

# Bridging the HIV Divide: Stigma, Stories and Serodiscordant Sexuality in the Biomedical Age

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**Abstract** At a time when advances in biomedicine have rendered people with HIV non-infectious under certain conditions, much public discourse on HIV remains stuck in a paradigm of ‘risk’, which does little to lessen the divide between people with and without HIV in society or challenge the way intimate relationships across this divide are typically stigmatised as undesirable and problematic. We rarely hear the stories of couples who live with mixed HIV statuses and how they themselves perceive and manage their so called ‘serodiscordance’. In this article, we examine such stories by mixed-status couples in Australia. In stark contrast to the dominant discourse, these couples invoked narratives of love, the everyday unimportance and manageability of HIV, and recent developments in HIV medicine, thereby challenging the way serodiscordant sexuality has been cast in public health research. Drawing on Ken Plummer’s work on hidden sexual stories, we consider not only the content of their stories, but the broader significance of stories to the world in which they are enacted, of storytelling as a rally for social and political recognition and legitimacy. Reflecting on our own role in the co-production of research stories, we argue that by moving marginalised sexual stories out of silence, stigmatised communities and researchers can conjointly and incrementally shape a new public discourse and new forms of ‘intimate citizenship’.

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*You know, love is hard to come by, and love doesn't hold criteria or boundaries... Your partner being HIV-negative or HIV-positive should not impact the way you love (Oliver, 36 years, HIV-positive gay man).*

## Introduction

Couples with mixed HIV status exist wherever the epidemic exists, although rarely openly, due to the stigma that surrounds HIV, particularly in the context of sex. Yet these so called 'serodiscordant' couples, where one partner has HIV and the other partner does not, have been instrumental in recent 'game-changing' breakthroughs in HIV medicine (Sidibé 2011). Several clinical trials with serodiscordant couples have now demonstrated that effective antiretroviral treatment renders people with HIV sexually non-infectious under certain conditions, reducing the chance of transmission to a sexual partner to near negligible (Cohen et al. 2011; Rodger et al. 2014).

These advances in the prevention of HIV are still being debated and investigated, and hence much public discourse on serodiscordance remains preoccupied with 'risk' (Persson 2013a). The literature is dominated by public health and behavioural research, which continues to conceptualise serodiscordant couples through the lens of sexual risk behaviour and risk management (e.g. LaCroix et al. 2013; Starks et al. 2014; Baggaley et al. 2013), along with an enduring tendency to describe such partnerships as beset by psychosocial stressors, relationship tensions and prevention pitfalls, requiring an array of interventions (e.g. Mendelsohn et al. 2015; Talley and Bettencourt 2010; Beckerman and Auerbach 2002). Although the literature raises many valid issues, the persistent pairing of serodiscordance with difficulties and danger precludes more nuanced and diverse accounts of intimate mixed-status couples and does little to counter the way serodiscordant sexuality is cast as unsafe and undesirable, nor challenge what is referred to as the 'sero-divide' between people with and without HIV in society.

The stories of couples themselves and the ways they perceive and manage their mixed HIV status are rarely heard. Since the onset of the HIV epidemic, there has been no shortage of stories about living with HIV, including memoirs and autobiographies (e.g. Monette 1988; Ariss 1997; Wyatt-Morley 1997; Menadue 2004; Decker 2006; Brown 2008; Strub 2014), and more recently online blogs.<sup>1</sup> But personal stories of serodiscordance are far more difficult to find, with the exception of a few books (e.g. Peterson 2003) and documentaries (e.g. Leo Chiang's *One + One*) and the more recent emergence of a small number of often short-lived blogs.<sup>2</sup> Given its customary representation as 'high-risk', the transgressive

<sup>1</sup> E.g. *POZ blogs*, *imstilljosh*, *HIV Blogger*, *HIV/AIDS Blog Central*, and *Blogging Positively*.

<sup>2</sup> *You, Me and the Virus Makes Three* (BetaBlogs), *HIV Negative Spouses* (Blogspot), *Magnetic Matrimony* (HIV/AIDS Blog Central), and *Shawn and Gwenn: A Boy, a Girl, a Virus*.

suggestiveness of serodiscordant sex is undoubtedly what has long kept serodiscordant stories ‘unspeakable’.

It is these stories that are our focus in this article. We draw on material from a qualitative research study with serodiscordant gay and heterosexual couples in Australia, a country with a low prevalence of HIV. A national cross-sectional survey indicates that about a quarter of people with HIV have a regular serodiscordant partner (Grierson et al. 2009, 2013). What really stood out in our study was that many couples spoke about their relationships in ways that ran largely counter to the dominant discourse. In stark contrast to the usual framing of serodiscordance as a problematic and risky sexuality, they invoked narratives of love, the everyday insignificance and manageability of HIV, and the safety and validation provided by recent developments in biomedical science. This galvanised our interest not only on the content of their interviews, but also in the social and political significance of storytelling.

Drawing on Ken Plummer’s (1995) sociology of stories, we explore how serodiscordance was narrated among these couples and consider what such narrative enactments can ‘do’ or accomplish. That is, stories cannot be separated from the life worlds in which they are told, and therefore hold both personal and political significance. It was clear among these couples that the social silence that surrounds serodiscordance *enabled* their relationships, because of its capacity to protect against prejudices and curiosity and provide a sense of normality. Yet it was also a source of frustration and umbrage, and a common motivation to take part in the study. The confidentiality and receptive style of the research interview provided both a safe and co-constructed medium for serodiscordance to be articulated and demystified. Plummer’s work on sexual stories has kindled our thinking on the social dimensions of this process; how a *different* kind of ‘story of serodiscordance’ was co-produced and brought into ‘being’ in the research context; and how marginal ‘tales of the intimate self’ become, in a sense, ‘world-making’ and ‘create new realities’ by claiming space and recognition, by pushing back against stigmatising discourses, and by insisting on the right to choose what to do with one’s body, relationships and pleasures (1995: 34–38).

### Telling Marginal Stories

‘Narrative’, Roland Barthes wrote in a much quoted passage, ‘is present in every age, in every place, in every society’. Stories are ‘simply there, like life itself’ (1977: 79). Or as Walter Fisher (1984) put it, human beings are *homo narrans*; ‘story-telling animals’. We are meaning-makers; constantly engaged in crafting and making sense of the world and our place in it through the telling of stories (Plummer 1995: 20). The ‘narrative turn’ in the 1980 s saw scholarly interest in stories and storytelling intensify as part of a broader epistemological shift across the social sciences and humanities, away from positivism and scientific generalities and towards human experience and subjectivity (De Fina and Georgakopoulou 2011; Polkinghorne 1988; Raine 2013). This turn, or rather ‘many overlapping turns’ (Hyvärinen 2010: 70) gave rise to myriad theories of the role of stories in social life and in the production of knowledge (Czarniawska 2004; Raine 2013), as well as to

diverse disciplinary and methodological approaches to narrative inquiry (Chase 2005; Holstein and Gubrium 2012; Riessman 2008).

Our intention here is not to examine this vast field of study, nor to pursue any particular method of narrative inquiry. We do however draw on some important conceptual ideas from this field, which we find relevant and helpful for exploring the 'story' about serodiscordance as it emerged across the couples' interviews. First, we do not approach research narratives uncritically, as if they were straightforward representations of reality or transparent windows onto authentic subjectivity (Walkerline 1985; Atkinson 1997; Razack 1993). Stories, Georgakopoulou suggests, are better understood as performative, contextual and incomplete processes of 'selves-in-the-making' (2014: 14). Second, we are 'never the sole authors of our own narratives' (Czarniawska 2004: 5). Like subjectivity, no story ever spins on its own axis, as if abstracted from a broader context; every story takes a position and is told in relation to the world in which it is embedded and produced (Plummer 1995: 15; Czarniawska 2004: 5). In short, the truth value of stories is not our concern here. We are interested in stories as sociological phenomena; the relationships they bear to a culture, their performative role and place in a particular social world. 'Whatever else a story is, it is not simply the lived life', Plummer argues: 'It speaks all around the life' (1995: 168).

Plummer notes that a chorus of motley sexual stories has burgeoned in the media and in popular culture over the past century. Yet there are also sexual stories that remain largely untold and hidden from sight (1995: 114–115); stories that speak to experiences of the world that do not fit into socially accepted narratives or that subvert dominant knowledge paradigms (Razack 1993: 55). Why, Plummer asks, do people decide to tell these sexual stories? 'Indeed, why do they turn what was not so long ago a private, secret world into a public one?' (1995: 13). The telling of hidden sexual stories may perform many tasks; channel emotions, assemble a sense of self or refuse an identity, lend coherence to a life, break the silences that sustain social marginality, challenge established knowledge, or transcend, 'break beyond' and 'asunder' (Plummer 1995: 173–175). In this way, 'small stories' can reveal 'big issues' (Georgakopoulou 2014: 9) and, as such, however incrementally, they 'harbour change' (Plummer 1995: 173–175). With these ideas in mind, we explore how couples in this study told the 'story of serodiscordance', not necessarily to reveal the 'truth' about their sexual lives, but to make of themselves social and biographical subjects and thereby forge a new form of 'intimate citizenship' (Plummer 1995: 6, 34–35).

## Method

Our discussion draws on *YouMe&HIV*, a qualitative study of serodiscordant gay and heterosexual couples in New South Wales, which is the Australian state with the largest population of people with HIV. As the first study of its kind in Australia, it aimed to build a picture of the social, medical and sexual worlds of these couples and to understand how they experience and manage their mixed HIV status. The study was conducted by the Centre for Social Research in Health at UNSW in

collaboration with the Kirby Institute, the Australian Research Centre in Sex, Health and Society, and several community HIV organisations. Following ethics approval by the UNSW Human Research Ethics Committee, participants were recruited through flyers, word-of-mouth, and the websites and print media of HIV community organisations. Recruitment materials specified the purpose of the study: to better understand the experiences of couples in the biomedical age and to develop recommendation for policy and health promotion. Study participants had to be 18 years or older, and to be in a committed and sexually active serodiscordant relationship of at least 2 months. HIV status was based on self-report, and 'committed' relationship was self-defined. The study was open to both couples and individual partners so as to not disadvantage individuals whose partner did not want to participate, as well as to optimise recruitment and maximise the diversity of stories and relationships represented in the study.

Interviews were conducted between mid-2013 and late-2014, either face-to-face or by phone, depending on participants' preference and location. Except for three couples who opted to be interviewed together, partners were interviewed separately to ensure they were able to speak freely and confidentially. In all, 38 people took part in an interview, including 30 men, six women and two transpersons, of whom 18 were HIV-positive and 20 HIV-negative. Thirteen couples ( $n = 26$ ) and 12 individual partners participated, representing 25 couples in total. These included 16 gay couples, seven heterosexual couples, one gay man/transman couple, and one heterosexual man/transwoman couple. The high proportion of gay men reflects the pattern of HIV infection in Australia, which has a concentrated epidemic and an estimated 26,800 people living with HIV (Kirby Institute 2014). Fourteen participants resided in Sydney, the largest city in Australia, while 24 resided in various regional areas. There was considerable diversity among participants in terms of age (25–70 years), cultural background, education, and relationship length, ranging from 2 months to 20 years, with an average of 3–4 years. Most couples co-habited. Of the 25 HIV-positive partners in these couples, 20 were taking antiretroviral treatment and had an undetectable viral load, and three were about to start treatment. All HIV-negative partners had tested for HIV at some point during the relationship, with two-thirds testing every 3–6 months. About half the couples had consensual condomless sex.

The interviews were guided by a semi-structured schedule and digitally recorded, then transcribed verbatim and de-identified to protect confidentiality. All participants were allocated a pseudonym. The interviews covered a range of social, medical, relational and sexual issues relevant to serodiscordance and were thus broader in scope than the particular analysis in focus here. Interview transcripts were coded independently by the three authors for the purpose of separate publications addressing different questions of interest to the study. For this article, the first author coded the transcripts, organising the material into thematic categories with explicit or contextual relevance to the 'talking about' serodiscordance, with specific attention to the following themes, which constitute the focus of our article: the social silence around serodiscordance, the telling and being told about HIV, the 'articulation' of serodiscordance in everyday life, and any advice they would give to other serodiscordant couples. Using thematic analysis, the

foundational method for qualitative analysis (Guest 2012), these categories were organised into sub-categories, focusing on inductive identification of recurrent and divergent themes. The resulting thematic codes were then analysed in detail to build a rich understanding of the overarching ‘story’ of serodiscordance that arose across individual interviews. The other two authors were actively involved in discussing emerging themes and interpretive possibilities, providing significant input on successive drafts of this manuscript.

## Social Silence

People take part in research for all sorts of reasons, as did the participants in this study. But a common motivation among these participants was a desire to normalise serodiscordant relationships, to ‘put them on the map’, and thereby help other couples. There was a shared sense that, outside the realm of public health and medical research, serodiscordance is largely absent from public discourse. Mixed-status relationships were seen as shrouded in social silence and secrecy; a ‘taboo kind of topic’ as 30-year old Aldo put it. Most participants did not know any other serodiscordant couples, or were unsure if some of their friends were. ‘I don’t think people like to talk about that much’, said 25-year old Connor whose partner had been diagnosed only a few months after they had met. Several admitted that they themselves had known little or nothing about serodiscordance prior to their current relationship. ‘I didn’t even know what it meant until it was actually relevant to me’, Cody explained, a 35-year old man who, when diagnosed 2 years prior, suddenly found himself in a mixed-status relationship with his long-term partner: ‘I just don’t think it’s visible... it’s not something that’s brought up often at all’. Forty-eight-year old Charlie, who recently met his positive partner, spoke along similar lines:

Before being in one, I had never heard the word “serodiscordant”. I didn’t know any serodiscordant couples... I’m not quite sure why I didn’t know about it, it’s just, I’ve never heard it spoken about... So it’s just never occurred to me that it’s existed and then I suddenly became in one and I thought, “Holy shit! I know nothing about this. What the hell do I do?”

This was echoed by Damien, a negative partner: ‘There’s no manual on how to go about this... there’s very limited information out there about couples in this situation’. HIV-related stigma and misconceptions were believed to drive this lack of visibility and dialogue around serodiscordant relationships, both in affected communities and society more broadly. Many believed that serodiscordant sexuality remained tightly glued to notions of transmission, contagion and ‘high risk’ and that this perception had long sustained a divide between HIV-positive and HIV-negative people; what one couple referred to as ‘the apartheid’ and others described as ‘disgusting’, ‘terrifying’ and ‘bloody hurtful’. Because of this, most couples tended not to disclose their serodiscordance to other people, including family and friends, as a way to avoid negative and uninformed reactions. ‘We don’t really advertise it’, positive partner Merlin explained, ‘Because I guess we are worried about judgements’. In this sense, the couples were complicit in the silence, as it offered protection from HIV-related stigma and enabled a sense of normality. Thirty-four-

year old Adam, who had two HIV-negative children with his positive wife of 7 years, said:

If I told my family, that would be their concern, you know, that: “Oh, so she’s positive. You’re not. How do you make sure you’re not?” you know. And then all the potential ignorance they might have around the risk of transmission.

Although many considered HIV to be far less stigmatised today, compared with the early epidemic, there was a real sense of frustration that social attitudes towards serodiscordant sexuality were lagging behind major advances in the treatment and prevention of HIV (Persson, in press). In one way or another, and with varying degrees of comprehension, almost all participants made reference to the mounting scientific evidence that effective treatment of HIV renders serodiscordant sexuality more or less safe under certain conditions (Cohen et al. 2011; Rodger et al. 2014; Lasry et al. 2014). Cody argued that if more information about serodiscordance was made available, particularly in view of this paradigm shift in HIV medicine, it could help to also shift community attitudes:

It might work towards breaking the stigma of people dating other people who have got HIV... I think it would have a positive impact if there was more about it being acceptable, and the low risk, and all the things that you can do to make a successful relationship... If you normalise that, then it breaks down the barrier.

Georgia, a 44-year old positive woman, was one of very few participants who were engaged in public speaking and advocacy work because of her desire to educate people:

So that people don’t look at a person as a “positive” or “negative” person, but looks at a person as a person... The sooner we get rid of fear and discrimination and stigma, the sooner we can all get on with living, which is what it’s about. You know, life is so precious.

Although few participants were prepared to be open about their relationship, either publicly or in their everyday lives, many felt that they wanted to contribute to ‘breaking down that barrier’ in some way and, like Georgia and Cody, emphasised the need to raise awareness about mixed-status couples. Our research study was seen to offer a safe opportunity to do so. For example, Bruno, a 47-year old positive man who met his negative partner 3 years ago, was clear about the message he wants the community to hear:

Nothing’s been an issue. Duncan’s not caught it... I would like them to know, you know... for them to grow their knowledge that, you know, “I’ve been living this way for so long and I’m fine, I’m healthy. And then me and Duncan have been together for this long and we’re okay. You should be too”, kind of thing.

Positive partner Hugo, aged 69, argued that mixed-status couples can do ‘a lot to destigmatise [HIV]’ by showing that serodiscordance is possible, that it is ‘no big deal’. As we see in the following sections, this theme of ‘no big deal’ infused most

participants' narratives. Even as challenges and fears were laid bare, and many diverse experiences described, their stories tended to follow a similar arc, with couples keen to emphasise the ultimately ordinary and manageable nature of their relationships.

### **Telling and Being Told**

The interviews covered the terrain of discovering serodiscordance; the telling and being told about HIV. Of the 25 couples represented in the study, 13 had met prior to one partner being diagnosed with HIV, and 12 couples had entered their relationship with full knowledge of their mixed HIV status.

#### *Couples Who Met Before Diagnosis*

Couples whose relationship preceded the HIV diagnosis often had to tackle an upsurge of challenges as a result of an unexpected or late diagnosis, or sex outside the relationship, including broken trust, serious illness, altered life plans, and possible unknown transmission to the other partner. Stories of shock and fear, anger and resentment were common and several positive partners thought their partner would leave, as Cody explained:

I had unprotected sex with somebody else and, voila! Look what happens... I expected to be kicked out and that was the end of the relationship. You know, I actually transferred money from my savings when it happened and put it into my account just assuming I'd be moving out the day I told him. But he said, "Don't be fucking stupid"... Very surprised. I probably wouldn't have reacted like he did.

But against such expectations, negative partners were highly invested in narratives of compassion and loyalty, often framing their partner's diagnosis as 'our' problem. Twenty-seven-year old Emma described her reaction when her husband, a refugee from a country with a high HIV prevalence, was diagnosed shortly after they married: 'It was just shock. It was kind of like, "Wow! Is this real?" And Dawit took it really hard... [But] you know, it's something that we thought, "Oh, we'll just get through it together"'. In another example, 51-year old Cameron was 'emotionally devastated' when his partner of 13 years was diagnosed despite them being strict about safety when having sex outside the relationship. But leaving was not on Cameron's horizon:

That thought never really occurred to me because I just saw it as one of those many challenges that, you know, couples go through and need to work through... quite the opposite was required. He needed some support.

For some, the diagnosis hit like a cruel blow in the first heady weeks or months of new love. While couples who did not survive this experience are obviously absent from this study, those who did participate were keen to point out that any thoughts of leaving the relationship were fleeting and quickly discarded. 'I don't remember if I had any thoughts of running away, but obviously you think of it', said 38-year old



Ramón whose partner had been diagnosed only a few weeks after they ‘started dating’:

It was very confronting. It was very tough, but I always felt that I shouldn’t want to just run away. I decided to stay and face whatever we had... I decided, he wasn’t, he wasn’t sick. He didn’t have any symptoms. I knew that it wasn’t fair for him, or for both of us, starting the relationship just to stop it just because of [the diagnosis], that there could be ways to manage the infection and just go around it.

For these couples then, the diagnosis, though steeped in emotional turmoil, was nonetheless typically framed as a problem overridden by commitment or love, and as a shared challenge on par with any manner of issues couples face, which could be worked through and managed together.

### *Couples Who Met After Diagnosis*

Love was also an overarching theme among the 12 couples who had met (often years) after the diagnosis, as exemplified by this quote from 48-year old Duncan whose positive partner disclosed to him soon after they met:

I was head-over-heels in love with him. It was just, we just clicked. And, you know, when he told me, it was a bit of a shock, but it sort of didn’t really make a great deal of difference... Oh well he actually said to me, you know, “Just go away for a few days and think about it”, and I just said, “No, I don’t really need to”.

These couples had the advantage of knowledge but, even so, disclosing was invariably fraught with apprehensions for the positive partners. ‘I’ve had my fair share of rejections’, as Duncan’s partner Bruno said: ‘It’s a lot easier now. It’s, it’s never easy, you know, explaining to someone for the first time, but compared to years ago when there was a hell of a lot more stigma’. Thirty-six-year old Oliver similarly described how disclosing was shaped by decades of stigmatisation and assumptions about people’s reactions:

When I first met Simon, one of the first things I told him was that I’m living with HIV. And [he] was amazing about it. I had all these pre-concept ideas about how [he] would, would instantly judge me. And, “Oh shit, he’s not gonna like me anymore. Shit, he’s not interested in seeing me anymore... because I live with HIV”. And how wrong was I?

In Simon’s own words: ‘Second thoughts, absolutely not ... Everyone’s got issues in life and you embrace it... I’m not scared of it’. Negative partners described a range of emotional reactions to being told about their partner’s HIV when they first met. But any recounting of initial shock or qualms tended to be quickly subsumed within narratives of acceptance and rationality, which pivoted around a central theme of HIV being a different disease to what it once was. Or as 32-year old Jasper put it, ‘It’s made out to be a lot worse than what it really is’. Typical of many negative partners, 48-year old Charlie spoke of taking a pragmatic approach:

I thought, “Yeah, that’s not a problem. I can just protect myself and do everything, and it will be fine”... I don’t have a bit of drama with it... I didn’t go racing out and finding more information on it. I didn’t freak out about it either. It was like, “Okay, how can I make this work?”

Not wanting to position their partner as unsafe, or themselves as ‘at-risk’, was clearly a strong subtext in the negative partners’ narratives, whether they had met before or after diagnosis, as was the desire to de-dramatise serodiscordance. As we describe below, these themes of manageability and relative inconsequentiality continued to flow through couples’ stories about serodiscordance in everyday life.

### **Serodiscordance in Everyday Lives**

Serodiscordance was by no means without challenges, particularly, as noted above, at the start of a relationship or at diagnosis, when couples had to find a way to communicate in order to make sense of their emotions and work out how to deal with their mixed HIV status. On a more ongoing basis, issues included disclosure and privacy concerns, reproductive desires and strategies, and worries about the positive partner’s present or future health. Sex and prevention was the most commonly raised issue by both partners in response to our open question: ‘What do you see as the main issue, if any, being in a serodiscordant relationship?’ Negative partners tended to emphasise sexual limitations, as 30-year old Aldo did: ‘It doesn’t really come into my mind very often at all. It’s just annoying, that’s all... sexually annoying’. Or as Duncan said: ‘We can’t go as far with sex as we’d like ... Everything else is just sort of normal’. Positive partners were more likely to express anxieties around sexual safety and potential transmission, sometimes grappling with feelings of infectiousness and unworthiness as romantic partners, while negative partners tended to worry about their partner having those feelings, as Charlie put it:

I don’t see him as being diseased, you know. It’s just like this is a condition that he has, you know. But sometimes it’ll get to him, and he thinks of himself as diseased and potentially harming me, which is very worrying, yeah, very distressing for him, which, of course, you know, stresses me out a bit. But we work through it.

However, none of these issues were regarded as being beyond the realm of what any other couple deals with. A theme that cut across almost all couples, including those who had been through some exceedingly difficult experiences, was the importance of developing strategies, getting on with life and not making HIV a bigger issue than it had to be. As negative partner Daniel, aged 37, said: ‘we’ve already talked through it and worked through it, and we practise everything we’ve talked through’. Consequently, rather than HIV being a persistent ‘theme’ in the relationship, Daniel concluded, ‘it’s become more of an integration in our existence’. Hugo, a positive partner, elaborated along similar lines:

It’s on the periphery of our relationship... I would liken it to a relationship where one person may have diabetes or one person may have had cancer and is now in remission or hasn’t had symptoms or anything for years and years.

That's about the extent of it... We don't sweat on it. I guess because there's no reason to sweat on it... We've talked about it. We've expressed our feelings. Got over the shock and got on with life.

It was a sentiment that was repeated time and again by both positive and negative partners: that HIV 'doesn't play a big part' (Connor, negative partner); 'it's not really a big issue at all' (Aldo, negative partner); 'it's not the centre of our lives' (Dennis, positive partner), 'it's is not in the forefront of everything' (Emma, negative partner); 'it's not really a big issue here in the house, no. It's nothing' (Jasmine, positive partner); 'there's not really much emotion or resonance around it' (Leo, positive partner); 'we've been pleasantly surprised by how little it actually affects our day-to-day life' (Cameron, negative partner); and 'it's miniscule' (Jasper, negative partner).

Alongside these normalising efforts, there was another sub-theme, which was even further at odds with gloomy and problematising representations of serodiscordance. Several partners explained that, rather than being merely a ruinous blow or an ongoing impediment to be endured, HIV had brought positive things to the relationship and forged a bond between them. As positive partner Georgia described in relation to her very late diagnosis, which resulted in serious health complications 2 years into a new relationship:

In the beginning, with the new diagnosis, that was very challenging for both of us... [But] my partner will tell you 100 per cent that it's made us closer. It's made our relationship stronger ... That sense of commitment is at another level that I've not experienced in previous relationships.

Others described how intimacy and trust in the relationships had significantly deepened as a result of being forced to tackle difficult issues together with their partner, such as fears around transmission or grievances around the circumstances of the diagnosis. Leaving such emotions unspoken could make a relationship untenable, 28-year old Damien noted, whose long-term partner had not followed 'the precautions that we agreed that we would take' when having casual sex with others:

It's forced us to I guess have this dialogue that maybe a lot of couples wouldn't have unless they were going through some other crisis... I think within relationships people can take a lot of things for granted and I think, particularly in our situation, you can't. There are things, uncomfortable things that you have to discuss. You can't avoid them... everything has to be thrown out in the open, you know. You can't hide it any longer and, when it does come out, I think it definitely has... the potential to turn into such a positive thing.

As Damien's quote suggests, serodiscordance was characterised in some narratives as potentially being more or better than just 'normal'. Having to confront a partner's HIV status was seen by some as having the capacity to become the very catalyst that made a great relationship. Before meeting his partner, 42-year old Blake had long ruled out having an intimate partnership or even sex with a negative man. He spoke

of his amazement to discover that serodiscordance had provided a means to cultivate some highly conducive relationship qualities:

It brings a realness and a rawness, if you like... even in our very first conversations when we first met, we just went straight to some really kind of edgy, raw topics... and maybe HIV is the platform that's allowed us to both meet on that level of authenticity and openness... It's a really conscious relationship in terms of communication, feelings, care, nurture, protection. It's just all that stuff. It's really, yeah, I guess [serodiscordance]'s been the platform for all of that stuff to really come to the fore. Yeah. Wow! Here I was thinking it's a big issue... And here it is, being the very thing that has brought us so close.

Overall, as these stories suggest, the couples did not shirk from talking about any difficulties they experienced in relation to their serodiscordance, but nor did they belabour them. More often than not, such tales were simply one part of a broader 'realist' narrative that defied, sometimes explicitly, one-sided discourses of serodiscordant relationships as problematic, undesirable or unsafe. Against the HIV-related stigma and misconceptions that underpin such discourses and envelope serodiscordant relationships in social silence, mixed HIV status was narrated as peripheral and highly manageable in the context of everyday life, and as bringing both challenging and positive aspects to the relationship. As we describe next, this was the message that participants clearly wanted to communicate when asked what advice they would give couples in a similar situation.

### **Advice to Other Mixed-Status Couples**

Asking participants to give advice to hypothetical others who face the prospect of a mixed-status relationship provided further insights into the practical, emotional and 'ideal' ways of living with serodiscordance. Nearly all emphasised honesty and trust as both necessary keystones and positive by-products of a successful serodiscordant relationship. As positive partner Merlin described it, 'You have to not be lying to your partner about what you're doing sexually with other people... So, yeah, [serodiscordance] kind of adds an opportunity to be honest'. While honesty and trust are valued relationship qualities generally, they take on particular meanings in mixed-status partnerships, not only in relation to sex outside the relationship, as well as within, but also in relation to viral load test results and taking medication because of the potential risks to both partners' health posed by dishonesty or lack of communication. 'If there's no trust, it's just not gonna work', negative partner Troy said. Cody, a positive partner, similarly noted: 'The only way it's gonna work is if you actually can be honest about everything'.

Knowledge was seen as helpful, even critical to honest dialogue. Participants urged other mixed-status couples 'out there' to educate themselves by asking questions, doing research and speaking to health care professionals, 'so you don't have to be ignorant and you don't have to be paranoid', positive partner Dennis said. In their view, if fully informed, couples would find it easier to 'nut out where [their]

emotions are coming from' (Charlie, negative partner), to 'understand the risks' (Lucinda, positive partner), and find 'ways of managing that and making it less of an obstacle' (Merlin, positive partner). Positive partner Leo likened it to preparing for a trip:

Go into it wholeheartedly. Be aware. Be absolutely aware. Glean all the information you can. It's about the bond. You don't decide who you fall in love with and, if you do fall in love with a person and that's what's going on, acknowledge it. And that comes with clear, articulate clarification of what that means. Because it's a journey together and, in order to be able to do that, you've got to have the right things, just like if you were going on a road trip.

One message that was implicit in much of their advice, and explicit in the quote by Leo, was the idea that HIV is a joint concern, which might explain the endurance of some of these couples. 'It's as much your issue as it is their issue', negative partner Charlie insisted: 'If you just treat [HIV] as their issue, you're gonna fail. It's a shared thing. It's not just about someone having a disease and you not having a disease'. A related message to other mixed-status couples was that, it is altogether possible to work out how to live with serodiscordance and overcome any challenges it may pose, not least when couples realise that medical advances have radically transformed HIV, not only in terms of mortality but also transmissibility (Persson, in press). Indeed, there was a tendency across the interviews to emphasise the chronic rather than infectious nature of HIV, with many negative partners in particular pointing out that, stigma aside, HIV should not be perceived as necessarily a greater relationship obstacle than other health conditions. In 43-year-old Eliza's words:

In an ideal world, your decision about whether to get into a relationship with someone with HIV would be like a decision to get into a relationship with anybody. And, you know, if they have an illness, then it could be HIV, it could be cancer, it could be diabetes. There's lots of serious illnesses that impact peoples' relationships.

In his advice to other couples, Cameron contextualised serodiscordance in a similar way: 'Don't let a potential partner's HIV status influence your decision in any way because... the serodiscordance can be managed... Yes there is an added complexity, but relationships are full of complexities'. This, in the end, was the central theme of the 'story of serodiscordance' that emerged in these interviews: do not let outdated misconceptions or fears of HIV impact on potential love. Despite sexual and social challenges, most couples managed HIV well and felt safe with each other. As Jack, a negative partner, summed it up:

[It's] really important information to get out there in terms of, you know, trying to debunk the myth that you couldn't have a good serodiscordant relationship... I've been living it for 20 years, you know... Don't let serodiscordance get in the way of having a loving, fulfilling relationship. Because I'm proof that it doesn't need to be.

## Reflections on the (Co)production of Intimate Citizenship

So what do these serodiscordant stories tell us? On the face of it, they present a far happier picture of serodiscordance than what is normally found in the literature. But, as Plummer suggests, 'It is not simply *what* people say that is [of] concern, *but the complex social processes involved in the telling*' (1995: 13). In alignment with the ethos of reflexivity in research, we do not subscribe to the illusion that in-depth interviews render visible the authentic inner worlds of the interview subjects, as if 'direct copies' of 'reality' (Plummer 1995: 12). Nor are we driven in any simple way by a sentimental, emancipatory ambition to 'give voice to otherwise muted groups' (Atkinson 1997: 327). Still, there are several 'complex social processes' at play in the production of the stories presented here; processes that include agendas on the part of both the couples and the researchers that together bring these stories into a particular kind of being, as much 'real' as political.

By telling their stories, these participants broke the silence that protects serodiscordant couples from social censure and intrusions, yet consigns them to the category of invisible 'others' and allows misconceptions and stereotypes to persist. Together with a simple human wish to be heard in a safe way, there was a clear desire to demystify serodiscordant relationships as manageable, ordinary and not necessarily defined by HIV, thereby creating an important counter-narrative to inflated discourses of high-risk that frame intimacy across the 'sero-divide' as inherently problematic. As writer and filmmaker Minh-ha Trinh argues, the story-telling subject is also an 'un-making subject' (1989: 149), particularly in contexts of stigma and marginalisation, where stories are often told *against* typecast identities, *against* prescribed subjectivities (Georgakopoulou 2014). As such they expose *social* 'truths'. And for that reason, the stories of muted groups matter, because they 'reveal things about the world that we *ought* to know' (Delgado 1990: 95).

Many marginal stories remain dormant 'awaiting their historical moment' when they can be safely told and heard (Plummer 1995: 35). Perhaps the contemporary biomedical era provides such a moment for serodiscordant couples; when stories that counter stigmatising discourses and preoccupations with risk can be validated with reference to authoritative claims from science that even condomless serodiscordant sex can be safe in the context of HIV treatment. We are already seeing the gradual emergence of a broader movement, particularly in North America, which includes the articulation of new identities in relation to HIV, such as 'undetectable', 'HIV equal' and 'HIV neutral'; identities that through the use of HIV treatments in various configurations are able to refuse and thus destabilise the conceptual 'sero-divide' between those with and without HIV (Duran 2014; Nelson 2014; Sullivan 2014; [www.hivequal.org](http://www.hivequal.org); [www.thestigmaproject.org/#!/summer-2012/c1apc](http://www.thestigmaproject.org/#!/summer-2012/c1apc); Sobo 2014).

This is also where the story-telling impetus of the couples in our study coalesces with our own political and philosophical compass as long-standing researchers in this field. We share the frustration that society's knowledge about HIV lags behind the extraordinary strides in biomedicine, which have transformed the virus—and what it means to live with it—beyond all recognition. We hasten to acknowledge that this is obviously far from true for all people living with HIV globally; people

still get infected and people still die. So we remain cautious of the contemporary ‘HIV normalisation’ discourse (Persson 2013b). But it is certainly a valid point for many people and couples in Australia, a high-resource country where HIV treatment is readily available and is both subsidised and heavily promoted by the government, resulting in high treatment coverage by international standards (Kirby Institute 2014). *And that’s a story that also needs to be heard.*

To engage critically and reflexively with research stories is to also recognise that we, as researchers, are part of the story-telling process; that ‘it is deeply social’ (Plummer 1995: 12). As Joseph (2012) puts it, we ‘play a tandem role as dual narrator, or secondary storyteller’. We encourage people to tell their stories in certain ways through our questions, our theories, what we subtly allow or block with our responses and body language, and what we focus on or look for—whether marginality or normalcy, disempowerment or agency, risk or safety. And then, once retold through our writings and read by others, research stories churn through multiple interpretations, opening up questions about whose story it becomes (Plummer 1995: 12, 21; see also Razack 1993; Mazanderani and Papparini 2015). While we do not wish to overstate researchers’ power over the direction and content of stories, we also have little doubt that the affirmative way we promoted this study, our lack of narrow preoccupation with ‘risk’ and ‘challenges’, and the receptive, non-censorial style of the interviews themselves all facilitated a performative context in which particular narratives were able to unfold. Our readiness to listen to a *different* kind of story about serodiscordance coincided with the couples’ desire to normalise it, whether through overly positive stories or simple renderings of everyday experiences not usually reflected in public health discourse.

This is story-telling as activism; a rally for social and political recognition and legitimacy. By moving hidden stories out of silence, stigmatised communities and researchers can conjointly contribute to the shaping of ‘a new public language’ and to emergent platforms that receive and distribute those stories, ‘ultimately creating more and more spaces for them to be heard’ (Plummer 1995: 149). In this way, the telling of previously muted stories makes a difference, not only to personal lives but to our societies and cultural sensibilities. By championing rival identities and alternative imaginings, they stretch wider our horizons of understanding. This, Plummer argues, is the political role of marginal sexual stories: the forging of new forms of ‘intimate citizenship’. The rights and responsibilities implicated in the concept of citizenship are not inherent or incontrovertible, but ‘depend upon a community of stories which make those same rights plausible and possible’ (1995: 150). As regards serodiscordance research, such rights could be promoted by focusing less on ‘risk’ and more on the social politics and lived experiences of bridging the ‘sero-divide’. It is our hope that the stories we have engaged with here can contribute, in some small way, to a long overdue intimate citizenship among those who live in mixed-status relationships.

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## Compliance with Ethical Standards

**Conflicts of interest** The authors declare that they have no conflict of interest.

**Ethical Standards** Ethics approval for this study was granted by the University of New South Wales Human Ethics Committee (Approval Number HC12627). Informed and written consent was obtained from all individual participants in the study. All procedures performed in studies involving human participants were in accordance with the ethical standards of the UNSW ethics committee, the National Health and Medical Research Council, and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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