioners also often referred to this technique unprompted (usually in relation to heterosexual men), but unlike patients, who saw sperm washing as a present or future possibility, clinicians described it as a procedure used in the past.

“When I started [working in this area 12 years ago], if you were a man with HIV and you wanted to get a woman pregnant, then you had to go to Chelsea and Westminster fertility unit for sperm washing.”

“I remember the days when it was all terribly elaborate for heterosexual couples – you know, if he was positive and she was negative and they wanted to conceive – sperm washing and all of that stuff.”

“At that time, when positive men wanted to conceive, we were still referring for sperm washing... Hardly anyone ever these days pursues that sort of route.”

Practitioners regarded sperm washing as ‘nearly unnecessary’ and ‘almost redundant’ because they universally recognised that HIV-positive men who were on treatment and whose viral load was **undetectable** – that is, the vast majority of HIV patients – were extremely unlikely to transmit the virus.

“Undetectable viral load means you can have children without having to go through all these procedures.”

“If you’ve got an undetectable viral load and your partner knows your diagnosis, you can have unprotected sex.”

“Most consultants, if they see that the patient is on antiretrovirals, undetectable and compliant with the medication, they tell them to just do it naturally.”

Few practitioners said that there was *no risk* of HIV transmission, but they emphasised that the risk was ‘negligible’ and ‘probably non-existent’. Some commented on the lack of awareness of how minimal the risk of HIV transmission is – among the general public and even among healthcare professionals.

“I really don’t think a lot of people would know that if you’re undetectable the risk of transmission is very, very small. I mean, even if you were, you know, a GP, would you be aware of that? You probably wouldn’t be.”

“It seems like everyone has an assumption that it isn’t possible to have a family [when you’re HIV-positive]. And to be honest, before I worked in sexual health, I would have thought the same as well.”

Practitioners also noted that the awareness among people living with HIV, although it had been growing, was still relatively low and patients had a tendency to overestimate the risk of HIV transmission.

“It just surprises me how little a lot of people still know about the risks. I mean, I still see ladies who have no idea what the risk of their baby acquiring HIV would be. And it’s really quite sad, you know. You can see that massive sort of relief when you’re actually telling them that, you know, these are possibilities.”

Even though patients often commented on how important being undetectable was for their intimate relationships – in that they no longer had to worry about transmitting HIV through sex – they rarely mentioned undetectability as something that might be relevant in relation to parenthood. In fact, only two men made an explicit connection between sexual and reproductive relationships when talking about the implications of being undetectable.

One man recalled being told by his doctor about how antiretroviral treatment prevented HIV transmission:

“I didn’t actually know that once you are on treatment and you know you’re undetectable then, you know, you can’t, you’re not going to pass on HIV, even to a child. And so, yes, so that was new information for me. So up until then I guess I thought that, yes, I’m now disqualified.”

The other man who mentioned undetectability in relation to parenthood nevertheless referred to sperm washing first:

“I think I’ve read about techniques, about people washing your sperm and being able to select the ones that are free from the virus. And I’m 100% undetectable. You know, I shouldn’t be saying that, but I have unprotected sex with [my partner] because he prefers it. And he never converted in all these years. So I think it’s very possible that I can father children and they won’t have HIV. And I think there’ll be a lot of people as well that maybe through technology or through other things can father children. So I don’t think that, in the near future, or maybe right now, it would be an issue, you know.”

Asking men about parenthood revealed a complexity in their understanding of undetectability and, by extension, of HIV transmission. Knowledge about sexual relationships did not seem to easily translate to knowledge about reproductive relationships. This had implications for how the men perceived specific pathways to parenthood.

Patients saw **surrogacy** as the way for gay men to pursue biogenetic fatherhood. Some men were unsure about whether surrogacy was an option for HIV-positive men and implied that their HIV status might be one complication too many for considering what is already a complex procedure.

One man reflected on how becoming HIV-positive had made him rethink his attachment to the idea of having children who are biogenetically related:

““I always imagined maybe I would do, like, surrogacy or something. And then I realised, well, [having HIV] might affect that – because I don’t even know how that would work now given my status. Would I transmit HIV to the baby? I knew that they could do things to stop it, but would that make the whole process even more expensive? And then, at that point, I thought, how much of an inconvenience am I causing just so that I can have a genetically, biologically related child? And is that really even that important to me? And I don’t think it is anymore. In the past maybe I would be a bit precious about it, but it doesn’t matter to me now. I really don’t care.””

Another man, when considering the possibility of becoming a father via surrogacy, was concerned about HIV infection, even if the risk of transmission could be completely ruled out:

““First of all, how safe is it for the kid? Would you pass on the virus to the kid? And would you pass on the virus to the host, whoever carried the kid? And at the moment I don’t think anybody would be able to do that. If someone said, oh, would you mind carrying a baby for me – but, by the way, I’m HIV-positive – they’ll go, whoa, whoa, no, or maybe not. If I were the person who was asked that question, I don’t think I’d say yes – I’d definitely say no. I’d say, oh god, no. Even if the doctor said, alright, this patient, he wants to have a kid, we’ll remove the virus but we have to let you know that he’s HIV-positive – I think people would still have a problem accepting it. At least I would.””

The concern about the unlikely event of transmitting HIV to a surrogate was echoed by another man who had direct experience with a US-based surrogacy agency and a more detailed understanding of the implications of being HIV-positive for finding a surrogate. He recalled a conversation he and his partner had had with the agency:

““We were told they’d had situations where they said, it’s great, your sperm is clean, and the surrogate goes, no, I’m not doing it. It’s just, you know, a human factor, people get scared. They were just like, you know, the sperm may be wonderful but in real life the surrogate balks and they freak out at the very last moment. They said, we don’t want you going through all that stuff to only find that out. In theory, it’s a possibility, we could go through the whole thing and it could be totally fine, but in practice it’s very unlikely. They told us about a surrogate who just freaked out, because she read [the contract] the way it’s written. Supposedly it’s just very legalistic and very worst case scenario – you know, as in, you cannot sue us if you become HIV-positive kind of thing.””

A number of men had female friends who had asked them in the past – to various degrees of seriousness – about being a **sperm donor**. Some men suggested that being HIV-positive made them no longer suitable to provide friends with their sperm.

““I’ve always had close girlfriends – which is obviously a bit unfortunate given where I’m aiming at – but I’ve always had these girls that aren’t, like, in love and I would sort of joke and say, oh well, you know, if you get to 35 and you haven’t got a kid, I’ll give you one. But obviously you’ve then got this problem because you can’t actually give someone this healthy baby.””

““Lesbian friends of mine, they’re like, oh, would you be my sperm donor? That was always a bit of a joke, you know. But then, when these questions arose once I was diagnosed with HIV, it was like, oh, I don’t think you want that.””

Being asked to donate sperm posed a dilemma for some men because the question raised not only important issues about parenthood but also, in some cases, concerns about **HIV disclosure**.

“ [My colleague] first asked me [to be her sperm donor] when I didn't know about [my status]. And then when it was raised again, I was already HIV-positive. So I [had] kept on saying yes, yes, yes, but then I thought, like, no. I didn't want to tell her, you know, that I had HIV. So, yes, I never told her. And then, when she asked me more recently, that was with the knowledge that I can, you know, I can prevent passing HIV on, then I was like, yes, yes. But then [if she were to ask me again] I guess I will have to think about how I would tell her about HIV. ”

“ It's not quite anymore just a conversation about, do I want to have children? It's also, do I want to disclose my HIV status to my friend? And then, by default, would she then want to... well, she would definitely want to disclose that to – if she had a partner at that point – her partner. But would they then want to disclose that to their parents to explain why there are additional steps that we're all going through? And does that then become this big compound disclosure that I'm not sure I really want to do? So the conversation would have just been about if I wanted to be actively involved in the child's life and to what degree. The HIV diagnosis has definitely made it far more complex. ”

Adoption and fostering

Partly because of the perceived inability to pursue biogenetic parenthood, patients were more likely to consider **adoption** as a way of having children. Some presented adoption as 'the only option'.

“ One day me and my partner talked about, like, if you didn't have HIV, you could have your child with a woman and – you know, you could give your own sperm and have a child. But because we are both HIV-positive we don't have that option. So the only way for us is to adopt a child. ”

“ Well, I know it can't be my own specimen because it's infected. But adoption, yes. Giving somebody an opportunity for a better life – I think it's a beautiful thing to do. ”

However, many men expressed uncertainty about the adoption process and some were unsure whether HIV-positive people could actually be considered as adoptive parents.

“ We don't want to [ask adoption agencies if we can adopt] because once we do that, we can't... go back. So before we get to that stage we will ask around first. If it's not possible then we might just, you know, scrap the whole idea. Because at this stage we don't know if it is possible for an HIV-positive gay couple to adopt kids. ”

“ I haven't done any research or anything, so I've absolutely no idea how agencies or organisations view that. ”

Some practitioners were also uncertain about how open adoption agencies were to people living with HIV.

“ They certainly say they're very open to gay men and lesbian couples adopting, but I'm not sure if they say, you know, we would consider HIV-positive people. I think people have to go and ask that. I don't know if they say that's definitely a possibility. ”

“I presume the adoption agencies don't see having HIV as a problem. I assume they probably did ten years ago and they'd have moved on. But I don't know that for sure.”

A number of patients pointed out that they did not know what they could expect if they disclosed their HIV status to an adoption agency or if they themselves were expected to do so as potential adoptive parents.

“If I were to go down the adoption route I wouldn't know whether I should mention it or whether I have to mention it... And that's something that you should know before you approach an adoption agency because if for any reason it might bias their decisions then it's probably better I don't mention it. But then are there any repercussions with that? Would I be considered to have lied to them? I'm sure legally it can't affect the decision made, but then there's a difference between what's legal and what's actually going to happen in the minds of the people who are making the decisions – because you may well get somebody who isn't informed at all and is thinking to herself or himself, oh god, I wouldn't want to send a child into this home, they might get infected.”

One man saw his HIV-positive status, along with being gay, as another characteristic that could put him at the 'bottom of the list' of potential adopters:

“I have a perception that you would be kind of bottom of the list, whether that's right or wrong. It's probably another X on your background. And it's so competitive anyway that, yes, it's probably another bad thing.”

Another man pointed out that birth parents might be opposed to the possibility of their child being placed with adoptive parents who are both gay and HIV-positive:

“The chance is some parents don't want to give their child to HIV-positive people. And some parents don't want to give their child to guys, I mean, gay people. So that's really been a worry, it's a big problem.”

It was very rare for the men to talk about **fostering** unprompted. One man reflected on it after being asked, following a discussion about different parenthood possibilities, if fostering was something he would consider doing in the future:

“I definitely think that that could be very rewarding, to be able to give a child support. I think that I would be quite good at that, to be honest. I think I've lived a bit of a hectic life. I have quite a broad view on life and quite an open mind to many things in life and therefore I could, perhaps, be quite supportive, to someone that, you know, perhaps might be going through the same issues that I went through. You know, they might be doing drugs, they might be HIV-positive, they might get hep C. They might not understand all of it, you know, so then it's nice to be able to turn to someone that you can learn from. So as a foster parent, you could possibly do that. It's not something that I've thought about until you just mentioned it now. If I become a foster parent when I'm an old man, I'll have you to blame!”

Recommendations and future directions

1. Healthcare practitioners in charge of telling patients that they are HIV-positive should reassure them at the time of diagnosis that having children is a possibility for people living with HIV. Practitioners should be prepared to communicate this information to all patients, irrespective of their gender and sexual identity.
2. Practitioners should be able to explain in greater detail the practicalities of pursuing parenthood through means that HIV-positive men might consider, including adoption, surrogacy and sperm donation. Alternatively, practitioners should be able to signpost to relevant resources those interested in finding out more about different pathways to parenthood.
3. Practitioners should be aware that many patients perceive sperm washing as a requirement for HIV-positive men who want to pursue biogenetic fatherhood. It should be considered how this perception of sperm washing might affect patients' understandings of their reproductive possibilities and of the mechanics of HIV transmission.
4. Practitioners should be aware that patients may not consider having undetectable viral load as relevant to parenthood, even if they demonstrate a good understanding of what it means to be undetectable for their sexual relationships. It might be worth mentioning reproduction when explaining how antiretroviral treatment affects HIV transmission.
5. Practitioners should consider the reproductive contexts in which men living with HIV might find it difficult to manage HIV disclosure. Requests from female friends to be a sperm donor should be considered as well as ways of communicating about HIV with adoption agencies and fertility clinics.
6. Adoption agencies and fertility clinics should be provided with up-to-date evidence about HIV. Policies and guidelines related to HIV in the adoption and fertility sectors should be examined to evaluate whether practices are evidence-based. HIV practitioners should also be aware of current practices in adoption and fertility treatment.
7. Further research should examine why patients are likely to overestimate the risk of HIV transmission and what ways of communicating about risk are appropriate at the time when undetectable equals untransmittable. Differences in the perception of risk in sexual and reproductive relationships should also be explored in greater detail.
8. This report draws on qualitative research and outlines contexts in which parenthood might be relevant in HIV care of gay and bisexual men. Further research should examine the prevalence of different views about parenthood and the relative significance of the issues outlined in the report for HIV-positive men.
9. Further research is also needed to better understand the variation of views about parenthood between different groups of men and the perspectives of men whose views are underrepresented in this report, notably bisexual men, men in their early 20s, Black men and men without university education.

MAIL Study Team

CHIEF INVESTIGATOR

Dr Robert Pralat (University of Cambridge)

PRINCIPAL INVESTIGATORS

Professor Jane Anderson (Homerton University Hospital NHS Foundation Trust)

Dr Tristan Barber (Chelsea and Westminster Hospital NHS Foundation Trust)

Dr Fiona Burns (Royal Free London NHS Foundation Trust)

RESEARCH ASSISTANT

Ms Elizabeth Yarrow (University of Cambridge)

ACADEMIC SUPERVISORS

Professor Sarah Franklin (University of Cambridge)

Professor Martin Johnson (University of Cambridge)

COLLABORATORS

Dr Marta Boffito (Chelsea and Westminster Hospital NHS Foundation Trust)

Dr Tabitha Freeman (University of Cambridge)

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Contact

For inquiries about the study, email Robert Pralat at rp422@cam.ac.uk.

