

No ordinary mainstream illness: How HIV doctors perceive the virus

Author:

Persson, Asha; Newman, Christy; Hopwood, Max; Kidd, Michael; Canavan, Peter; Kippax, Susan; Reynolds, Robert; de Wit, John

Publication details:

Qualitative Health Research

v. 24

Chapter No. 1

pp. 6-17

1049-7323 (ISSN)

Publication Date:

2014

Publisher DOI:

<http://dx.doi.org/10.1177/1049732313514139>

License:

<https://creativecommons.org/licenses/by-nc-nd/3.0/au/>

Link to license to see what you are allowed to do with this resource.

Downloaded from <http://hdl.handle.net/1959.4/53171> in <https://unsworks.unsw.edu.au> on 2024-04-20

This is the final post-print version of an article published as:

Persson, A., Newman, C.E., Hopwood, M., Kidd, M.R., Canavan, P.G., Kippax, S.C., Reynolds, R.H., de Wit, J.B. (2014) No ordinary mainstream illness: How HIV doctors perceive the virus. *Qualitative Health Research*, 24(1): 6-17. <http://dx.doi.org/10.1177/1049732313514139>

Qualitative Health Research is available online at: <http://qhr.sagepub.com/>

Abstract

Research has shown that social representations of HIV can constitute barriers to health workers' willingness to provide HIV care. Considering a growing shortage in the HIV primary workforce in western countries, we examine how HIV is perceived today by doctors involved in its care. In 1989 Sontag predicted that once the virus became better understood and treatable, the dehumanising meanings that defined the early epidemic would vanish and HIV would turn into an ordinary illness. However, research shows that HIV still carries stigma, including in the health care sector. Drawing on qualitative interviews, we found that HIV doctors in Australia perceived HIV as a far from ordinary chronic illness, because of its extraordinary history and its capacity to extend in multiple clinical and social directions. These rarely explored perspectives can contribute to the social reframing of HIV and to strategies to build a dedicated HIV workforce in Australia and elsewhere.

Keywords

health care, primary; HIV/AIDS; illness and disease, social construction; relationships, patient-provider; research, qualitative; stigma

In 1989, writer and political activist Susan Sontag concluded her seminal essay “AIDS and its metaphors” with a call to challenge the social and political deployment of AIDS as a repository for our deepest fears. The disease, she argued, needed to be detached from its abundance of unsavoury and dehumanising metaphors, which inflicted untold stigma and elicited so much guilt and shame (1990, p. 182). Writing at the end of the decade that saw the emergence of HIV/AIDS, Sontag hoped that AIDS would one day become just an “ordinary” illness no longer fraught with meanings. She predicted that this would happen once the virus became “much better understood and, above all, treatable” (1990, p. 181). Since the time of Sontag’s musings, HIV/AIDS has undergone an astonishing transformation quite unlike any other major contemporary disease. As a result of effective treatments, HIV/AIDS has made a transition from a lethal and devastating disease to a manageable chronic condition for many people with HIV in the developed world (Siegel & Lekas, 2002). Clinically, HIV is now a very different illness to what it once was even just a decade or two ago.

Socially, the disease has also changed. The extreme terror and demonization that surrounded HIV during the early epidemic have greatly subsided over time with the dramatic reduction in mortality, along with a growing insight that the virus is nowhere near as transmissible as first feared, nor contained to particular marginalized populations. However, as relatively recent research has suggested, it would be premature to argue that HIV is now widely perceived in developed countries as a mainstream chronic disease on par with diabetes and asthma, or that HIV does not still carry some stigma in the community, including in parts of the health care sector (Persson, Barton, & Richards, 2006; Hutton, Misajon, & Collins, 2012; Kinsler, Wong, Sayles, Davis, & Cunningham, 2007; Sayles, Ryan, Silver, Sarkisian, & Cunningham, 2007). The revolution that has taken place within HIV medicine has not necessarily translated in a comprehensive way to the broader society and broader health care sector. So if

HIV infection is not yet “just an illness,” as Sontag envisaged; how is the virus and those affected by it perceived today?

To explore this question, we draw on a larger study that examined the role of the HIV general practice workforce in Australia in the context of a changing epidemic and its impact on HIV care. Researchers have argued that perceptions of HIV among health care workers and medical students have implications for the future clinical care of the disease (Martin & Bedimo, 2000; Patsdaugher, Grindel, O’Connor, & Miller, 1999). As treatment advances continue to improve health and longevity for people with HIV, the demand for HIV primary care services will also, by extension, continue to grow because the number of people with HIV gradually increases. Indeed, there are emerging concerns about an impending HIV workforce shortage in Australia (Mallitt, Jansson, Crooks, McGuigan, Wand, & Wilson, 2012), in the United States (Adams, Chacko, Guiton, & Aagaard, 2010) and the United Kingdom (Defty, Smith, Kennedy, Perry, & Fisher, 2010). In our study, we identified similar concerns about the sustainability and capacity of the HIV general practice workforce in Australia to care for people with HIV as this population grows, ages and moves increasingly outside of metropolitan areas (Newman, de Wit, Kippax, Reynolds, Canavan, & Kidd, 2012).

At the end of 2011, an estimated 24,700 people were living with a diagnosed HIV infection in Australia, which has a population of nearly 23 million. The country’s HIV epidemic can be described as low-level, relatively stable, and concentrated primarily among gay men in urban areas. However, over the past decade, surveillance data indicate that HIV infections are rising and that the demographic and geographical profile of the epidemic is gradually shifting (Kirby Institute, 2012). This will have increasing implications for HIV medical care in different parts of Australia (Carman, Grierson, Pitts, Hurley, & Power, 2010). HIV care is currently provided in a range of settings, including public hospital outpatient units and sexual health

centres. However, a special feature of the Australian approach is that care is also available from general practitioners (GPs) working in private community-based medical practices (Pell, Donohoe, & Conway, 2008). Approximately 120 GPs across Australia are currently accredited to prescribe HIV medication, which amounts to less than 1% of the total GP population nationally (Australasian Society for HIV Medicine, 2013).

Interviews with key stakeholders who participated in the first phase of our study suggested that “the ways in which HIV medicine is ‘represented’ (or perhaps even socially constructed) will influence who wants to do that work” (Newman, Kidd, de Wit, Reynolds, Canavan, & Kippax, 2011, p. 1156). To explore this idea further, we consider a critical yet rarely examined perspective in the literature on social representations of HIV: that of GPs who provide care to HIV-positive people. Attitudes toward HIV and HIV patients among general health care workers have been reasonably well-documented (see Martin & Bedimo, 2000; Lawlor & Braunack-Mayer, 2004). However, little is known about how HIV doctors themselves perceive the virus and those affected by it, or indeed how they might make sense of stigmatising meanings that still linger even as the clinical prognosis of HIV has radically changed.

In our analysis of qualitative interviews with HIV GPs, we found that HIV continued to be positioned as a disease with a distinct capacity to resonate and ramify beyond the virus’ biological existence. However, HIV was no longer seen as giving rise to an “epidemic of signification” (Treichler, 1987), but rather to an epidemic of complexities and comorbidities. Our analysis also revealed an intricate tension between calls for greater mainstreaming of HIV medicine and an emphasis on HIV and its care as historically and socially unique. Understanding the perspectives of those who practice contemporary HIV medicine adds another important voice to the “social construction” of HIV, which can contribute to debates and strategies around how to develop and sustain a dedicated workforce in the primary care management of HIV.

An Epidemic of Signification

Across the Western world, the early epidemic gave rise to a plethora of biomedical and popular representations of the virus. The immense power of HIV to generate meanings was famously referred to by Paula Treichler in 1987 as “an epidemic of signification”. Treichler’s turn of phrase captured how the replication of the virus in people’s bodies was paralleled by the replication of a “dense discursive jungle” as society and scientists grappled with this new disease, wildly speculating how it spread, who was at risk and who was to blame (1987, p. 272). As she and other scholars (e.g. Clatts & Mutchler, 1989; Sontag, 1990) have noted, the enumerations were endless: God’s punishment, contagion, gay plague, decay, disintegration, death, invasion, warfare, battlefield, chaos, doom, promiscuity, deviance, decadence, perversity, zoophilia, carriers, perpetrators, victims, vectors, pariahs, lepers, terrorism, scientific experiment gone wrong, government plot, cold war conspiracies, and on it went.

As many scholars have observed, HIV’s intense symbolic resonance was embedded in a complex array of cultural anxieties and morally charged meanings around selfhood, corporality, suffering and mortality. Because of this capacity to evoke deep-rooted fears, HIV became invested with profound stigma. Risk and blame were deflected onto “others,” primarily onto already socially marginalized groups, following existing patterns of inequality and prejudice, such as homophobia, sexism and racism. Acquiring HIV thus became associated with particular identities (gay men, drug users, sex workers, blacks) rather than with particular practices, because these “others” were attributed with deviant characteristics (depravity, excess, perversion) that were deemed to be the source and conduit of the disease (Deacon, 2005; Gilman, 1988; Herek & Glunt, 1988).

A substantial body of research has shown that these stigmatising meanings were rife also within the health professions in western countries and constituted a critical barrier to working in

HIV medicine and caring for patients with HIV. Through to the late 1990s, numerous studies in the USA, Europe and Australia showed that, despite relatively high levels of knowledge about HIV and its transmission, the virus continued to evoke irrational fears of infection among some nurses, physicians and medical students. These studies also revealed widespread homophobic and judgmental attitudes toward marginalized populations most commonly affected by HIV, along with an unwillingness to provide HIV care, concerns around professional reputation and stigma by association (Bermingham & Kippax, 1998; Kopacz, Grossman, & Klamen, 1999; McCann, 1999; Morin, Obadia, Moatti, & Souville, 1995; Van Serveleen, Lewis, & Leake, 1988). A more recent U.S. study showed that although there had been a substantial reduction in homophobia among physicians since the 1980s, HIV-phobia remained relatively persistent (Smith & Mathews, 2007).

However, some past studies also found that more contact with HIV patients was associated with less prejudice (Bermingham & Kippax, 1998; McCann, 1997) and that initial fears around working with affected populations diminished as a result of clinical experience, which helped to humanize people with HIV (Patsdaughter et al., 1999). Conversely, as some researchers speculated, clinicians who were already non-judgmental of gay men and other affected groups were perhaps more likely to be drawn to work in the field of HIV to begin with (Bermingham & Kippax, 1998). Adding another layer to the picture, a multi-state U.S. survey conducted in the HIV treatment era suggested that reluctance to treat HIV patients was not associated with homophobia or fear of contagion as previous studies found, but was more likely related to a lack of training and a perception of HIV medical management as highly complex (Martin & Bedimo, 2000).

Given such findings, it is surprising that overall so little research attention has been given to those who have daily contact with HIV patients and are intimately involved in their care. A

few notable exceptions have examined clinicians' experiences in the so called post-AIDS period following the introduction of effective treatments in Australia (Lowth, Yallop, Reid, & Fitzgerald, 1999; Yallop, Lowth, Fitzgerald, Reid, & Morelli, 2002) the UK (Rosengarten, Imrie, Flowers, Davis, & Hart, 2004) and San Francisco (Gerbert, Bronstone, Clanon, Abercrombie, & Bangsberg, 2000). Ambivalence was a common theme in these studies. Although the clinicians clearly welcomed the dramatic changes brought about by treatments, they also expressed a sense of loss around the emotional intensity and pioneering spirit of the early epidemic. In their view, the post-AIDS epidemic had become less personal, more technical and defined by greater complexity and uncertainty for both clinicians and patients. Given that the epidemic has continued to change substantially since that time and is currently facing new challenges; it is timely to again examine the perspectives of those who are invested with the professional rights and responsibilities of determining what HIV means today as a clinical and public health issue.

Method

The HIV General Practice Workforce Project was a three-year Project Grant funded by the National Health and Medical Research Council. The aim of this project was to identify the factors that influence Australian GPs to pursue and sustain a special interest in HIV medicine across different caseload and geographical settings. Data included interviews with policy key informants (Newman et al., 2011; Newman et al., 2012) as well as with clinicians providing HIV care in general practice. Ethics approval was received from the National Research and Evaluation Ethics Committee of the Royal Australian College of General Practitioners and ratified by the Human Research Ethics Committees of participating universities.

To comprehensively address the aim of the research, our analysis of this data has focused on a range of complex and related dimensions of HIV care, which are presented in a series of published and forthcoming publications. In this article, we focus on the interviews conducted

with 31 GPs who were (at that time) actively engaged in providing HIV medical care and who had received special accreditation to prescribe HIV medications in general practice settings. In-depth interviews were conducted either in person (21) or by phone (10) between September 2010 and October 2011. We used a semistructured question guide to examine the career trajectories, motivations and experiences of these HIV GPs. All were offered AU\$150 reimbursement in recognition of lost income. Participants included 19 men and 12 women. Although not requested, more than half (18) offered a description of their sexual identity as gay (12) or heterosexual (6). Other demographics include age range (32-62; more than half aged 50 and older), and ethnicity (24 self-identified as Anglo-Australian; seven as Asian, European or Middle Eastern).

Almost all received their medical training in Australia, with the one exception also trained in an English-speaking developed country. Participants had experience in caring for people with HIV across all states and territories, but mainly in New South Wales, Victoria, Queensland and South Australia. Almost all (27) were based in metropolitan settings with the other four located in regional Australia. Slightly more than half (18) reported a high caseload of HIV positive patients, with the remaining (13) participants reporting fewer HIV-related consultations. In this article, we distinguish between GPs who became involved before (15) and after (16) the introduction of effective HIV treatments in 1996.

Christy Newman was responsible for overseeing participant recruitment, scheduling interviews, conducting most interviews, and managing interview transcription and de-identification. Asha Persson developed the analysis of these transcripts by identifying key themes and subthemes in the data and organising these into a meaningful coding framework. This process was informed by guidelines for thematic analysis (Braun & Clarke, 2006), identifying recurrent patterns in the data and testing these through comparison with variations both within potential themes and across the whole data set. The manuscript was then workshopped by the

writing team, drawing on the areas of expertise of each author including HIV prevention, care and treatment, HIV patient advocacy and community histories, and experiences of living with HIV. Rigour was ensured through an iterative process of discussion and revision, both within the writing team and in consultation with the study's Expert Committee including representatives of Australia's peak HIV and general practice organizations.

Results

Similarly to the HIV doctors who participated in a UK study conducted in the post-AIDS period by Rosengarten and colleagues (2004), the GPs in our study spoke about the current epidemic through “a historical lens” that served to contextualize how vastly different HIV and its care are today. Those who were involved in the early epidemic recalled their memories of that time, likening it to “a war” in which they were in constant “crisis mode.” It was an exhausting, stressful and confronting time for these early GPs, many of whom identified as gay, as they provided palliative care for dying peers and witnessed their communities go through enormous pain and grief amidst intense social hostility. It was widely agreed that the crisis changed with the advent of effective treatments in the mid-1990s and that, as one GP stated, “being an HIV doctor these days is, in a lot of ways, a lot easier”.

So Much More than a Virus

The sense of loss among clinicians in the post-AIDS era, which was identified by previous studies, was not expressed by any of the early GPs in our study. As one of those GPs put it, “I think the really exciting days are over, which is a good thing.” The “depression” and “impotence” that many recalled feeling in the face of the relentless death and suffering of that era had now been replaced by a great sense of satisfaction of being able to help people with HIV live healthy, full lives. However, excitement was far from absent in the interviews, but emerged as a prominent theme among all GPs, regardless of when they began this work. HIV medicine was

repeatedly described as an exciting, intellectually stimulating and constantly evolving field. HIV was seen as a “fascinating infection” and there was strong sense of being part of something historically unique. This was an especially poignant theme among those who had personally seen the epidemic change over time:

It’s been an extraordinary thing to watch. I mean there aren’t many areas in medicine [that] have made such enormous change that you could have been involved with, so it’s been fantastic to see, you know, patients who were on death’s door for years and now at the gym with you ... It has been an amazing area of medicine from that point of view ... I can’t think of one other disease that it’s been so rewarding to be involved with, in a way, because I mean we’ve had a turnaround that you would never have envisaged ... I think there are still challenges, you know, happening and there’s a lot of new stuff happening ... It’s certainly an interesting field to be involved in.

The transformation of HIV from a terminal to a chronic condition was a common theme across the interviews, with much emphasis on people with HIV now being able to live more or less normal lives. However, as the above extract also hints, although the disease has become incomparably more manageable, HIV was not considered either uncomplicated or ordinary. Similarly to Treichler’s conceptualization, HIV was presented as highly productive in the interviews. However, in contrast to the excessive meanings and metaphors that HIV generated in the early epidemic, the virus was described by the GPs as now generating a proliferating range of complications and comorbidities, including “other chronic illnesses – cardiovascular, renal, bone issues.” HIV was referred to as a “multi-organ” condition that continued to surprise and evolve as people live longer with the virus, affecting not only parts of the body in new and unexpected ways, but other dimensions of life too.

It's still exciting. I think following through, this is I guess the first time in the history of HIV [that] we are seeing people growing old with it and we are seeing things that . . . we weren't able to predict or we didn't understand.

It does branch into every aspect of life, it's, you know, it's a bit of sexual health, it's a bit of public health, it's a bit of medicine, it's a bit of, you know, social work, it's a bit of, there's a bit of fun involved . . . I mean there's not too many chronic illnesses like that, I don't think.

Ageing was singled out as an area of increasing focus and significance in HIV care today, partly because people with HIV are now growing older for the first time in the epidemic and partly because HIV tends to accelerate ageing. This places people with HIV at greater risk than their non-infected peers of age-related complications and organ damage, such as heart disease and cognitive impairment. As one participant put it, this meant that HIV GPs now had to “become geriatricians as well.” In other words, as more ramifications of the virus unfolded, HIV had to be re-situated within additional domains of medicine beyond sexual health and infectious disease.

Another critical ramification mentioned by many GPs was the psychosocial dimension of HIV. This was by no means considered a new concern, but rather “an integral part of looking after people with HIV.” However, it was seen as producing added challenges today because of its intersection with ageing and longer life-spans, giving rise to a growing cohort of clients who struggled with issues such as poverty, social isolation, depression, drug use and the traumatic legacy of the early epidemic.

I mean there have always been huge mental and psycho-emotional issues related to HIV and AIDS, so that's never gone away. But it has, the focus has changed with that, I suppose; maintaining people in that sense. So, you know, there's a huge amount of psychiatry and social work that comes with this as well.

To these GPs, the psychosocial dimensions of HIV meant that the provision of HIV care involved far more than “just looking at the purely medical stuff,” as one GP put it. On the whole, as we have outlined, contemporary HIV medicine was construed as comprising “pretty much a bit of everything,” because as the virus extended in time, so did its many and unforeseen upshots. This capacity of HIV to be “more than a virus” (AIDSImpact, 2011) generated new or added challenges for the GPs in terms of the knowledge and care required of them. However, as we discuss below, it also generated what many valued as the most unique aspects of their work.

“Travelling the Road” with a “Unique Set of People”

The GPs described their HIV-positive patients in a similar fashion to how they described the disease itself: as interesting, challenging and changing. The vast majority nominated their relationship with their patients as one of the greatest motivations and rewards of working in HIV medicine. “What's actually kept me here: it's the patients and that commitment to patients; basically . . . you're part of their lives.” The GPs' sense of privilege at being involved with a disease that had undergone such an unprecedented historical transformation was echoed in their sense of satisfaction of being involved in the longitudinal care of their patients, or as one GP elaborated:

The opportunity to be engaged with the patient over a prolonged period of time through multiple parts of their lives, and that's, you know, rewarding and a great privilege . . . It's very worthwhile to be able to assist them and support them, encourage them, play a part.

This continuity in care held particular significance for those who were still caring for patients whom they had diagnosed in the eighties. However, metaphors such as “travelling” and “journey” were common across all the interviews and were used by GPs to describe the often intimate and emotional experience of seeing their patients improve with time, not only clinically but in their lives more broadly.

Seeing people have more insight into their condition and managing it well, and achieving, and doing things in their life they want to do. Getting over their own personal prejudices or self-doubt, or and yeah, gaining in the health outcomes . . . So you probably get closer to your patients here, in a degree, because you’re along the journey with them for a longer period of time . . . So there’s the capacity to get more satisfaction seeing personal growth in that setting.

Travelling the road with patients from diagnosis . . . it’s been rewarding in seeing people change and evolve and accept their HIV and partnerships. And in women [who] have children and become pregnant, and have uninfected children and relationships.

What really stood out in these interviews was the reiteration of a unique relationship that, like the productive capacity of the virus itself, went beyond the clinical space and bore little resemblance to the impersonal professionalism so often said to define clinical interactions. As one GP stated, “I feel a huge bond with a lot of my patients,” echoing the closeness and trust that people with HIV have similarly emphasized as one of the most valued aspects of their relationship with a primary care giver (Mallinson, Rajabiun, & Coleman, 2007; Roberts, 2002; Persson, Richards, Barton, & Reakes, 2009).

Well, the relationships that you establish with patients that can, that's very special I think . . . It's a very personal practice. I mean people let you into their lives and it's extraordinary what they tell you and what you share . . . You develop wonderful relationships with people.

I love this area . . . The main thing for me is the interactions, the rapport that I have with my patients . . . Most patients that I have end up staying with me because we've travelled this together. And that is a rewarding thing for me.

In stark contrast to the intense demonization of people with HIV that dominated public discourses in the early epidemic, and the more restrained "othering" that continues today, most GPs spoke about their patients with great affection. They described them as "delightful," "lovely," "fascinating," "real characters" and "great people" with "a right to human dignity;" words that quite consciously pushed back against the long history of stigmatising representations. As one GP emphasized: "They're really nice people, which I think is what would surprise some of the people who are so condemning. They don't realize that these are decent people." Illustrating how contact with people with HIV can dispel prejudices among health workers, another GP recounted having his preconceptions disproved when entering HIV medicine in the 2000s: "I thought they're going to be all difficult, manipulative and a little bit weird . . . But it's not like that . . . They're just you and me. They're just people with general needs."

The insistence that HIV patients are "just people" not only carries political import in view of the epidemic's dark history, but also places the patients squarely within the domain of general practice. Juxtaposed with this, however, were other themes that made clear that most GPs saw their patients as far from "ordinary." They spoke about them with a great deal of admiration and

respect, as a distinct group that courageously lived with HIV in the face of stigma, uncertainty and often social disadvantage.

You do get to work with a pretty unique set of people who can really teach us a lot about tolerance, you know, and learning to live with ill health or uncertainty. You know, a lot of these men have been diagnosed in their twenties, thirties and, you know, still braving it twenty years later. I think that's amazing.

However, the entwinement of HIV with psychosocial ramifications was also seen by many GPs as one of the major challenges of working with affected populations. As exemplified by the two quotes below, they described a sub-set of patients with “high and complex” needs and for whom socioeconomic marginalization, drug use or mental health issues converged to complicate or disrupt clinical plans and delivery of care:

Probably the biggest challenges are some of the patients; let's just say probably personality disorders or people who are IV drug users. They're the biggest challenges because [of] trying to keep them adherent to the medications and trying to keep tabs on what they're doing and where they are.

And then there's the challenges of looking after a group of people, some of whom are very disadvantaged, who may be infrequent attenders who, despite your best efforts, may not follow your clinical plans . . . [So the] outcomes are not always good.

These diverse circumstances among their patients were seen by some GPs as a direct argument against the historical tendency to generalize people with HIV: “I don't think we'd want to stereotype this group at all,” as one GP stated. Others referred to significant differences in

needs between the newly diagnosed and those who had lived with HIV for a long time, between younger and older patients, and between the experiences and expectations of those in resourced urban areas with large affected populations and those who lived in regional areas.

A related theme was the changing demographics of the epidemic. Most GPs still saw predominantly gay clients, reflecting the enduring epidemiology in Australia. However, some reported an increase in young people, women, and migrants from culturally diverse backgrounds, particularly from African countries with high prevalence of HIV. Several GPs predicted that the epidemic would continue to develop in these directions and pointed to stark differences between these older and newer patient groups. Whereas inner-city gay men were often described as “well-informed” and “easy” patients who were “equal partners in their care,” other populations were seen as having far more challenging needs and a very different experience of living with HIV:

I have sort of different kind of sub-groupings of patients with HIV. And some of them are, you know, the very well educated, well read, reading up on new stuff all the time, keeping really abreast of it . . . And the other group I see is a lot of sort of like African, ex-refugee type women and they know nothing. So they're much more dependent on me . . . They are in need of lots of support. And they tend to come to me for everything, whether that be, you know, forms for housing through to, you know, support letters to get a sister out for immigration or . . . They're terrified of going to any other agencies if their HIV status might somehow or other be declared . . . I mean they've got a different set of issues, but those ones can be quite challenging and this feeling that you've got to fix it up because nobody else is going to.

The narratives in this section point to HIV as highly productive, not only in terms of comorbidities, but in terms of giving rise to unique relationships and forms of care. The GPs

spoke warmly about their patients as exceptional and courageous, while also presenting them as “just people” and as being far more diverse than old stereotypes would have it. Next, we examine these themes in relation to Sontag’s hypothesis and contemporary HIV care.

No Ordinary Mainstream Disease

Read against Sontag’s anticipation of a future reframing of HIV, the interviews revealed an intriguing tension between describing HIV as normal yet special; between wanting to mainstream the disease versus emphasising its distinct care needs; between positioning HIV as just another chronic illness versus highlighting its extraordinary history and the continuing stigmatization and marginalization of those affected. At first glance, there seemed to be a strong narrative among some GPs that the specialized care that was once required was no longer warranted:

From the nineties it was a very specialized, it was a very isolated and specialized care of people who were dying. And I think now HIV care is very mainstream and should be more mainstream, and there should be more GPs who actually can do it.

This concept of HIV as somehow unique and isolated, I don’t see it as . . . It’s one of many chronic diseases and the more we mainstream it, I think the more people integrate into the existing services, the better the care can be.

However, careful reading suggested that normalising narratives of HIV as “just another thing” were often invoked less as a reflection of reality than as a political counterpoise against the homophobia and otherness that have so profoundly segregated HIV over the years, as the following quote makes clear.

You should graduate with that ability the same as if you have to treat someone who has got diabetes or got some other condition that you’ve learnt all about at med school . . .

Why does there have to be this extra course? Why is it so special and different? That annoys me because it does place it in this “other” basket: “Oh, it’s separate. You don’t really need to know about it.” And to me that stems from homophobia.

Although many GPs thought that HIV had indeed become more accepted, as Sontag hoped it would one day, the vast majority described HIV as still relatively stigmatized and misunderstood, including in parts of the general health sector. Contrary to Sontag’s predictions, effective treatments and increased knowledge had not been quite enough to bring to an end HIV’s fraught history and turn it into “just an illness.”

I think there is a lot of stigma still . . . A lot of patients with HIV choose to hide their status from their regular general practitioner. They live out in the suburbs and they will see a general practitioner and disclose all apart from this . . . because the patient or the client doesn’t feel safe to disclose that to local people, to the local health provider services.

There is still overt discrimination against people who are HIV positive . . . I see it regularly within the hospitals. I see it regularly within general practice. And I just, it drives me to absolute tears because they’re so stupid. And it just illustrates the ignorance of some of our doctors that people can be so ignorant as to not be able to understand people because they’re, they’ve got this disease in front of them.

There was a sense that although HIV had become far less invested with negative meanings, it had not been reframed by a more informed discourse so much as having “fallen off the radar” of public consciousness. As a result, many GPs believed that the community remained

largely ignorant about HIV and that prejudices were still “lurking there under the surface,” ready to manifest periodically in media commentaries or in criminal prosecutions for HIV-related offences. This lingering stigma, buttressed by public apathy and the lack of a public reframing of the virus, was seen as an enduring barrier to HIV becoming just another illness:

It’s part of the package that can be trotted out when politicians and social commentators are seeking to inflame a bit of divisiveness. So I don’t think in that sense that it’s become as mainstreamed . . . I still think there’s that thing between mainstreaming it as a disease and wanting to be, you know, viewed as just part of the society plus that thing about, “but we need a bit of extra special care.” And I think it still does . . . because of the societal stuff around the disease; it does still need some special attention.

The notion of HIV as qualitatively different from other chronic conditions became even more evident when the GPs were asked how they thought their work might be perceived by others. Whereas family members and friends were generally seen as supportive and proud of their work, two contrasting themes emerged in relation to medical practitioners outside of HIV medicine. Some described other practitioners as “envious” of their “exciting” line of work, or full of awe and admiration that they had chosen such a “noble” and “difficult” field of medicine, or else voyeuristic and “curious” because of HIV’s continued status as “a bit of mystery illness.”

I think they’re marginally jealous. Because we were right, you know . . . You can’t catch it off a patient, they’re not dangerous, it wasn’t futile, you know? It’s, yeah, it’s good. It’s a little bit of “ooh” and “aah.” Still a little bit of dinner party conversation, you know. You mainly talk about your more flamboyant cases rather than the crisis, which is, you know, well and truly over.

I've been at medical reunions, basically, where my colleagues that I trained with squillions of years ago said, "Wow! How lucky you are to do the type of work you're doing. We're stuck in rheumatology," or, "We're stuck in this," or "We're stuck in that. How exciting what you're doing." And I said, "Yes, it's more than interesting."

Others relayed being met with prejudices or perplexed reactions and even pity by colleagues who perceived HIV as being on the "unglamorous side of medicine," as one GP put it. Several noted that the stigma and homophobia that still surround HIV in society and in the broader health sector sometimes extended also to those working in this field, describing what sociologist Erving Goffman (1963) referred to as "courtesy stigma."

I still think there's a significant amount of stigma and fear in the community. And I think that health professionals that choose to work in this area often share in some of that stigma . . . There are some so-called conservative parts of the community that are still apprehensive, fearful and discriminatory, and stigmatising toward HIV. And the whole domain of HIV. And that has, that also includes health professionals that work in the field.

There's that thought that, "Oh, he must have HIV because he works with people with HIV." Or, "She must be a drug user because all her patients are."

It is noteworthy that courtesy stigma was more pronounced among heterosexual men, women, those in regional areas, and newer GPs, partly echoing a U.S. study by Reece and colleagues (2007). One possible reason is that non-gay HIV GPs in Australia are less likely to work in inner-city high caseload clinics in the heart of gay communities and more likely to work

in environments less sheltered from uninformed or prejudiced attitudes. Despite such variations, the GPs shared the impression that others perceived them as being different and outside of mainstream general practice by virtue of their HIV work. They countered this by arguing that because the implications of HIV are many and varied, general practitioners are ideally suited to provide care to people with HIV.

Concluding Remarks: An Epidemic of Complexities

If HIV has not yet become “just an illness,” then what is it? One word that for many GPs seemed to capture the contemporary epidemic was “complexity.” The studies cited in the background section found that this word was commonly used to describe the new world of treatments and side effects in the post-AIDS era. However, in this study it took on broader meaning. The theme of complexity dominated across the interviews as both experienced and newer GPs talked about how the disease itself, along with treatments, patient needs and demographics were continually changing and diversifying, posing new challenges in term of care and knowledge.

This complexity called for time-consuming and multi-layered consultations. As one GP explained, “we’ve got to look at how the whole person operates.” Or as another GP stated: “You can’t do HIV in five or ten minutes. It’s much more broad than that.” The participants spoke at length about trying to juggle and address the many and diverse needs generated by the comorbid capacity of HIV—“be they medical, social, psychological.” The skills and time required to address this epidemic of complexities were widely seen as poorly remunerated and at times emotionally taxing. However, in nearly all the interviews, the tendency of HIV to branch into so many dimensions of human life was rendered as both the most challenging and rewarding aspect of their work. When asked what advice they would give other GPs or medical students who might consider entering this field, it was precisely this complexity that many highlighted:

If you want to have complex patients who require a lot of thought and that's what stimulates you about being a doctor then you'll do HIV . . . You've got to look at where your philosophy is. So it's a philosophical stand . . . It's complex. But you're a doctor; you should be able to deal with complexity. So yeah, it's very satisfying. Very rewarding. Not financially rewarding, but very rewarding from the point of view of keeping people well, dealing and knowing things that can go wrong and being able to recognize them and deal with them.

This quote provides a fitting segue into our concluding remarks about the contemporary meanings of HIV and the future of the HIV clinical workforce. The themes of complexity and comorbidity in the interviews had certain resonance with Treichler's "epidemic of signification" in that they revealed the enduring capacity of HIV to be more than a virus. However, the GPs' renderings of HIV also departed from the negative gist of Treichler's concept in crucial ways. The dehumanising meanings and metaphors embodied in her description of the early epidemic have faded—though not disappeared as Sontag hoped—and thus opened up space for alternative meanings to surface. One of the most important yet largely unacknowledged significations to emerge in our analysis was the way the dark but also extraordinary history of HIV had produced a unique legacy of holistic and long-term care in the Australian setting, often underpinned by deeply personal and valued doctor-patient relationships that, like the disease itself, were considered far from ordinary in a general practice context.

In the literature on social representations of HIV, scant attention has been given to how doctors in this field experience their engagement with the epidemic personally and professionally, or how they make sense of the virus and affected populations. Given that previous research has shown that perceptions of HIV and lack of contact with HIV patients can constitute barriers to

health workers' willingness to provide HIV care, the perspectives of doctors who do provide such care today can critically contribute to the social reframing of HIV and, consequently, to strategies to recruit and sustain a dedicated HIV workforce in Australia and elsewhere.

The core message we can draw from the interviews examined here is that taking on the complexity of HIV involves not only proper medical training and knowledge but, as the GP observed above, it also requires a kind of “philosophical” commitment to the ethos of HIV care. Because of its unusual and turbulent history, HIV is not “just an illness” that requires a bit of care. The management of chronic HIV infection is only sustainable through a genuine capacity for continuity of care and the willingness of GPs to be the anchor for that care; the point of security and connection even as HIV extends, at times unpredictably, beyond itself into multiple dimensions of medicine and life. However it is precisely this dynamic, according to these GPs, which makes HIV medicine such an exciting and rewarding field of medical practice for the primary care practitioner.

Our findings are not necessarily representative or generalizable. The findings need to be situated in their specific epidemiological and cultural context, but they nonetheless provide a unique opportunity to learn from those who provide HIV care in general practice settings. Their views can contribute to emerging and important debates about how to plan for and facilitate the delivery of HIV care also in other cultural and country settings that face a looming imbalance between supply and demand. As with any research, our analysis is far from exhaustive and future research could usefully explore the perceptions of HIV among doctors working in different settings and with different kinds of epidemics, but also the relationship between HIV GPs and other clinicians, including other medical specialists and allied health workers in and outside of HIV medicine.

Another relationship that received some critical attention in the 1990s and 2000s, but which could benefit from being revisited in new light, is that between HIV doctors and people living with HIV, especially those from marginalized or migrant communities and those in regional areas that tend to be less well-engaged with concentrated delivery sites for HIV care. Such analyses would help to highlight and address shifting discourses and points of tension in HIV care, especially at a time when both HIV doctors and people with HIV in Australia and elsewhere are facing not only local changes and challenges in the epidemic, but also unknown ramifications from the recent global commitment and bold approach to end the HIV epidemic in our lifetime (Whittaker, 2011; Australian Antiretroviral Guidelines Panel & Australasian Society for HIV Medicine, 2012; United Nations General Assembly, 2011).

References

- Adams, J., Chacko, K., Guiton, G., & Aagaard, E. (2010). Training internal medicine residents in outpatient HIV care: A survey of program directors. *Journal of General Internal Medicine*, 25(9), 977-981. Retrieved from <http://link.springer.com/article/10.1007%2Fs11606-010-1398-6?LI=true>
- Australian Antiretroviral Guidelines Panel & Australasian Society for HIV Medicine (2012). *ARV guidelines with Australian commentary*. Retrieved from <http://arv.ashm.org.au/>
- Australasian Society for HIV Medicine (2013). *HIV prescriber program*. Retrieved from http://www.ashm.org.au/default2.asp?active_page_id=277
- Bermingham, S., & Kippax, S. (1998). HIV-related discrimination: A survey of New South Wales general practitioners. *Australian and New Zealand Journal of Public Health*, 22(1), 92-97. doi:10.1111/j.1467-842X.1998.tb01151.x
- Braun, V., & Clarke, V. (2006). Using thematic analysis in qualitative psychology. *Qualitative Research in Psychology*, 3(2), 77-101. doi:10.1191/1478088706qp063oa
- Carman, M., Grierson, J., Pitts, M., Hurley, M., & Power, J. (2010). Trends in the location of the HIV-positive population in Australia: Implications for access to healthcare services and delivery. *Sexual Health*, 7(2), 154-158. doi.org/10.1071/SH09063
- Clatts, M. C., & Mutchler, K. M. (1989). AIDS and the dangerous other: Metaphors of sex and deviance in the representation of disease. *Medical Anthropology*, 10, 105–114. doi:10.1080/01459740.1989.9965956
- Deacon, H. (2005). *Understanding HIV/AIDS stigma: A theoretical and methodological analysis* [HSRC Research Monograph]. Cape Town: HSRC Press.

- Defty, H., Smith, H., Kennedy, M., Perry, N., & Fisher, M. (2010). GPs' perceived barriers to their involvement in caring for patients with HIV: A questionnaire-based study. *British Journal of General Practice*, 60, 348-351. doi:10.3399/bjgp10X501840
- Gerbert, B., Bronstone, A., Clanon, K., Abercrombie, P., & Bangsberg, D. (2000). Combination antiretroviral therapy: Health care providers confront emerging dilemmas. *AIDS Care*, 12(4), 409-421. doi:10.1080/09540120050123819
- Gilman, S. (1988). *Disease and representation: Images of illness from madness to AIDS*. London: Cornell University Press.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. London: Penguin Books.
- Herek, G., & Glunt, E. (1988). An epidemic of stigma: Public reactions to AIDS. *American Psychologist*, 43(11), 886-891. doi:10.1037/0003-066X.43.11.886
- Hutton, V., Misajon, R., & Collins, F. (2013). Subjective wellbeing and 'felt' stigma when living with HIV. *Quality of Life Research*, 22(1), 65-73. doi:10.1007/s11136-012-0125-7
- Kinsler, J., Wong, M. D., Sayles, J. N., Davis, C., & Cunningham, W. E. (2007). The effect of perceived stigma from a health care provider on access to care among a low-income HIV-positive population. *AIDS Patient Care and STDs*, 21(8), 584-592. doi:10.1089/apc.2006.0202
- Kopacz, D. R., Grossman, L. S., & Klamen, D.L. (1999). Medical students and AIDS: Knowledge, attitudes and implications for education. *Health Education Research*, 14(1), 1-6. doi:10.1093/her/14.1.1
- Lawlor, A., & Braunack-Mayer, A. (2004). Doctors' views about the importance of shared values in HIV positive patient care: A qualitative study. *Journal of Medical Ethics*, 30, 539-543. doi:10.1136/jme.2002.001560

- Lowth, A., Yallop, S., Reid, J., & Fitzgerald, M. (1999). Looking beyond the optimism surrounding new treatments: Issues for HIV service providers and people living with AIDS. *Australian Social Work*, 52(3), 31-36. doi:10.1080/03124079908414133
- Mallinson, K., Rajabiun, S., & Coleman, S. (2007). The provider role in client engagement in HIV care. *AIDS Patient Care and STDs*, 21(s1), S77-S84. doi:10.1089/apc.2007.9984
- Mallitt, K-A., Jansson, J., Crooks, L., McGuigan, D., Wand, H., & Wilson, D. (2012). Demand for HIV clinical services is increasing in Australia but supply is decreasing. *Sexual Health*, 10(1), 43-46. doi: <http://dx.doi.org/10.1071/SH12051>
- Martin, J. E., & Bedimo, A. L. (2000). Nurse practitioner, nurse midwife and physician assistant attitudes and care practices related to persons with HIV/AIDS. *Journal of the American Academy of Nurse Practitioners*, 12(2), 35-41. doi:10.1111/j.1745-7599.2000.tb00281.x
- McCann, T. V. (1997). Willingness to provide care and treatment for patients with HIV/AIDS. *Journal of Advanced Nursing*, 25, 1033-1039. doi:10.1046/j.1365-2648.1997.19970251033.x
- McCann, T. V. (1999). Reluctance amongst nurses and doctors to care for and treat patients with HIV/AIDS. *AIDS Care*, 11(3), 355-359. doi:10.1080/09540129947974
- Morin, M., Obadia, Y., Moatti, J-P., & Souville, M. (1995). Commitment, value conflict and role strains among French GPs in care for HIV positive patients. *AIDS Care*, 7(Suppl. 1), S79-S83. doi:10.1080/09540129550126867

Newman, C. E., de Wit, J. B. F., Kippax, S. C., Reynolds, R. H., Canavan, P. G., & Kidd, M. R.

(2012). The role of the general practitioner in the Australian approach to HIV care:

Interviews with 'key informants' from government, non-government and professional

organisations. *Sexually Transmitted Infections*, 88, 132-135. doi:10.1136/sextrans-2011-

050130

Newman, C. E., Kidd, M. R., de Wit, J. B. F., Reynolds, R. H., Canavan, P. G., & Kippax, S. C.

(2011). What moves a family doctor to specialise in HIV? Interviews with Australian

policy key informants. *Culture, Health & Sexuality*, 13(10), 1151-1164.

doi:10.1080/13691058.2011.607904

Patsdaughter, C., Grindel, C., O'Connor, C., & Miller, K. (1999). Students' decisions to select

HIV services for clinical experiences. *Nurse Educator*, 24(3), 35-39. Retrieved from

http://journals.lww.com/nurseeducatoronline/Abstract/1999/05000/Students__Decisions_to_Select_HIV_Services_for.14.aspx

Pell, C., Donohoe, S., & Conway, D. (2008). Health care services for men who have sex with

men in different Australian states and territories since the emergence of HIV. *Sexual*

Health, 5(2), 161-168.

Persson, A., Barton, D., & Richards, W. (2006). *Men and women living heterosexually with HIV:*

The Straightpoz study, volume 1. Sydney: National Centre in HIV Social Research, the University of New South Wales.

<http://nchsr.arts.unsw.edu.au/pdf%20reports/Straightpoz.pdf>

Persson, A., Richards, W., Barton, D., & Reakes, K. (2009). *Men and women living*

heterosexually with HIV: The Straightpoz study, volume 2. Sydney: National Centre in

HIV Social Research, the University of New South Wales.

<http://nchsr.arts.unsw.edu.au/pdf%20reports/Straightpoz2.pdf>

- Reece, M., Tanner, A., Karpiak, S., & Coffey, K. (2007). The impact of HIV-related stigma on HIV care and prevention providers. *Journal of HIV/AIDS & Social Services*, 6(3), 55-73. doi:10.1300/J187v06n03_05
- Roberts, K. J. (2002). Physician-patient relationships, patient satisfaction, and antiretroviral medication adherence among HIV-infected adults attending a public health clinic. *AIDS Patient Care and STDs*, 16(1), 43-50. doi:10.1089/108729102753429398
- Rosengarten, M., Imrie, J., Flowers, P., Davis, M., & Hart, G. (2004). After the euphoria: HIV medical technologies from the perspective of their prescribers. *Sociology of Health & Illness*, 26(5), 575-596. doi:10.1111/j.0141-9889.2004.00406.x
- Sayles, J., Ryan, G., Silver, J., Sarkisian, C., & Cunningham, W. (2007). Experiences of social stigma and implications for healthcare among a diverse population of HIV positive adults. *Journal of Urban Health*, 84(6), 814-828. doi:10.1007/s11524-007-9220-4
- Siegel, K., & Lekas, H-M. (2002). AIDS as a chronic illness: psychosocial implications. *AIDS*, 16, S69–S76. Retrieved from http://journals.lww.com/aidsonline/Citation/2002/16004/AIDS_as_a_chronic_illness__psychosocial.10.aspx
- Smith, D. M., & Mathews, C. (2007) Physicians' attitudes toward homosexuality and HIV: Survey of a California Medical Society – revisited (PATHH-II). *Journal of Homosexuality*, 52(3/4), 1-8. doi:10.1300/J082v52n03_01
- Sontag, S. (1990[1989]). *Illness as metaphor* and *AIDS and its metaphors* (combined edition). New York: Anchor Books, Doubleday.
- Treichler, P. (1987). AIDS, homophobia, and biomedical discourse: An epidemic of signification. *Cultural Studies*, 1(3), 263-305. doi:10.1080/09502388700490221

- United Nations General Assembly (2011). *Political declaration on HIV and AIDS: Intensifying our efforts to eliminate HIV and AIDS*. Retrieved from http://www.unaids.org/en/media/unaids/contentassets/documents/document/2011/06/20110610_un_a-res-65-277_en.pdf
- Van Serveleen, G. M., Lewis, C. E., & Leake, B. (1988). Nurses' knowledge, attitudes, and fears about AIDS. *Journal of Nursing Science and Practice*, 1(3) 1-7.
- Yallop, S., Lowth, A., Fitzgerald, M. H., Reid, J., & Morelli, A. (2002). The changing world of HIV care: The impact on health professionals. *Culture, Health & Sexuality*, 4(4), 431-441. doi:10.1080/13691050110149918
- Whittaker B. (2011). Australia should lead a global HIV prevention revolution. *HIV Australia*, 9, 7-8. Retrieved from <http://www.afao.org.au/news/archive/australia-should-lead-a-global-hiv-prevention-revolution>