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ORIGINAL PAPER

When HIV Figures in Family Life: Exploring the Relational Reach of Serodiscordance

Christy Newman[1] · **Asha Persson**[1] · **Jeanne Ellard**[2]

Abstract

Social research has been building an increasingly powerful challenge to the public health framing of HIV serodiscordance as pertaining only to sexual transmission risk within couple relationships. Aligned with this critique, our qualitative research with couples of mixed HIV status in New South Wales, Australia, revealed that serodiscordance held relational and cultural meanings which extended beyond the couple domain, encompassing a range of other relationships and issues, particularly those pertaining to families. A deductive thematic analysis of the data on families within these interviews revealed two major themes, disclosing serodiscordance to extended family members, and pursuing serodiscordant parenthood, which presented different challenges for same-sex and opposite-sex couples. We conclude that, despite incredible advances in the medical management of HIV, there continue to be diverse implications of serodiscordance within both intimate and extended family relationships. Understanding the implications of disclosing serodiscordance beyond the couple relationship, and recognising the complex intersections between the public and private dimensions of serodiscordance, offer promising ways forward in supporting families affected by HIV in settings which are culturally comparable to Australia.

Keywords HIV infection · Serodiscordance · Family relationships · Sexualities · Qualitative research · Australia

Background

The concept of 'serodiscordance', that is, a relationship between an HIV-positive person and an HIV-negative person, first emerged as an outcome of effective testing technologies in the 1990s (Rule and Slavin 2017). Since that time, the concept

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✉ Christy Newman
c.newman@unsw.edu.au

[1] Centre for Social Research in Health, UNSW Sydney, Sydney, NSW 2052, Australia

[2] Australian Federation of AIDS Organisations, Sydney, Australia

has become central to biomedical understandings of the way HIV infection is managed within couples with mixed HIV status and has begun to receive intensive critical engagement from the social sciences in the last few years. For example, Persson (2012) has argued against a normative public health interpretation of serodiscordance as a site of 'risk' for sexual transmission, demonstrating the much broader range of social risks and complexities that couples often negotiate, including the symbolic threat to intimacy and romance which condoms can represent. A 'socially situated' (Persson 2012: 214–15) interpretation recognises that serodiscordance will mean different things depending on the particular configurations in play within intimate relationships, and across different social, economic and political contexts (Persson and Hughes 2016).

However, across this growing literature, the notion of serodiscordance continues to be applied almost exclusively to couple relationships in the context of sexual transmission risk. This overlooks the many other kinds of social relationships that feature in the lives of people with HIV, including those relationships which represent, or are actively defined as, 'families'. As we have argued elsewhere (Persson et al. 2017b)there is a broad body of work on the impacts of HIV diagnosis on families, but much of it was published in either the pre-treatment or early combination treatment era (e.g., Bor et al. 1993; DeMatteo et al. 2002; Rotheram-Borus et al. 2005) or is focused primarily on children (e.g., Sherr et al. 2014; Fielden et al. 2006) and on resource-poorer settings such as Africa and China (e.g., Robson et al. 2006; Yu et al. 2016). There has also been a preoccupation in the literature with the more negative dynamics that can feature in families affected by HIV, including psychosocial impacts, financial distress and poverty, and gendered expectations around care responsibilities (e.g., Rotheram-Borus et al. 2005; Bor et al. 1993; Sherr et al. 2014). Far less attention has been paid to the potential or actual contributions that families can make in supporting each other in the context of living with HIV infection. Thus, there is a need to develop a robust empirical and social science informed literature on how families living in resource-rich settings figure in the diagnosis, management and care of HIV infection in the contemporary 'treatment era', to help extend our understanding of how serodiscordance is being lived today.

In this paper, we examine the ways narratives of 'family life' featured in interviews about serodiscordance collected between 2013 and 2014 for the *You, Me & HIV* study, which was based in New South Wales (NSW), Australia. The primary aim of this study was to understand what serodiscordance meant to mixed-status couples in an era in which the potential for 'non-infectious corporealities' (Persson 2013) was becoming not only *achievable* for many people with HIV, but also actively *promoted* by governments and community advocates as key to ending HIV/AIDS (UNAIDS 2012). However, in analysing the interview data, we observed that both HIV positive and negative partners often explained their experiences of their intimate relationships with reference to a broader set of relational issues and challenges, particularly those relating to family life. Two issues which participants discussed most extensively through this lens of 'family' were the complexities of *disclosing serodiscordance* to extended family members, and the challenges of achieving *serodiscordant parenthood*, with differing challenges apparent for those in same-sex and opposite-sex relationships. We argue that these two elements provide timely evidence of the importance of extending our understanding of the range of people who are affected by and implicated in HIV serodiscordance, beyond and encompassing of the couple relationship, in an era of effective biomedical management of HIV.

Australia has been relatively successful in managing the local HIV epidemic, with an estimated 26,444 people living with HIV in Australia in 2016, and 37,225 notifications recorded since 1984 (The Kirby Institute 2017). Male-to-male sex has been the main route of transmission reported throughout this period, but a growing proportion of people living with HIV in Australia identify as heterosexual, as female, and/or were born outside of Australia themselves, or had a partner born outside of Australia (The Kirby Institute 2017). A range of developments in the biomedical management of HIV, including treatment-as-prevention in people living with HIV, and pre-exposure-prophylaxis in those at high risk of acquiring HIV, have begun to show an impact on rates of new infections (Grulich et al. 2018) and are beginning to change understandings of transmission risk, and hopefully, the stigma associated with HIV (Persson et al. 2015).

Methods

You, Me & HIV was the first qualitative study specifically investigating the experiences of gay and heterosexual *couples* of mixed HIV status in Australia, with a focus on Sydney and regional parts of the state of NSW.

Ethical approvals were secured from both the UNSW Human Research Ethics Committee and the ACON Ethics Committee. While the method has been described in detail elsewhere (Persson et al. 2016; Newman et al. 2016; Persson et al. 2015; Persson et al. 2017a), critical information is provided below. The project was conceptualised by AP and JE, data collection conducted by AP, and data analysis led by AP. The analysis and writing of this manuscript was led by CN, with input from AP and JE. As a brief summary of data collection processes, the participants were recruited through word of mouth, flyers, and print and online media managed by our partner organisations in the Australian HIV sector. Interested participants contacted AP to check if they were eligible to take part, e.g. aged 18 years or older, in a committed and sexually active serodiscordant relationship of at least 2 months, living in metropolitan or regional NSW. Participants could take part as either a couple or an individual, to not disadvantage those individuals whose partner did not want to also take part. All interviews were conducted by AP, either face-to-face or by phone, depending on the location and preference of the participants. Three couples opted to be interviewed together, but the remaining couples were interviewed separately to support greater openness and confidentiality. The interview guide was semi-structured, covering an expansive range of social, medical, relational, and sexual issues relevant to serodiscordance, and participants were encouraged to explore these and any other aspects of their story in depth (Persson et al. 2016).

The final sample comprised 38 participants; 18 HIV-positive and 20 HIV-negative. Twenty-four participants identified as gay men (10 HIV-positive), six as heterosexual women (4 HIV-positive), five as heterosexual men (2 HIV-positive), one as a bisexual man (HIV-positive) and two as transgendered (1 HIV-positive transwoman and 1 HIV-negative transman). Ages ranged from 25 to 70 years. Fourteen participants resided in Sydney, and the rest throughout regional NSW. Twenty-seven were born in Australia, (two to parents born elsewhere), and 11 were born overseas. Thirteen couples (n = 26) and 12 individual partners participated, representing 25 relationships in total, including one "throuple" (involving three partners). Of these 25 relationships, 16 were between gay men, seven between heterosexual women/men, one between a transman/gay man and one between a transwoman/straight man. Relationship length ranged from 2 months to 20 years. Half (n = 12) of the relationships had commenced with knowledge of serodiscordance, while the other half (n = 13) had received the diagnosis during the relationship. In 20 of the 25 relationships represented, the positive partner was using antiretroviral therapy (ART), and an additional three were planning to commence.

All de-identified interview transcripts underwent a process of constant comparison coding. For this paper, a deductive approach to thematic analysis was taken (Braun and Clarke 2006), once we realised that accounts of 'family life' were quite extensive. The framing of our analysis was informed by critical and sociological accounts of how families are conceptualised and enacted in social life today (Dempsey and Lindsay 2014; Wall and Gouveia 2014). We do not, therefore, view family as a static or universal concept, nor do we aspire to reveal any observable, generalizable evidence regarding how HIV figures in the everyday family lives of serodiscordant couples (Morgan 2011). We do, however, recognise that despite the many changes in the forms and meanings of family which have occurred over the past few decades, particularly in western contexts, the 'relational language' of family remains powerful (McCarthy 2012), and continues to shape experiences of health and wellbeing. Our interest is therefore in understanding what the deployment of stories about family life reveals about the meanings and practices of serodiscordance today.

Results

In analysing the interviews for data pertaining to families and family life, two primary themes were identified: disclosing serodiscordance to extended family members, and pursuing serodiscordant parenthood. The results section explores each of these in depth, with the latter theme split to examine the distinctive perspectives of same-sex and opposite-sex couples on pursuing and achieving parenthood.

Disclosing Serodiscordance to Extended Families

Most couples thought very carefully about who would be told about the serodiscordance in their relationship, and many had decided to deliberately keep this information from some or all extended family members. Some participants believed parents, in particular, would be unable to comprehend that HIV was no longer a death sentence. As Emma, a negative heterosexual woman in her 20s, explained:

> [My partner] comes from Africa … it's still quite a scary disease over there … He told [his mother] originally but … she doesn't understand that he actually has it … So he just sort of left it … [From] what she's seen, when people have [HIV], they just die.

Fears based on cultural perceptions of HIV clearly played a part in this case, but were similarly expressed by participants with parents born in Australia. Aldo, for example, a negative gay man in his 30s, expressed great concern about the consequences for his family relationships if he were to disclose his partner's HIV status to his mother:

> My brother's HIV positive and … gay as well … When I told my mum [I was gay], that was probably the biggest concern she had … "Oh my God, my two boys are gonna get HIV and then get AIDS, and die!" So I just don't want her to worry. And I don't want it to change her opinion of [my partner] either.

While Aldo is seeking to safeguard his relationships by not telling his mother that his partner is HIV positive—protecting his parent from information that might cause distress, and protecting his partner from a potentially negative parental response—we can see that there is a representation of family here which suggests there is a potential or at least anticipated limit to what those relationships can absorb. Thus, in considering together these two examples of 'carefully not telling' mothers about the serodiscordance in their children's relationships, we can see that despite incredible advances in the medical management and lived experiences of HIV, some families—or particular people within families, often the older generation—are represented as ill prepared for challenging their own misconceptions about what HIV means today.

A number of the HIV positive participants were very concerned that the family members of their negative partners would attempt to disrupt or interfere in their relationship if they were made aware of their serodiscordance, due to an anticipated misunderstanding of the risk involved in transmitting HIV within the relationship. As Oliver, a positive gay man in his 30s, put it, 'I am always worried that his friends or his family are gonna say, "You shouldn't be going out with him because he's HIV positive … because you can catch it." I'm always constantly worried about that.' Bruno, a positive gay man in his 40s, wanted to hold off on disclosing to his partner's family until they had known him for a while:

> I'm sure it'll come out, it'll happen one day … And then they can think, "Oh, all this time I've known you and you've been fine! Nothing's been an issue. [Partner]'s not caught it, touch wood and…" You know what I mean? … "I've been living this way for so long and I'm fine, I'm healthy. And then me and [partner] have been together for this long and we're okay. You should be too," kind of thing.

This desire to delay disclosure for as long as possible seems to hold two purposes: to ensure that a relationship has been built between the positive person and their 'in-laws', so that there is trust and familiarity, perhaps even affection, in place before this new information is revealed; the second is to provide a body of evidence over time which can reassure the negative partner's family that serodiscordance can indeed be managed successfully.

Some negative partners were similarly concerned about how their families would react to learning of their serodiscordance and chose to avoid disclosing rather than put their relationship under further stress. Adam, a negative heterosexual man in his 30s told us: 'That would be their concern: "Oh, so she's positive. You're not… Even if it's a small risk, why is that a risk you're gonna take?"' Another dimension of disclosing serodiscordance was the question of who has the right to tell the family. A few negative partners found it difficult to leave the decision about disclosure to their positive partner. For example, Damien, a negative gay man in his 20s, described a series of relational challenges in negotiating who is told, and not told, within their families:

> He told me to tell no-one [and] that was non-negotiable … [But] I've said [to him], "What do we do if you have to go to hospital? You're in a car accident and I have to disclose, and your mother's there and wanting to know everything," as she does. I said, "What am I gonna tell them?"

This quote reveals the complexities that can be experienced by negative partners in understanding their role in disclosing serodiscordance, particularly given the responsibilities they may hold in providing support to their partner and navigating the emotional intricacies of extended family relationships. Negative partners can also feel restricted in not being permitted to share with their own families about the role that HIV is play in their own lives, particularly when they felt close and open with their families about most other issues. We did, however, hear some encouraging stories from couples who had disclosed their serodiscordance to families. As Connor, a negative gay man in his 20s, explained of his disclosure:

> My parents both know that [partner]'s positive. They both know that we have a sexual relationship. They don't really probe too much into my private life … [So] they don't seem too concerned or worried about me. At least not to my face.

It appears in this case that some couples do not necessarily require anything more from their families than an understanding or at least a quiet acceptance that they are in a serodiscordant relationship. The negative partner may also appreciate being accorded the right to make their own decisions about their sexual relationships and being trusted to manage any risk that may be associated with that.

Pursuing Serodiscordant Parenthood (i): Same-Sex Couples

Our analysis of how ideas about families figured in narratives about serodiscordance also revealed a number of quite distinctive ways of conceptualising and achieving parenthood in the context of mixed HIV status. While this is a qualitative study, which means we have to be cautious in setting up comparisons within this small sample, it is useful to observe that while a desire for parenthood was reported by same-sex couples, only opposite-sex couples had achieved conception and birth in the context of a serodiscordant relationship in this study. However, a number of gay-identified men in mixed status relationships were co-parenting children conceived in prior heterosexual relationships or through donor conception. We will focus in this section on the 'reimagining' work undertaken by gay men regarding parenting possibilities in the context of serodiscordance, and the final section will focus on the experiences of the three heterosexual couples who had conceived children in this context.

The first observation to make is that most of the gay-identified men in our study had strong views to share about parenting, and this included those with direct experiences of parenting, either as biological, step, foster, or donor fathers. For example, Charlie, a negative man in his 40s, reported a very active parenting life: 'I've got three children … I have 50/50 custody of my son. And … I go [interstate] and see [my girls] four or five times a year. [So] I've done my bit of breeding, thanks [and] I think three kids is pretty good … Especially for a gay guy.' Charlie explained that for his HIV positive partner, becoming involved with a gay man with children was entirely unexpected: 'I told [him] that he's now officially a step-father and he was like, "Oh my God!"' An important side comment from Charlie about the importance of staying HIV negative provided additional insights into the way that HIV figured in the enactment of parenthood for this gay couple: 'And being a parent, I don't wanna be HIV positive and have to worry about that. It just makes things a bit more complicated.' This suggests that while parenting was a pre-existing desire that Charlie was happy to have been able to fulfil in his life, adapting to serodiscordance in his relatively-new intimate partnership was still framed as a potential threat to his capacity to fulfil his responsibilities as a parent.

Other men reported a range of experiences of parenting children conceived in previous heterosexual marriages, either as biological or step fathers. For example, Marcus, a negative gay man in his 50s, explained:

> I always wanted to have a family and have children, and so I … tried to put [my homosexuality] off as something that wasn't realistic … because "I wanna have children, I wanna have a family, I want to be like everybody else," you know? So I worked and played sport, and I got married at the age of 19 [and had] children … [When I told my wife] I was gay … we split up amicably and said we'd share the children [but she] made it increasingly difficult, so I hardly ever [saw them].

This story of a married man coming out as gay and losing his wife and children as a result is a familiar trope in the social construction of homosexuality. Interestingly, however, for Marcus, it was through forming a long-term relationship with a man, who happened to be living with HIV, that he was able to configure a new family, which then supported his reconnection to his (now adult) children. At the time of the interview, both partners were actively considering the possibility of fostering children:

> [My HIV positive partner and I are] looking at … having children for respite care … They offered us one to adopt but we said, "Look, we would have to think about that" … Especially at our age. But children … would be great

> …'cause my [older] children now are just like, they're like second part of the furniture here. It's great.

For some gay couples, personal desire was viewed as less significant a factor in achieving parenthood than the cultural and regulatory environment regarding non-heterosexual reproduction. For example, Oliver, a positive gay man in his 30s, explained that he would 'love to have kids. Our family consists of a little dog and a cat at the moment and I would love to add children to that equation.' But he continues this narrative by explaining that the formative desire for parenthood he held from early in his life was complicated by both his sexuality and his HIV diagnosis:

> I've always wanted to be a dad. When I was first diagnosed, the first thing I did was cry in the park watching the children play in the playground. I know that sounds weird but for a long time there I thought children [were] out of the equation and now I know that children are in the equation. And both [partner] and I have talked extensively about that. Not right now'cause [my relationship is] new. It's only two months old … [But] once the Australian government lift the rules on gay adoption, yeah, probably adoption … I don't see why [a] serodiscordant or any gay relationship shouldn't be allowed to have children. What a privilege to have a child, you know? … I can't wait for the day when we're settled enough and have our own place to have a child.

Oliver's account begins with what seems like a clear example of 'biographical disruption' (Bury 1982), believing as he had that being diagnosed with HIV meant abandoning plans to conceive children. Now that he is in what he hopes will be a long-term, serodiscordant relationship, Oliver's interpretation has shifted. HIV is no longer seen as the only barrier to becoming a parent, but simply one factor in a web of policy issues affecting people in non-heterosexual relationships, including in this case, adopting children.

Finally, a number of stories were shared regarding the option for gay men to become parents via surrogacy, which was seen to create opportunities but also additional complexities for serodiscordant gay couples (Murphy 2015). For example, Damien, a negative gay man in his 20s, discussed the challenges of planning surrogacy arrangements when their friends and family were unaware that one of them was living with HIV, particularly the issue of which partner would be the sperm donor:

> One of our best female friends has come to us and said, "I would like to offer you guys the [opportunity for me to] be your surrogate." So we went and spoke to other friends [who asked], "Well, who's gonna be the [donor?]" … And then [partner] said, "Oh well, [Damien] is older than I am [so] we thought that he'd go first." And I said, "But what are you gonna say when your mother keeps asking and our friends keep asking [when it's your turn]?" And he said, "I don't know. I'll just tell them there's a problem with my sperm or something. They might shut-up then" … [So] even just the thought of social negotiation is difficult.

For this couple, who had discovered their mixed infection status shortly after their friend's initial offer to become a surrogate, serodiscordance had added an unanticipated layer of complexity to their plans. New and unexpected ethical questions were emerging for this couple in considering who was entitled to have access to their serostatus information, including considering whether conceiving a child with someone (even when they are at no risk of acquiring HIV) brings with it an additional expectation of full disclosure: 'do we need to tell our friends? … Surrogacy is such an intimate situation, would it be fair to not say anything?' This suggests that serodiscordance is navigated as an issue that extends well beyond the intimate couple, in this case the same-sex couple, by influencing the ways in which families are being planned and conceived, even in these kinds of non-normative configurations.

Pursuing Serodiscordant Parenthood (ii): Opposite-Sex Couples

As noted, three heterosexually-identified couples in this study had overcome the barriers to conceiving children within a serodiscordant relationship. Two had made use of fertility services, but all three relied heavily on the effectiveness of antiretroviral medicines to ensure HIV was not transmitted to either the sexual partner or the child during the process of conception and birth (McDonald 2011). Descriptions of their country of birth are also provided in this section, because migration experiences did shape these accounts in particular.

Emma (negative woman in her 20s, born in Australia) and Dawit (positive man in his 30s, born in Africa) provided a poignant account of their path to parenthood. As Emma put it: 'We both wanted to be parents—it's something we wanted to do—and then for my partner to have [HIV], it changed everything.' Although Emma was only in her 20s, she was determined to pursue parenthood as soon as possible, and was advised that this meant travelling interstate (at that time) to a clinic providing fertility services to serodiscordant couples. This experience was exceedingly difficult, due to the financial costs and the clinical intervention itself, which was repeated multiple times, and the emotional costs of not conceiving for several years. The difficulties were compounded by not being able to share this experience with family and greatly added to the strain of it all, as they had not told anyone about Dawit's status. As Emma explained:

> Dealing with the IVF clinic [has been] more traumatising than anything else … It costs thousands of dollars [and] we went through so many cycles … [And] no-one knows. None of my family know… we'd have to come up with these big, massive lies as to why we're [flying interstate] all the time… Most of the time we just made up that [my husband] was going down there to help some family members out, and just make up these elaborate lies, which is hard to, you know, remember the lie you're spinning … And it went [on] for years and years … It is a big thing; keeping it quiet and … for people to not understand how precious our daughter is to us and why she is, you know, she is our everything … Love to be able to say that, but we just can't.

This quote brings together the two main themes of this paper: disclosure and parenthood. Serodiscordance is seen to extend well beyond the intimate domain of sexual practice within the couple relationship, to impact significantly on other forms of intimacy, such as conceiving children. And yet, despite the incredible stress of their situation, this couple did not feel able to share their experiences with their loved ones—relationships that are supposedly also built on intimacy—due to the risks of disclosure. It is these other forms of relational intimacy which can be overlooked in research and policy understandings of serodiscordance if the focus is exclusively on sexual intimacy.

Jasmin (positive woman in her 20s, born in Africa) and Adam (negative man in his 30s, born in Australia) had conceived two children during the course of their serodiscordant relationship. Both were conceived through condomless sex, relying on Jasmin's undetectable viral load to prevent the sexual transmission of HIV to Adam and to prevent mother-to-child transmission during delivery. While both of these sites of potential transmission represent a major focus of the clinical literature, in discussing their experiences, Adam's account of serodiscordant parenthood extends well beyond this domain. For example, although Adam had not disclosed to any of his own family—because 'we decided that we can't really see how the benefits of anyone knowing would outweigh the complications and difficulties'—he had observed a shift in the support received from friends and colleagues who were aware of their serodiscordance when he disclosed their plans to conceive children:

> You see the other side [when] deciding to have children … "Okay, if you wanna risk becoming positive yourself, that's no big deal. But, if you wanna risk bringing a kid into the world, that's another thing." [It's like] they've got a right to talk about or to have an opinion on, or to make a judgement about it, sort of behind your back.

Adam and Jasmin had made a decision to not have any more children, but Adam was keen to explain that this was shaped by the socioeconomic context of their lives, not their differences in serostatus: 'The decision not to have more children [is] a life decision … We don't have a lot of money [and] neither of us is sort of particularly advanced in our careers.' Adam also described a range of other socially situated issues that had shaped their motivation to not continue to expand their family, including the complex issue of breastfeeding. For many women who are HIV positive, but particularly those from cultures in which breastfeeding is considered an essential practice of motherhood, the fact that guidelines[1] did not explicitly support an HIV positive mother breastfeeding, created a difficult situation for parents who then felt they need to justify to their families, friends and community members why they were unable to breastfeed. As Adam put it, 'if you don't want to disclose HIV status, not breastfeeding is a difficult thing … [it's] where the science actually meets the sort of public health meets the emotional sort of lived experience of people.'

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[1] There is growing scientific evidence from Africa that the risk of mother-to-child transmission through breastfeeding is extremely low. WHO guidelines now support a mother to breastfeed if she lives in a resource-limited setting, is taking ART and has achieved an undetectable viral load, managed well over time, on the basis that the risk of malnutrition, infections and mortality resulting from formula feeding is greater than the risk of HIV transmission (WHO 2010). However, in many high income settings, including Australia, HIV positive women are still recommended to avoid breastfeeding, because there remains a very low risk of mother-to-child-transmission and formula feeding options are safe (NAPWHA 2017).

We see more evidence of the challenges of balancing the public and private dimensions of serodiscordant parenthood in the final story, provided by Eliza: a negative woman in her 40s, born in Australia, with a positive male partner (who did not take part in the study). Eliza described having conversations with her partner early in their relationship about 'wanting to have kids and not really knowing how the HIV would affect that.' In addition to discussing the clinical complexities of conceiving as a mixed status couple, Eliza argued for greater recognition and support to be provided for the social and emotional dimensions of becoming parents as a couple with mixed HIV status:

> There's a [serodiscordant parenting] boom … in some areas, and like that's a really good thing. But that is going to bring new challenges … Having [daughter] has brought up some stuff for [my partner] … not so much [about] telling her, but that other people will find out about his status and then discriminate against her. That maybe, you know, parents won't let their kids play with her … [or] who know what the right sort of PC thing is to say, but behind closed doors, they might say something quite different … So people [in serodiscordant relationships] are gonna need that kind of support and they're gonna need peers to be able to talk it through with and everything.

As is made clear in this extract, couples who achieve parenthood in the context of serodiscordance must look beyond the immediate clinical issues involved in conceiving safely to anticipate social issues emerging from becoming parents in a context in which HIV infection remains unusual, hidden, and potentially feared by others in their community and culture. For these couples, although transmission risk was sometimes a concern, it did not prevent them from seeking to overcome barriers to parenthood. It was the social processes involved in constituting these new families that created new challenges, particularly but not only related to anticipating who in their intimate sphere could be trusted with information and turned to for support regarding serodiscordance.

Conclusions

Despite many differences in the contexts and parameters of their relationships, the notion of 'family life' stood out as a domain of particular complexity and meaning in the accounts of the mixed HIV status couples who took part in our study. The two major themes we observed in the data on families focused on disclosing serodiscordance to members of extended family networks, and pursuing parenthood within a mixed status relationship. We believe our findings demonstrate that family life can be a site of support, love and possibility for couples of mixed HIV status, as well as a site of intensive negotiation of relational agreements and opportunities. While qualitative findings are not generalizable to other settings, particularly those with less well-resourced health systems, nor representative of population-wide experiences of serodiscordance, we believe this analysis adds a number of new and important insights to the literature on serodiscordance, particularly regarding the intersecting roles of sexuality and culture in the enactment of serodiscordance today.

Firstly, we can see in our data that the meanings and practices associated with HIV serodiscordance extend beyond the domain of the couple relationship, to encompass intimate connections with additional family members—parents, siblings, children, extended family—as well as other key people who contribute to the ‘personal communities’ (Holt 2011) of these couples. So, for example, we know that the issue of HIV disclosure has received most public health attention in relation to situations where transmission between serodiscordant sexual partners is a potential risk (Murphy et al. 2016; Truong et al. 2016). While that is entirely appropriate from a public health perspective, the question of which family members to disclose *serodiscordance* in a primary relationship to, and when, remains compelling and complex, even when there is absolutely no risk of transmission to others. While unwanted disclosure did not feature in these accounts, despite remaining a significant issue for many people with HIV in other research (Bell et al. 2016), protecting the quality and security of family relationships was the main concern for participants in planning and managing the disclosure of serodiscordance. The focus of these couples was often on anticipating how disclosure of HIV might complicate the relationships within families, or indeed, add unwanted stress to the primary couple relationship itself, which in some cases was already facing additional challenges in negotiating extended family acceptance of same-sex relationships, or navigating the challenges of international migration. This suggests that despite the incredible advances we have witnessed in the medical management of HIV in recent years, there are clearly still social limits on the adaptability of those broader family networks in which couples affected by HIV are located. We can conclude that serodiscordance needs to be deliberately conceptualized as a domain of social relationships encompassing far more than the intimate couple relationship, and paying careful attention to the diverse relational implications of enacting mixed HIV status intimacies within extended family networks (Persson et al. 2017b).

Secondly, we can also see an enduring tension across the accounts provided by our participants regarding the public and the private dimensions of serodiscordance. For example, in relation to disclosing serodiscordance, public health information about risk and prevention, as well as clinical evidence of non-transmission within the couple, were viewed as essential to maintaining trusted connections within family networks, once serodiscordance is revealed. In the case of achieving serodiscordant parenthood, public services and external resources were often required to become intimately involved in the private lives of these couples, whether they be heterosexual couples conceiving with the assistance of health services, or gay couples pursing parenthood via surrogacy, fostering or—potentially—adoption with the assistance of legal and social service agencies (Fransen-Dos Santos and Guarinieri 2017). Thus, while largely hidden within the private domain, carefully protected from the families, friends, colleagues and community members who are otherwise intimately entangled in their everyday lives, these activities are unavoidably linked to public resources and institutions (e.g., Kelly et al. 2011). Although there is an existing literature on family functioning and quality of life in the context of HIV (e.g., Blais et al. 2014; Rotheram-Borus et al. 2012), there would be considerable benefit in better understanding how this tension between the public and the private dimensions of serodiscordance is affecting the way that family relationships are formed and negotiated in the context of HIV today.

In conclusion, we believe there is much to be learned from the personal accounts of those navigating the complexities of serodiscordance and family life, with important insights for public health, health sociology and family and carer studies. In particular, given the medical and social contexts in which serodiscordance is lived continue to evolve and change, ongoing appraisal is required to ensure that there is a more deliberate and effective recognition in place regarding how HIV can figure in family life. Specifically, we believe greater understanding of the different forms of intimacy which intersect with experiences of HIV is required, well beyond the current focus on the intimate couple relationship. And beyond this, although parent–child relationships are clearly also critical to understanding contemporary families, there are many other types of extended family and non-biological-family relationships which are less often recognised in the research, particularly in higher resource settings such as Australia. While there have been continued efforts to recognise the role of families in HIV prevention, as well as in supporting people with HIV with treatment decisions and adherence, this remains far from a dominant model in the field. In addition, the research and practice guidelines on engaging families still largely rely on public health and clinical frameworks, with less attention paid to understanding what families mean and how they are enacted in relation to health today, including the distinctive meanings associated with this for people of diverse sexualities and cultures (Pequegnat and Bell 2012). The impact of increasing access to PrEP will also be important to understand in the coming years, although this will likely be mainly focused on intimate sexual relationships, rather than any of those broader family dynamics we have explored in this paper. Nonetheless, what PrEP reminds us is that as new technologies are made available, social relationships become reconfigured in new and sometimes unexpected ways (Race 2012; Davis 2015; Montgomery et al. 2010). We believe that we need to take better account of these reconfigurations as they pertain to the complex web of social relationships that are implicated in the life of individuals living with HIV, rather than only being focused on specifically 'risky' points of potential transmission.

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Compliance with Ethical Standards

Conflict of interest All authors declare that they have no conflict of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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