Caring for ‘underground’ kids: qualitative interviews with clinicians about key issues for young people growing up with perinatally acquired HIV in Australia

Asha Persson*a, Christy E. Newmana1 and Angela Millerb2

aCentre for Social Research in Health, University of New South Wales, Goodsell Building, Level 3, UNSW, Sydney 2052, Australia; bSydney Children’s Hospital, Paediatric HIV Service, Sydney, Australia

(Received 18 October 2013; accepted 12 November 2013)

Young people growing up with HIV are an emerging subpopulation in the global epidemic. Discursive representations of this population are largely dominated by the US-based research literature, which typically focuses on dysfunctions, sexual risks and negative public health outcomes. Against this background, our article examines clinical perspectives on key issues for young people with perinatally acquired HIV who are transitioning to adolescence and adulthood in Australia. We show that although the clinicians we interviewed raised many of the same issues found in the US literature, there was far greater emphasis on the well-being of their young clients and on the social complexities and impact of their condition, providing a narrative that departs from the usual framing of this population. We conclude that future research could usefully contribute to a richer understanding of these young people by focusing on stories of success, survival and resilience.

Keywords: perinatally HIV-infected children; transition to adolescence and adulthood; clinician perspectives; qualitative interviews; Australia

In this study, we examine clinical perspectives on young people growing up with perinatally acquired HIV, with particular focus on issues and experiences believed to be associated with transitioning to adolescence and adulthood. This is an emerging subpopulation in the global HIV epidemic, and one that is almost invariably described as ‘unique’ and ‘challenging’ in the research literature. The survival of HIV-positive children into adolescence and beyond in high-resource countries, and increasingly in low-resource countries, represents one of the great successes in the ‘battle against the disease that has claimed the lives of millions’ (Agwu & Fairlie, 2013, p. 1). But this success, researchers argue, has in turn brought with it new challenges as this population is starting to reveal some of the unknown and wide-ranging ramifications of long-term HIV infection and antiretroviral (ARV) therapy, which clinicians must identify and manage (Mofenson & Cotton, 2013; Sohn & Hazra, 2013; Wiener, Battles, & Wood, 2007).

These challenges have given rise to a growing body of literature that examines a gamut of medical and psychosocial issues for adolescents with perinatally acquired HIV. The majority of this literature comes from the United States, where around 4500 children and adolescents live with HIV (UNICEF, 2012). By comparison, in Australia, where our research took place, there is minimal published research and the population is very small with around 80 perinatally infected young people (Miller, Ziegler, & Palasanthiran, 2013).

*aCorresponding author. Email: a.persson@unsw.edu.au

© 2014 Taylor & Francis
about half of whom were born in Australia and half in sub-Saharan African and other countries with high HIV prevalence. Globally, over 3 million children under 15 years of age have HIV, with 90% living in sub-Saharan Africa (UNICEF, 2012). The US literature largely dominates the discourse on transition and has come to shape how young people with HIV in developed countries are defined and understood.

Our aim in this study was to provide a first picture of what Australian clinicians see as some of the key issues for this population as they move into young adulthood, and to examine how their views correspond with the US literature. Our analysis is based on findings from the first Australian study of perinatally infected young people, which examines transition issues from the perspectives of both clinicians and young people themselves. Here, we focus on the initial study phase, which included interviews with paediatric and adult clinicians who work with this population.

Key themes in the literature

Children growing up with HIV are likely to have certain experiences in common with other young people with potentially life-threatening illnesses, including ongoing medical treatment and visits to the clinic, periods of ill health and hospitalisation, missed school and a sheltered life. But the fact that HIV is a profoundly stigmatised infectious disease clearly sets it apart from other chronic childhood conditions (Fair, Sullivan, & Gatto, 2011; Mellins & Malee, 2013). Perinatally infected young people are also seen as different within HIV medicine itself. Unlike other people with HIV, they were infected before the development of their immune system and many have been subject to suboptimal ARV options, especially during younger years (Sohn & Hazra, 2013). The metabolic, neurodevelopmental and multi-organ effects of this are only now starting to emerge (Mofenson & Cotton, 2013). There are additional reasons why these young people are widely described as a unique and challenging client group. The US-focused literature identifies several clinical and social issues believed to distinguish this population and complicate their transition through adolescence. Among these, four themes are particularly dominant: transition to adult care, which we discuss elsewhere (Newman, Persson, Miller, & Cama, forthcoming); mental health disorders; psychosocial factors; and adolescent sexuality, which we outline below.

One of the most persistent issues in the literature, as we have noted elsewhere (Persson & Newman, 2012), is that perinatally infected young people are particularly susceptible to and more frequently diagnosed with psychiatric, cognitive and behavioural disorders, which are seen to impede their readiness for the independence and responsibilities of managing their disease as they get older (Chernoff et al., 2009; Foster, Waelbrouck, & Peltier, 2007; Hazra, Siberry, & Mofenson, 2010; Wood, Samir, Steenhoff, & Rutstein, 2009). This vulnerability to impaired cognitive development has been attributed to the neurotoxic effects of the virus (Benton & Ifeagwu, 2008; Kapetanovic et al., 2010), but it has also generated debate among researchers, with some questioning whether the HIV infection is the primary cause (see Steele, Nelson, & Cole, 2007). Mellins and Malee (2013, p. 15) recently noted that there is ‘an emerging consensus that the aetiology of psychiatric disorders and other mental health problems is a diagnostic challenge and multifactorial, given the abundance of risks and potential pathways to poor mental health in this population’.

These pathways, according to the literature, include certain psychosocial and socioecological factors. Unique to this population is the number of young people who have lost biological parents, often giving rise to complicated family situations or multiple care
transitions (Foster et al., 2007; Wiener, Kohrt, Battles, & Pao, 2011). In the United States, many belong to disadvantaged cultural minorities or come from backgrounds of poverty, drug abuse and community violence, which are described as added risk factors for poor mental health (Eastwood & Birnbaum, 2007; Elkington, Bauernmeister, Brackis-Cott, Dolezal, & Mellins, 2009; Flicker et al., 2005; Kang, Mellins, Ng, Robinson, & Abrams, 2008). The stigma surrounding HIV is also considered a likely contributor to psychiatric or behavioural issues in this population. Studies in Sweden, the United States and Canada found that the experience or perception of ignorance and prejudice in the community could be more harmful than the disease itself, giving rise to secrecy and self-protective isolation in families affected by HIV, which profoundly shaped how young people lived their lives (Abramowitz et al., 2009; Fair & Walker, 2011; Fielden et al., 2006; Rydström, Ygge, Tingberg, Navèr, & Eriksson, 2013).

These distinct issues are widely thought to intensify the already challenging dynamics of transitioning through adolescence. As the literature repeatedly stresses, when psychosocial and psychiatric problems in this population dovetail with teenage rebellion, impulsivity, experimentation, peer pressure and the desire to fit in, this can have critical implications for both individual and public health. This ‘perfect storm’ is believed to create a powerful barrier to continued adherence to HIV medication, with resultant implications in terms of developing viral resistance and reducing treatment options (Agwu & Fairlie, 2013; DeLaMora, Aledort, & Stavola, 2006; Foster et al., 2007; Malee et al., 2009), and to lead to increased sexual risk-taking, with consequences for preventing the transmission of HIV to others (Benton & Ifeagwu, 2008; Elkington et al., 2009; Kapetanovic et al., 2011). Adding to this concern, research suggests that disclosure of HIV to sexual partners is far from the norm among this population (Michaud et al., 2009; Peele, D’Angelo, Chandwani, Abramowitz, & Koenig, 2012; Wiener & Lyons, 2006). Fear of rejection is an obvious explanation, but as Fair and Albright (2012) point out, years of being told to keep HIV secret can also turn disclosure to partners into an acutely difficult and unfamiliar terrain.

Sexual practices and HIV prevention are key concerns in the literature. However, the research on sexual practice shows very mixed results, perhaps reflecting the multiple and contextual factors at play when HIV and adolescence converge (Elkington et al., 2012; Mellins et al., 2011). Some studies have found early sexual debut and/or high rates of unprotected sex in this population (Brogly et al., 2007; Elkington et al., 2009; Ezeanolue, Wodi, Patel, Dieudonne, & Oleske, 2006; Koenig et al., 2010; Tassiopoulos et al., 2013). Conversely, other studies have found that perinatally infected adolescents delayed sexual debut or were less sexually active than non-infected peers and less likely to have penetrative sex (Bauernmeister, Elkington, Brackis-Cott, Dolezal, & Mellins, 2009; Elkington et al., 2012; Mellins et al., 2011; Wiener & Lyon, 2006). In addition, there is little research on HIV prevention knowledge among this population, with a few studies reporting starkly different findings of poor knowledge (Wiener et al., 2007) and sophisticated knowledge (Fernet et al., 2007). Yet, there is an implicit assumption operating in much of this literature of poor prevention knowledge accompanied by a broad consensus that sexuality among adolescents with HIV is a public health concern that requires ongoing attention and intervention.

**Approach**

The aim of this exploratory qualitative study was to examine key issues for perinatally HIV-infected children transitioning to adolescence and adulthood. The study, the first of its kind in Australia, was conducted by the Centre for Social Research in Health at the University of
New South Wales (UNSW) in collaboration with the Paediatric HIV Service at the Sydney Children’s Hospital, the key service for this population in Australia. Ethics approval was granted by Sydney Children’s Hospital Network Human Research Ethics Committee and ratified by the UNSW ethics committee. The study was funded by an unconditional Gilead Fellowship and by the Australian Government Department of Health and Ageing.

While the broader study will describe the experiences of young people with HIV as well as their clinicians, this study focuses on the interviews conducted for the first phase of the study with paediatric and adult clinicians who work with young people before, during and after transition to adult HIV care. Twelve clinicians were interviewed between August 2012 and April 2013, following the provision of written consent. Although this is a relatively small number of participants, together they represent a significant proportion of clinicians working with this population in Australia. Eight clinicians were located in New South Wales, where the majority of children with HIV live, while four were from three other states. Clinicians were recruited through an email-alert circulated by the Australasian Society for HIV Medicine to their members and through snowballing. No clinician was approached directly; however, the sample comprised most of the clinicians identified as key in this field by the study’s expert committee, which includes HIV clinicians, HIV social researchers and representatives of HIV community organisations (Table 1).

Interviews were conducted by phone \( (n = 5) \) or face-to-face \( (n = 7) \) by either of the two researchers on the investigator team. The interview schedule was developed based on our previous analysis of the transition literature (Persson & Newman, 2012) and in consultation with the study expert committee. Interviews lasted 25–65 minutes, depending on the time each participant was able to provide, and were audio-recorded and subsequently transcribed verbatim. Potentially identifying information was removed from transcribed interviews to protect participant anonymity. Transcripts were coded independently in NVivo by [author] and [author] who have extensive experience in qualitative data analysis. Using thematic analysis, the foundational and most common method for qualitative analysis (Braun & Clarke, 2006; Guest, 2012), transcripts were read multiple times and coded according to key issues covered in the interviews, focusing on inductive identification of recurrent and divergent themes, which were then analysed in detail to build a contextualised understanding of differences and similarities across interviews. During this process, the investigators met regularly to discuss emerging themes and interpretive possibilities, and these were subsequently ‘workshopped’ with the expert committee and refined during the manuscript drafting process.

Findings

Echoing the literature, the description of perinatally infected young people as a ‘unique’ and ‘challenging’ population figured liberally in the interviews, along with ‘special’, ‘distinct’, ‘complex’ and ‘difficult’. However, the bases for these characterisations seemed to – subtly or explicitly – diverge from the core themes in the US literature. A notable difference was the general absence of emphasis on psychiatric, cognitive and behavioural

| Clinical professions of research participants. |  |
|-----------------------------------------------|---|
| Paediatric care (medicine)                    | 5 |
| Paediatric care (nursing and allied health)   | 2 |
| Adult care (medicine)                         | 4 |
| Adult care (nursing and allied health)        | 1 |
disorders, which were often discussed only when the interviewer brought them up (as part of the approved interview schedule). Most clinicians believed that the mental health and cognitive capacity of this cohort was extremely variable and likely shaped by a confluence of organic and social factors. However, as with many issues related to perinatal HIV, clinicians felt they were dealing with ‘unknowns’, partly because this is an emerging population, and partly because of their generally small client base, as well as the overall small population of young people with HIV in Australia.

I don’t think we know enough about longevity with HIV for people that have been infected as babies and what the drugs are doing to them, what the disease is doing to them, what it’s like living with a chronic illness but from birth that then has such a societal impact on them. So I think there’s lots of issues that we’re missing just because we haven’t lived that experience yet really. (Adult care clinician, nursing and allied health)

The primary themes in the clinician interviews were the interplay of HIV and adolescence and its potential impacts on: medication adherence, sexuality and well-being. The emphasis on adherence and sex was in line with the literature. But unlike the literature’s tendency to focus on dysfunctions and negative public health outcomes, the tone was largely one of concern for the young people themselves, often coupled with great commitment to their care and well-being, and at times with some anxiety about their own capacity to meet their clients’ many and complex needs. ‘I often worry’ was a phrase observed across the interviews. In this context, the concepts ‘unique’ and ‘challenging’ reflected several things: an appreciation of the unusual life situation of these young people as a tiny and hidden population, the many difficulties they and their families, along with the clinicians themselves, had to encounter and tackle, and the clients’ courage and resilience in the face of it all. We now turn to a discussion of the key themes.

**Negotiating the interplay between HIV and adolescence**

The clinicians agreed that HIV was still experienced as a stigmatised disease by their clients, and that the general community was fearful, disinterested or had very ‘outdated knowledge about HIV’, as one nurse put it. Several noted that HIV stigma was a particularly complex issue among the migrant African communities that many affected families belong to. The social impact of living with a chronic illness in a society still not accepting or up-to-date with contemporary successes in HIV prevention and care was seen as the most damaging aspect of HIV for young people. The clinicians spoke about their clients growing up in an environment of secrecy, often shaped by their parents’ experiences of intense stigmatisation during the early epidemic in Australia or in their country of origin: creating ‘generations of silence’, as a paediatric physician put it.

I think some of the ongoing challenges in today’s present time is the ongoing fear associated with living with HIV . . . for the families and the children that come to our service, for them it’s around, “Will I be accepted by others? Can I talk about my health condition with others? Can I disclose?” And fear of being rejected or not accepted in their community. (Clinician, paediatric care, nursing and allied health)

Several clinicians noted that this ‘ongoing fear’ and the self-protective secrecy and isolation it generated in families would subtly shape how young people felt about their prospects and abilities as people with HIV. Adding another layer, many of their clients came from disadvantaged backgrounds of considerable ‘emotional and physical hardship’, as one nurse put it; not a ‘two parents, just general upbringing, ballet classes kind of lifestyle’. Most had at least one parent who was HIV-positive, some had lost their parents and lived with extended family or were raised in foster care, and some came from migrant
backgrounds bringing with them layers of cultural trauma, with some families also dealing with issues regarding their immigration status and a lack of support in their new country.

To the clinicians, one of the defining issues for these young people was the tension between a sense of being ‘really different from others’ as well as ‘wanting to be like every other normal teen’, as one social worker stated. A recurring concern among their clients was the impact of HIV and medication on their life aspirations, particularly their ability to travel, form intimate relationships and have children. At the same time, they struggled to accept that ‘HIV affects their complete freedom’ (adult care physician) and were ‘fed-up with people telling them about their health and what to do … because they just wanna go and be young, and have a life’ (adult care nurse). In view of this tension, as one adult care physician summed up, ‘the main challenge is getting through adolescence and having a long-term perspective on health and life.’

Understanding barriers to medication adherence

Medication adherence was by far the most commonly raised concern among the clinicians. Poor adherence was a real problem that most had encountered in this client group, with sometimes critical implications. Physicians spoke of the difficulties of striking a balance between trying to ensure sustained viral control while also trying to preserve future treatment options in the face of non-adherence and the development of multidrug resistance. One physician described the stakes at play in his decision-making:

Well, if I give them these drugs now and they don’t take them properly, what’s the consequence of that? And then, what could I do later? So you don’t wanna burn up drugs that have low resistance. So, yet some of them have already got substantial resistance and they need those drugs. (Clinician, adult care, medicine)

Clinicians recognised that maintaining adherence was challenging for adolescents who felt that pill regimens and clinical monitoring constrained their freedom to travel and to be spontaneous and ‘do stuff’ that young adults want to do. Adherence was also seen to be complicated by significant changes in the adolescents’ lives, in particular moving from the structured and supported environment of paediatric care to having to take responsibility for their medication and health care, often in the midst of trying to also deal with the emotional pressures and turmoil of adolescence and a host of increasing demands put on them.

Suddenly they have to take responsibility for their own future plans, whether it be university or relationships, or employment. And some may have the life skills to do that but, like many adolescents, they may not. And I think that HIV then takes much of a backseat to what are the other issues they’re having to deal with …… So their adherence with appointments and with medication is poor, and they don’t seem to understand the necessity to have HIV being better considered in their life ‘cause they have all these other issues now that they have to deal with …… And suddenly, if they’re not living at home, they’re responsible; it may all start to fall apart. (Clinician, adult care, medicine)

Young people’s sense of ‘immortality’ and ‘infallibility’ was noted as another driver of poor adherence; the inability to think too far into the future or link behaviour with consequences, all of which might become, one physician noted, ‘ramped up to the max’ in the context of a serious illness. Some clinicians also speculated that, because of the enormous weight placed on adherence by the adults in their lives, medication refusal could become a powerful tool in adolescents’ need for autonomy, rebellion or control after years of having their decisions made by parents and clinicians. Several clinicians described their frustration and distress in trying to persuade some of their teenage patients to prioritise the
importance of adherence and to understand the seriousness and ‘potentially life-threatening’ consequences of not taking their medication.

I think it’s that problem of, that adolescent age where they don’t wanna do things because they’re tired of being told what to do and they wanna be independent and adult, but we still really need them to do certain things because, if they don’t, they’re not gonna make being an adult. (Clinician, adult care, nursing and adult health)

The role of parents was also mentioned as a potentially complicating factor in achieving adherence. Although most clinicians were keen to stress that the vast majority of parents and carers were ‘fantastic’ and ‘do a great job’ in supporting adherence in their children, some pointed out that a small number of families found it ‘difficult to stick to adherence for whatever reason’, as one paediatrician stated. Mental health and drug problems were mentioned by some, with others speculating that parental guilt over a child’s HIV infection had in some instances resulted in a kind of compensatory leniency and affected the willingness or capacity to enforce adherence.

The implication of non-adherence for HIV prevention was raised by several clinicians, but it was not a prominent theme, despite the current global focus on ARV treatment as a key prevention strategy to reduce HIV transmissions. The likely reason for this was that the health ramifications of poor adherence were a more immediate concern. Indeed, some expressly cautioned that, because of the unique clinical histories of many adolescents with HIV, they should be considered separately rather than simply ‘bunched together’ with the rest of the HIV-positive population in the push for ‘treatment-as-prevention’. Another reason why medication non-adherence in relation to prevention was not a major theme could be because, as we describe next, most clinicians believed that levels of prevention knowledge were actually quite high in this population, despite acknowledging that they did not necessarily have a good grasp of their clients’ sexual lives.

Appreciating the complexities of sexuality

Sexual health and HIV prevention were a concern among the clinicians, but the emphasis differed from the literature. This group echoed many of the key issues in other research, including sexual experimentation, binge drinking and unsafe sex, and non-disclosure of HIV to sexual partners. Yet the sexual practices of their young clients emerged as relatively ‘unknown’ in the interviews. The paediatric physicians primarily dealt with children who were not yet sexually active or would only see those issues emerging just as the adolescents transitioned to adult care, while the adult physicians did not always feel they had adequate information about their clients’ sexual history. Nonetheless, in contrast to the US literature, the impression among most clinicians was that this population was generally very aware and well-informed about HIV prevention, including knowledge about sexual safety and risks, availability of post-exposure prophylaxis and the legal requirement to disclose their status to sexual partners (at least in the state of New South Wales).

I think their knowledge is incredibly high and certainly much higher than what you would think, you know, an average 16 or 17-year-old across Australia would have … I think actually most of them take on a lot of that information really well. (Clinician, paediatric care, nursing and allied health)

One adult care nurse even described a sense of information overload in relation to prevention: ‘I always talk to them about safe sex just a bit, but they always are like, “Oh we’ve done all that … we’re sick of hearing about it!”’ However, clinicians were less certain that the adolescents were equally ‘well-versed in how to negotiate safe sex’ (adult
care physician), or sufficiently skilled and resourced to actually put their knowledge into practice. Because of these unknowns, they emphasised that it was important to keep the dialogue going, to build trust and work on an individual basis with these clients, rather than rely on existing HIV prevention materials, which are primarily tailored to adult gay men in Australia, and which virtually all the clinicians saw as inappropriate to this population.

I think it’s important to be able to have open communication around those issues because we don’t want it to go underground, and we don’t want young people to have the wrong information, or engaging in a risk-taking behaviour without knowing all the facts of how to be, what to do. (Clinician, paediatric care, nursing and allied health)

But this communication was not always seen as easy, especially among the physicians whose skill-set and experiences were based on working with either adults or children, not adolescents. ‘I guess for me, I don’t have good training in adolescent sexual development. So, as a clinician .... you try, but there’s some challenges, because it’s not something I deal with every day.’ Another adult physician stated: ‘Even just knowing what adolescents do and how they speak is a challenge for someone like myself.’ In addition, paediatric physicians felt that discussing certain matters with clients they had known as they were little was awkward for both them and the teens.

There’s a risk of sort of parentalisation by our service and, you know, young people may not want to disclose to people who’ve known them since they were two that, you know, about sexuality, drug, alcohol issues .... yeah, it’s funny with the kids you’ve known for a long time. (Clinician, paediatric care, medicine)

Where possible, physicians relied on nurses and social workers to communicate with adolescent clients about sex, relationships and other non-medical issues. Allied health workers were generally seen as better equipped to take on the complexity and delicacy of such issues. But while ongoing education and discussions about sex with this client group were seen by everyone as absolutely necessary, some clinicians expressed concern that the broader focus on sex in this population was too one-sided.

It seems to me a lot of people are obsessed with them having sex. So, yeah, when you look in the literature and stuff, a lot of it is just about disclosing and having safe sex. There’s not much about them and their issues .... And, once they do get to a certain age, it is all about the sex and disclosure .... I think we’re focusing on only one thing. (Clinician, adult care, nursing and allied health)

Several clinicians, especially allied health professionals, echoed this sentiment. They worried that the emphasis on sexual safety and prevention knowledge could obscure more emotional concerns and pressures around sexuality for these adolescents. In their view, forging a healthy sexual identity could be especially challenging, given the ongoing stigma around HIV and the lack of adequate HIV education and awareness both in the school system and in society more broadly:

Some of the young people have talked in the support groups about feeling toxic and that they’re this walking time bomb that others are afraid of .... All the people that I work with, young people, talk about wanting to be able to do anything to get rid of this virus, not just from themselves, but they don’t wanna be at risk of infecting other people. But, at the same time, it’s a huge burden to carry; that the emphasis is always on the positive person. And I know that a lot of the young people want there to be better public education so that everybody protects themselves. (Clinician, paediatric care, nursing and allied health)

The clinicians were acutely aware that navigating this landscape as a young person with HIV would be exceedingly daunting. The challenges of knowing when to disclose, or how to disclose, and the fear of rejection by a potential sexual or romantic partner meant that some of their clients delayed becoming sexually active or avoided relationships
altogether or, as some clinicians worried, possibly engaged in sexual activities that they did not want to discuss with their health care workers. This concern about the social impacts of HIV on young people’s lives leads us into the final and in many ways most fundamental theme in the interviews.

‘Underground lives’: social belonging and well-being

There was complete agreement among clinicians that broader society was ‘totally unaware’ of this population. Clinicians involved in community education programs commented that people are often very surprised to hear that there are children and young people living with HIV in Australia. ‘It’s not on people’s radar . . . I just think it doesn’t occur to people,’ a social worker noted. This was seen as starkly different to the attention given to other childhood diseases:

We can compare this to children who are affected by cancer or leukaemia, there’s no stigma attached and so there’s lots of support and visibility, whereas I think the children with HIV in Australia is, in some ways, an invisible group. There’s really limited awareness. (Clinician, paediatric care, medicine)

Most thought that this was unlikely to ever change, given the small number of HIV-positive children in Australia, which also means that many of them are geographically and socially isolated. ‘These individuals are just going to be totally overlooked by everything else that’s in the world,’ an adult physician said. ‘How can they possibly have a united voice about anything? They’re going to forever remain hidden individuals.’ The fact that HIV remains a stigmatised and poorly understood disease – still largely imagined through a lens of adult ‘transgressions’ – was also seen as perpetuating their position as a voiceless, ‘underground’ group of young people and profoundly shaping their experiences and interactions. As one paediatric physician observed, ‘the veil of secrecy is the hardest I think.’

A particularly poignant theme in the interviews was the recognition that children with HIV have to grow up and negotiate life and relationships from this highly unusual position, one which they could rarely share with the world, not even with close friends. Although several clinicians cited examples of one or two adolescents with good disclosure experiences, they all agreed that disclosure was typically an intensely difficult issue for this population and their families. Most of their young patients avoided disclosure altogether because they feared not being accepted, or worse, being bullied or publicly ‘outed’ on Facebook and other social media. The clinicians expressed great empathy towards these young people in having their communication shaped by censorship and dissembling. It could be argued that clinicians themselves face the dilemma of supporting their clients regarding privacy and control over disclosure, which can be seen to perpetuate the stigma associated with HIV and therefore impede the ‘normalisation’ of living with the virus (personal communication, Paediatric HIV Service staff). While clinicians recognised the social reality of this dilemma, it contradicted the values they wished to instil in their clients.

I think sometimes for families and for children/young people, it’s the fabrication, like the lie they have to create, or a secondary story, to be able to provide reasons or excuses for either being unwell or for having, needing to be absent to attend medical appointments. I think that fabrication is a lot of hard work and effort, and it’s hard for young people to think up a story when we’re wanting them to be open and honest about their feelings. (Clinician, paediatric care, nursing and allied health)

There was also considerable concern about limited opportunities for these adolescents to spend time with perinatal peers. Research suggests that young people with HIV feel that they are able to cope better if they have friends who share their condition (Lam, Naar-
The experience of meeting other young people with HIV has been shown to increase self-expression and confidence (Fair, Connor, Albright, Wise, & Jones, 2012). In Australia, there is a highly popular annual residential camp for HIV-positive children under 18 years old, which is organised by the [service] and funded by donations. The immense value of this camp, which includes group work and recreational activities, was mentioned by most clinicians:

[A]s health professionals, we’re really excited about the benefits of camp and how much young people can get from being able to connect and come together as a community . . . [The camp] facilitates . . . a peer support model of working with young people so that they feel comfortable to be able to just hang out . . . But it also adds I guess, secondarily, a bit of a respite from the not-thinking about their illness. It allows them to have a good time and show them that they can lead very, very happy lives, that they’re capable of being able to do anything just like any other young person. So not to be able to be held back just because you live with HIV . . . I think it normalises that experience of living with a chronic illness.

(Clinician, paediatric care, nursing and allied health)

A few clinicians spoke about the sense of loss and grief among some clients who were too old to attend, and the lack of support services for those who ‘graduate’ from camp. ‘What is there?’ one adult physician pondered. ‘I’m not sure there is a lot. And there never will be because there’s such a small number of them.’ Social isolation among this population was a recurring concern in the interviews because of the lack of resources and opportunities to connect with peers, especially at a vulnerable time in their lives when they might be grappling with the turbulence and demands of adolescence and likely to also be transitioning from highly sheltered and family-oriented paediatric care into the very different world of adult care (Newman et al., forthcoming).

This concern perhaps explains why most clinicians were very committed to and engaged in these clients, with adult physicians often providing care and time beyond their usual clinical interactions: ‘heavy, high levels of support’ as one described it. When asked what they saw as the key issue in working with this population, beyond core concerns of ensuring adherence, viral control and sexual safety, they mentioned the importance of ‘always having the door open for them’, and of building their young patients’ confidence by reinforcing the message that they ‘they are capable of doing things’ and of leading ‘very normal lives’. Or, as one adult physician concluded, ‘you have to give them hope. Give them a lot of hope.’

**Stories of struggle or success? Concluding reflections and future directions**

Our analysis found that several themes in the interviews were similar to those in the US literature, including the description of perinatally infected young people as ‘unique’ and ‘challenging’ and the focus on medication adherence, sexual health and psychosocial issues, but they tended to have a different emphasis. While psychiatric problems are a central component in the literature; this was not the case in our interviews. Also largely absent was the literature’s tendency to problematise adolescents with HIV as ill-equipped, deficient, at-risk and risky (Persson & Newman, 2012). The focus was less on public health concerns and more on the well-being of their young clients as they navigate the complex interplay of HIV and adolescence. US-based Elkington and colleagues, who have published extensively on this population, note that ‘studies of PHIV + youth have generally focused on negative outcomes (e.g. psychiatric disorders, sexual risk) with few studies examining positive outcomes in these youth’ (2012, p. 418). This focus on major challenges was similarly present among the clinicians, but they were also keen to point out that there is another story:

King, & Wright, 2007).
I should say that for some of these individuals they’re doing really well. And that they are getting on with their lives, that they have fully-suppressed virological suppression. They do understand the level of responsibility in making – they are making lifetime choices that are good choices. So it’s not all negative and we tend to focus on the worst case scenarios as being the most challenging, but maybe the others will just sort of ease into adulthood without any hiccups. Because we’ve got to remember that side as well. (Clinician, adult care, medicine)

Departing from the preoccupation with negative outcomes, the concept of ‘normality’ is invoked in a handful of qualitative studies with perinatally infected youth. One study from Sweden found that, despite many losses in their lives – the death of parents, feeling disconnected from their origin as migrants, being unable to travel freely overseas – the participants explained that ‘over time they had developed an acceptance of their condition and did not feel that HIV was a big issue in their lives’ (Rydstrom et al., 2013, p. 1361). Similarly in a Canadian study, perinatally infected participants ‘talked about HIV as being a relatively small part of their identity. For them, living with HIV is just a part of their regular routine that they rarely reflected upon’ (Flicker et al., 2005, p. 309). In another Canadian study, ‘Parents and care providers stressed the need for children to feel “normal” despite their HIV’ (Fielden et al., 2006, p. 1051). This sentiment was reiterated by some of the clinicians. One social worker argued that it was important to remember that HIV ‘is not their entire being’ and to validate that sense of normality in their clients; to make them feel that, ‘they can be enhanced, and encouraged, and empowered instead of feeling like they’re always pathologised, and that they’re only seen as their virus.’

In their research, Fair and Albright (2012) found that the desire to normalise HIV and the fact that HIV is not seen as normal in society creates a certain ‘cognitive dissonance’ in these young people. As we have outlined, the clinicians identified the tension between feeling different and wanting to be normal as a pivotal issue as well as a potential stumbling-block for this population as they transitioned from childhood. Yet it was in relation to this very tension that the notion of ‘unique’ took on meanings beyond clinical distinctiveness, reflecting a sense of awe at the ‘spirit’ and ‘strength’ shown by many of their clients in the face of great challenges. Mellins and Malee (2013, p. 16) recently noted that, even though multiple studies suggest that young people with HIV show signs of ‘resilience despite vulnerability’, the majority of research has remained firmly focused on risks. One social worker defended the salience of ‘resilience’ in relation to understanding and supporting the needs of this population:

I think it’s a really beautiful word in terms of summing up how lots of young people manage, because a lot of them have been through more than what lots of people would go through in a lifetime, in terms of the loss and managing chronic illness, and the uniqueness of HIV, and still they’re really, you know, functioning beautifully . . . . Even if they haven’t been able to maintain really high adherence all the time, they’ve got strengths in other ways . . . . I think there’s a real difference – especially for the kids who are, who have been infected perinatally and grown up with it – in terms of an extra level of understanding and compassion towards their peers, and towards injustice. And the need to be able to, to wanna just live an average, normal life but also with this heightened sense of, you know, what this is all about, in terms of their own life and their family connections. (Clinician, paediatric care, nursing and allied health)

In conclusion, not only do the findings presented here shed light on a hidden population in the Australian epidemic and community more broadly, but they also make available a narrative that breaks with the typical framing of adolescents with perinatally acquired HIV that we continue to observe in the literature from other, more populous, developed nations. In doing so, these accounts counteract the peril of essentialism and contribute to a broadening and deepening of the discursive representations of these young
people. Certainly, the existing research has much to teach us about the many and real challenges facing young people with HIV and those who care for them. Even so, a shift in focus from dysfunctions and negative outcomes towards resilience and survival stories might enable an even richer understanding. The perspectives described here provide a small step in that direction. Future research – including our own forthcoming analysis of interviews with HIV-positive children and adolescents undertaken for this study – could usefully examine coping strategies among these young people, as well as their support systems, sources of strength and outlook on life, and the experiences of those who are ‘functioning beautifully’, to see what we can learn from them about how to live and do well as a young person growing up with HIV.

Acknowledgements
The authors would like to thank the clinicians who participated in the research for their time and invaluable contribution to the study, as well as the Paediatric HIV Service for their assistance and collaboration, and the members of the study’s expert committee for their good advice and input.

Funding
This work was supported by an unconditional 2013 Gilead Fellowship; a UNSW Faculty of Arts and Social Sciences Research Promotion Grant; and CSRH core funding from the Australian Department of Health & Ageing.

Disclosure Statement
The authors have no conflicts of interest to declare. There are no financial interests or benefits arising from this research.

Notes
1. Email: c.newman@unsw.edu.au
2. Email: angela.miller@seisahs.health.nsw.gov.au

Notes on contributors
Asha Persson is a research fellow at the Centre for Social Research in Health (formerly the National Centre in HIV Social Research) at UNSW where she does sociologically informed qualitative research on various cultural and lived aspects of HIV, with particular focus on the experiences and needs of previously under-researched populations within the epidemic, including heterosexuals, children, and couples with mixed HIV status.

Christy E. Newman is a senior research fellow at the Centre for Social Research in Health (formerly the National Centre in HIV Social Research) at UNSW. She is a qualitative researcher interested in the social aspects of engaging different populations and professional groups with contemporary health imperatives and health services, particularly in relation to HIV and sexual health care.

Angela Miller was a senior social worker at the Paediatric HIV Service at Sydney Children’s Hospital for 10 years where she provided psycho-social support and counselling to children, families and pregnant women with HIV. In addition, she co-ordinated Camp Goodtime and the Positive Kids camps. Angela recently took up a new position as Senior Social Worker/Counsellor at the Short St Sexual Health Centre in Sydney.
References

Abramowitz, S., Koenig, L., Chandwani, S., Orban, L., Stein, R., LaGrange, R., & Barnes, W. (2009). Characterizing social support: Global and specific social support experiences of HIV-infected youth. *AIDS Patient Care and STDs, 23*, 323–330. doi:10.1089/apc.2008.0194.

Agwu, A., & Fairlie, L. (2013). Antiretroviral treatment, management challenges and outcomes in perinatally HIV-infected adolescents. *Journal of the International AIDS Society, 16*, 1–13. Retrieved from http://www.dx.doi.org/10.7448/IAS.16.1.18579

Bauermeister, J., Elkington, K., Brackis-Cott, E., Dolezal, C., & Mellins, C. (2009). Sexual behavior and perceived peer norms: Comparing perinatally HIV-infected and HIV-affected youth. *Journal of Youth and Adolescence, 38*, 1110–1122. doi:10.1007/s10964-008-9315-6.

Benten, T., & Ifeagwu, J. (2008). HIV in adolescents: What we know and what we need to know. *Current Psychiatry Reports, 10*, 109–115. doi:10.1007/s11920-008-0020-7.

Braun, V., & Clarke, V. (2006). Using thematic analysis in qualitative psychology. *Qualitative Research in Psychology, 3*, 77–101. doi:10.1191/1478088706qp063oa.

Brogly, S., Watts, H., Ylitalo, N., Franco, E., Seage, G., Oleske, J., ..., Van Dyke, R. (2007). Reproductive health of adolescent girls perinatally infected with HIV. *American Journal of Public Health, 97*, 1047–1052. doi:10.2105/AJPH.2005.071910.

Chernoff, M., Nachman, S., Williams, P., Brouwers, P., Heston, J., Hodge, J., ..., IMPAACT P1055 Study Team (2009). Mental health treatment patterns in perinatally HIV-infected youth and controls. *Pediatrics, 124*, 627–636. doi:10.1542/peds.2008-2441.

DeLaMora, P., Aledort, N., & Stavola, J. (2006). Caring for adolescents with HIV. *Current HIV/AIDS Reports, 3*, 74–78. doi:10.1007/s11904-006-0021-2.

Eastwood, E., & Birnbaum, J. (2007). Physical and sexual abuse and unstable housing among adolescents with HIV. *AIDS Behavior, 11*, S116–S127. doi:10.1007/s10461-007-9236-5.

Elkington, K., Bauermeister, J., Brackis-Cott, E., Dolezal, C., & Mellins, C. (2009). Substance use and sexual risk behaviors in perinatally human immunodeficiency virus-exposed youth: Role of caregivers, peers and HIV status. *Journal of Adolescent Health, 45*, 133–141. doi:10.1016/j.jadohealth.2009.01.004.

Elkington, K., Bauermeister, J., Robbins, R., Gromadzka, O., Abrams, E., Wiznia, A., ..., Mellins, C. (2012). Individual and contextual factors of sexual risk behavior in youth perinatally infected with HIV. *AIDS Patient Care and STDs, 26*, 411–422. doi:10.1089/apc.2012.0005.

Ezeanolue, E., Wodi, A., Patel, R., Dieudonne, A., & Oleske, J. (2006). Sexual behaviors and procreational intentions of adolescents and young adults with perinatally acquired human immunodeficiency virus infection: Experience of an urban tertiary care center. *Journal of Adolescent Health, 38*, 719–725. doi:10.1016/j.jadohealth.2005.06.015.

Fair, C., & Albright, J. (2012). ‘Don’t tell him you have HIV unless he’s “The One”’: Romantic relationships among adolescents and young adults with perinatal HIV infection. *AIDS Patient Care and STDs, 26*, 746–754. doi:10.1089/apc.2012.0290.

Fair, C., Connor, L., Albright, J., Wise, E., & Jones, K. (2012). ‘I’m positive, I have something to say’: Assessing the impact o a creative writing group for adolescents living with HIV. *The Arts in Psychotherapy, 39*, 383–389. Retrieved from http://www.dx.doi.org/10.1016/j.aip.2012.06.010

Fair, C., Sullivan, K., & Gatto, A. (2011). Indicators of transition success for youth living with HIV: Perspectives of pediatric and adult infectious disease care providers. *AIDS Care, 23*, 965–970. doi:10.1080/09540121.2010.542449.

Fair, C., & Walker, S. (2011). Pediatric HIV social workers: Perspectives on disclosure. *Qualitative Social Work, 10*, 415–433. doi:10.1177/1473325010373527.

Fernet, M., Proulx-Boucher, K., Richard, M-E., Levy, J., Otis, J., Samson, J., ..., Trotter, G. (2007). Issues of sexuality and prevention among adolescents living with HIV/AIDS since birth. *The Canadian Journal of Human Sexuality, 16*, 101–111. Retrieved from http://www.sieccan.org/abstracts/vol16no34.html

Fielden, S., Schechter, L., Chapman, G., Alimenti, A., Forbes, J., Sheps, S., ..., Frankish, J. (2006). Growing up: Perspectives of children, families and service providers regarding the needs of older children with perinatally acquired HIV. *AIDS Care, 18*, 1050–1053. doi:10.1080/09540120600581460.

Flicker, S., Skinner, H., Read, S., Veinot, T., McClelland, A., Saulnier, P., & Goldberg, E. (2005). Falling through the cracks of the big cities: Who is meeting the needs of HIV-positive youth?
Foster, C., Waelbroeck, A., & Peltier, A. (2007). Adolescents and HIV infection. Current Opinions in HIV and AIDS, 2, 431–436. doi:10.1097/COH.0b013e3282ced150.

Guest, G. (2012). Applied thematic analysis. Thousand Oaks, CA: Sage.

Hazra, R., Siberry, G., & Mofenson, L. (2010). Growing up with HIV: Children, adolescents and young adults with perinatally acquired HIV infection. Annual Review of Medicine, 61, 169–185. doi:10.1146/annurev.med.050108.151127.

Kang, E., Mellins, C., Ng, W., Ronbison, L., & Abrams, E. (2008). Standing between two worlds in Harlem: A developmental psychopathology perspective of perinatally acquired human immunodeficiency virus and adolescence. Journal of Applied Developmental Psychology, 29, 27–37. doi:10.1016/j.appdev.2008.02.001.

Kapetanovic, S., Leister, E., Nichols, V., Miller, T., Tassiopoulos, K., Hazra, R., . . ., Williams, P. (2010). Relationship between markers of vascular dysfunction and neurodevelopmental outcomes in perinatally HIV-infected youth. AIDS, 24, 1481–1491. doi:10.1097/QAD.0b013e32833a241b.

Kapetanovic, S., Wiegand, R., Dominguez, K., Blumberg, D., Bohannon, B., John Wheeling, J., & Rutstein, R. (2011). Associations of medically documented psychiatric diagnoses and risky health behaviors in highly active antiretroviral therapy-experienced perinatally HIV-infected youth. AIDS Patient Care and STDs, 25, 493–501. doi:10.1089/apc.2011.0107.

Koenig, L., Pals, S., Chandwani, S., Hodge, K., Abramowitz, S., Barnes, W., & D’Angelo, L. (2010). Sexual transmission risk behaviors of adolescents with HIV acquired perinatally or through risky behaviors. JAIDS, 55, 380–390.

Lam, P., Naar-King, S., & Wright, K. (2007). Social support and disclosure as predictors of mental health in HIV-positive youth. AIDS Patient Care and STDs, 21, 20–29. doi:10.1089/apc.2006.005.

Malee, K., Williams, P., Montepiedra, G., Nichols, S., Sirois, P., Storm, D., . . ., PACTG 219C Team (2009). The role of cognitive functioning in medication adherence of children and adolescents with HIV infection. Journal of Pediatric Psychology, 34, 164–175. doi:10.1093/jpepsy/jsn068.

Mellins, C., & Malee, K. (2013). Understanding the mental health of youth living with perinatal HIV infection: Lessons learnt and current challenges. Journal of the International AIDS Society, 16, 1–13. Retrieved from http://www.dx.doi.org/10.7448/IAS.16.1.18593

Mellins, C., Tassiopoulos, K., Malee, K., Moscicki, A-B., Patton, D., Smith, R., . . ., Seage, G. (2011). Behavioral health risks in perinatally HIV-exposed youth: Co-occurrence of sexual and drug use behavior, mental health problems, and nonadherence to antiretroviral treatment. AIDS Patient Care and STDs, 25, 413–422. doi:10.1089/apc.2011.0025.

Michaud, P-A., Suris, J-C., Phil, R., Kahlert, C., Rudin, C., & Chesneaua, J-J. (2009). To say or not to say: A qualitative study on the disclosure of their condition by HIV-positive adolescents. Journal of Adolescent Health, 44, 356–362.

Miller, A., Ziegler, J., & Palasanthiran, P. (2013). Paediatric HIV in Australia: 30 years of a changing landscape. HIV Australia, 11, 25–28.

Mofenson, L., & Cotton, M. (2013). The challenges of success: Adolescents with perinatal HIV infection. Journal of the International AIDS Society, 16, 1–13. Retrieved from http://www.dx.doi.org/10.7448/IAS.16.1.18650

Newman, C., Persson, A., Miller, A., & Cama, E. (forthcoming). Bridging two worlds: Provider perspectives on transitioning young people with perinatally acquired HIV into adult care in a low prevalence setting.

Peele, Y., D’Angelo, L., Chandwani, S., Abramowitz, S., & Koenig, L. (2012, March 14–17). Determinants of HIV serostatus self-disclosure among adolescents participating in the adolescent impact study. Presented at Society of Adolescent Health and Medicine Annual Meeting, New Orleans, LA.

Persson, A., & Newman, C. (2012). When HIV-positive children grow up: A critical analysis of the transition literature in developed countries. Qualitative Health Research, 22, 656–667. doi:10.1177/1049732311431445.

Rydstrom, L-L., Ygge, B-M., Tingberg, B., Navèr, L., & Eriksson, L. (2013). Experiences of young adults growing up with innate or early acquired HIV infection: A qualitative study. Journal of Advanced Nursing, 69, 1357–1365. doi:10.1111/j.1365-2648.2012.06127.x.
Sohn, A., & Hazra, R. (2013). The changing epidemiology of the global paediatric HIV epidemic: Keeping track of perinatally HIV-infected adolescents. *Journal of the International AIDS Society, 16*, 1–13. Retrieved from http://www.dx.doi.org/10.7448/IAS.16.1.18555

Steele, R., Nelson, T., & Cole, B. (2007). Psychosocial functioning of children with AIDS and HIV infection: Review of the literature from a socioecological framework. *Journal of Developmental & Behavioral Pediatrics, 28*, 58–69.doi:10.1097/DBP.0b013e31803084c6.

Tassiopoulos, K., Moscicki, A-B., Mellins, C., Kacanek, D., Malee, K., Allison, S., . . ., Seage, G. (2013). Sexual risk behavior among youth with perinatal HIV infection in the United States: Predictors and implications for intervention development. *Clinical Infectious Diseases, 56*, 283–290. doi:10.1093/cid/cis816.

UNICEF. (2012). *Childinfo: Monitoring the situation of children and women – HIV/AIDS*. Retrieved September 26, 2013, from http://www.childinfo.org/hiv_aids.html

Wiener, L., Battles, H., & Wood, L. (2007). A longitudinal study of adolescents with perinatally or transfusion acquired HIV infection: Sexual knowledge, risk reduction self-efficacy and sexual behavior. *AIDS Behavior, 11*, 471–478. doi:10.1007/s10461-006-9162-y.

Wiener, L., Kohrt, B-A., Battles, H., & Pao, M. (2011). The HIV experience: Youth identified barriers to transitioning from pediatric to adult care. *Journal of Pediatric Psychology, 36*, 141–154. doi:10.1093/jpepsy/jsp129.

Wiener, L., & Lyon, M. (2006). HIV disclosure: Who knows? Who needs to know? Clinical and ethical considerations. In M. Lyon & L. D’Angelo (Eds.), *Teenagers, HIV and AIDS* (pp. 105–126). Westport, CT: Praeger.

Wood, S., Samir, S., Steenhoff, A., & Rutstein, R. (2009). The impact of AIDS diagnosis on long-term neurocognitive and psychiatric outcomes of surviving adolescents with perinatally acquired HIV. *AIDS, 23*, 1859–1865. doi:10.1097/QAD.0b013e32832d924f.