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The Changing Worlds
of HIV Medicine
and the General
Practitioners who
Provide it**

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Workforce Worries: The changing worlds of HIV medicine and the general practitioners who provide it

Christy Newman

Introduction

HIV medicine has changed since the early years of the epidemic. Doctors no longer have nothing to offer, and their patients are not necessarily going to die of an AIDS related illness, at least not if they have continuing access to effective treatments. The world of the general practitioners (GPs) who provide HIV care has also changed: this is no longer a frontline emergency. In fact HIV is often now described as a manageable, chronic condition; as routine and relatively predictable, with genuine hope for the future.

So why then, in the face of all this scientific and clinical optimism, is there a nervousness building about where the next generation of HIV doctors is going to come from? If the medicine works so well, why are we starting to worry about how to find the doctors to provide it?

There are two parts to my paper, both relating to the question of how an individual becomes engaged in an area of professional interest. The first part involves some reflection on my own experience of becoming engaged with HIV as an area of research interest, and the second part focuses on the experiences and roles of GPs who have a special interest in HIV medicine in Australia, and why I think they matter.

Becoming 'engaged' in HIV as an area of research interest

In 1987, I was in my final year of primary school in Fremantle, Western Australia; I was extremely proficient in choreographing my own dance routines to The Bangles, George Michael and the like. This was also the year that Kylie got married on Neighbours, and that Countdown broadcast its final show. But 1987 is also significant as the year that I, and many other people around Australia, was first introduced to the idea that a new era in infectious disease was upon us. The now infamous Grim Reaper campaign has been much discussed since it was broadcast, with debate often focusing on the controversial use of fear as a health education strategy, and the inadvertent stigmatising of gay men, who were by association implicated in the 'bowling down' of 'innocent' members of the community. Without going into those debates, the point I want to make is that HIV was first introduced into my life – and the lives of many other people around Australia – as a *representation*.

HIV was not meaningful to me as a health issue affecting me, or someone I loved, or as a feature of the place I lived or the world I occupied. Rather, all I really knew of this thing called HIV – or at that stage AIDS – was a set of carefully constructed media images and ideas, deliberately designed to evoke an emotional response that would frame HIV as a national emergency. The campaign was so successful in achieving this that even people who were born *since* this campaign was broadcast still make reference to the Grim Reaper if asked what they know of HIV¹. My interest in these kinds of images and their meanings is probably quite revealing of my undergraduate degree in communication and cultural studies from Murdoch University, which continues to influence the way that I frame and approach my research. But HIV meant little to me in a personal or professional sense until I started a PhD in 2000 with an ex-Murdoch lecturer of mine (Professor Catherine Waldby) at the National Centre in HIV

Social Research at The University of New South Wales. My PhD looked at the cultural politics of reader letters in popular health magazines such as *Men's Health*² and *Nature & Health*³, as well as community magazines produced by and for populations affected by HIV and related diseases including *Talkabout* (people living with HIV), *The Professional* (sex workers) and *Users' News* (illicit drug users)⁴. This inspired a continuing research interest for me regarding the discursive constitution in media texts of health issues such as HIV and their imagined publics⁵.

But I'm skipping ahead a bit, because something else is important to this issue of how I became 'engaged' in an area of professional interest like HIV. I knew almost no-one when I moved to Sydney in 1998, and in looking for things to fill my time, I answered an ad in the *Sydney Star Observer* for volunteer carers at CSN – Community Support Network – which provides home-based care to people living with HIV. This organisation began in the early years of the epidemic as an informal network of friends and carers who were getting together to help their loved ones come home from hospital to die. By the time I became a volunteer in 1998, the organisation was much more formalised, with clients and carers matched on the basis of their needs and availability, and care focused on providing practical help around the house: cleaning, shopping, cooking, getting to appointments, and so on. This shift speaks in some ways to the increasing successes that new combination HIV therapies were having by that time. Nonetheless, in my experience, the people who I came to know through CSN either on a regular or a short-term basis were usually not at all well. Most had been living with HIV for many, many years. They were often very poor, quite isolated, and dealing with a whole range of physical and mental health issues which were extremely challenging. So I had the opportunity to come to learn a little more about HIV, and in particular, to become interested in how it was possible that this virus could have been so invisible in my world to that point, when it had so completely changed the worlds of the people I now knew.

When I started working at NCHSR as a contract researcher in 2004, HIV became something that I would think about in my working life each day, it formed the backbone to a program of research and writing that I found I loved. So I see my professional engagement in this field as being partly due to my own interest and experiences in the community, but very much also due to the opportunities that my colleagues and mentors provided me at NCHSR. In those first few years as an 'early career researcher', I had begun to conceive and develop a few of my own areas of research interest, which included HIV in the media. But I was also very busily going about the process of conceiving, carrying, birthing and raising two rather boisterous young girls. Throughout this time, my involvement in HIV was sustained really by sheer luck in the timing of my research contracts, which gave me some continuity of employment through a period of considerable uncertainty. But this involvement was also sustained by my own interest in staying involved, and that was in large part because I had stumbled upon a topic area that I was able to turn into the start of my own program of research. So this is where I want to start talking about GPs.

The first time that I interviewed a GP was when I was employed by Professors Susan Kippax and Michael Kidd to work as a Research Fellow on the Primary Health Care Project on HIV and Depression in 2006. This was a wonderful project (funded by the National Health and Medical Research Council) which examined the diagnosis and management of depression among HIV positive and negative gay men with a particular interest in how those issues were negotiated in general practice settings. This included

interviews with both doctors and patients, and so I got the opportunity – six months pregnant at the time – to go out and interview doctors working in high HIV caseload practices in Sydney, Adelaide and a rural-coastal city in New South Wales.

When I tell people today that I do quite a lot of research with doctors, a common response is: 'Wow, that must be awful!' And I never fail to be surprised by that. I find talking to doctors to be genuinely fascinating. I really hadn't spent any time thinking about GPs or any other doctors, up to that point, apart from feeling very fond of my own GP. But I found that I loved this research. I loved thinking about the way that these doctors talked about their patients, the careful language they used, the assumptions they made, and the aspects of our discussion which seemed to be harder for them to participate in at times.

As part of that first set of interviews, I also became aware that my questions about depression were often answered by talking about the more general experience of being a doctor. So for the first time, I started to think about workforce. Here is a quote from one of the papers we published from that study to show you what I mean by the kinds of side comments that began to pique my interest:

HIV cases are going up and up and up. For us, the practice is within the core. It's bursting! ... [A] lot of people are going to burn out. And as you know there are fewer and fewer doctors wanting to do it because they've been told that it's really hard to do HIV. It's not that hard, it just takes a lot of effort and will⁶.

I found this fascinating: what was this apparent disconnect between the perception and experience of HIV medicine? Was it true there were fewer doctors wanting to do it? And how much of this panic was only relevant to GPs working in the so-called 'core' of the epidemic: what about other parts of Australia? It was from this point that I started to think there could be something going that could form the basis of a study on the experiences of GPs who provide HIV care around Australia.

Why do we need GPs to become engaged in HIV care?

In America, a small number of memoirs were published in the nineties by clinicians who worked on the 'frontlines' of the HIV epidemic in that country. They described the experiences of 'AIDS doctors' working in, for example, inner city hospitals in New York⁷ and San Francisco⁸, with injecting drug users in the Bronx⁹, and with gay men in small town Tennessee¹⁰. Across the diversity of these and related stories, a central narrative of transformation is apparent, with HIV described as having had a life changing impact on these doctors, leading to a greater sense of compassion, purpose and self-awareness. So in a literary sense at least, the experiences of HIV clinicians in the US have been documented and, most importantly, personalised.

As far as I am aware, we don't have any comparable memoirs by Australian clinicians, despite anecdotal evidence that the lives of many doctors were also transformed by their participation in the HIV epidemic. We also know, anecdotally, that many of the cohort of general practice and specialist clinicians who became involved in HIV in the eighties and early nineties are still doing this work today. Others are not: some have died, some have retired, some moved into other areas of work because of what is commonly described as 'burnout' or simply a change in professional interest. But of that group of doctors who *are* still doing this work, many are now getting close to the age at which they are starting to make retirement plans. There are another group of doctors who have been accredited to prescribe HIV medications for the last few years,

or even decades, but who are now choosing to let that status lapse. So some very interesting questions are becoming relevant at this point in history about how it is that GPs become engaged in the HIV epidemic, in different settings, and over time.

What exactly am I talking about when I say ‘the HIV epidemic’? It is estimated that around twenty thousand people are living with HIV in Australia today¹¹. And although these numbers do change a little, around one thousand new diagnoses are made each year, most of which are attributed to unprotected anal intercourse between men. This has been the pattern in Australia since the first case of HIV was diagnosed in 1982, which is almost thirty years ago now. So although HIV has had the most significant impact on gay communities in Australia, almost one quarter of new diagnoses reported between 2005 and 2009 were attributed to heterosexual contact, and of these, more than half were in people who were themselves from countries with a high HIV prevalence, or who had partners who were. Injecting drug use accounts for only a very small number of HIV transmissions in Australia. In comparison to Australia, the global HIV pandemic is having a far more catastrophic impact elsewhere (see UNAIDS for the most up to date information on this).

Australia is considered a world leader in many aspects of our response to HIV: prevention in particular has been heralded for the immediacy and bravery of the bipartisan commitment to doing what history now agrees is what needed to be done. But we are also known for having made some unusual and in many ways quite brave decisions about how HIV treatment and care services would be delivered. In particular, I’m talking about the special role that was made possible in Australia for skilled and accredited medical practitioners to provide HIV care in private general practice¹².

So people living with HIV in Australia are able to access care from GPs working in the community. These GPs are either ‘s100 prescribers’ – clinicians trained and accredited to prescribe HIV medications – or non-prescriber GPs who can address all the other aspects of health in their positive patients, but who will usually share the care of treatment and other HIV specific issues with specialist HIV clinicians. Having the option to access care in the community means not having to always get to a hospital or a specialist clinic, which can be much more inconvenient and potentially also stigmatising. But it has not been at all common for HIV care to be made available in general practice settings in other parts of the world. Countries like the US and the UK have been trying over the last few years to facilitate this shift, but they are facing difficulties because it just hasn’t been part of GP work in those places to date.

So it seems we’ve been quite lucky in Australia. But a series of changes have been observed in the local epidemic that are starting to have an impact on the way we provide HIV care. While it is much more complex than this, I can summarise them as the slowly increasing number of people living with HIV, the progressively older average age of that population, the growing number of people affected by HIV who identify as heterosexual or who are from culturally and linguistically diverse backgrounds, and the movement of people affected by HIV away from the main urban centres and into suburban and regional areas¹³. These and other changes have led to a number of concerns being expressed in policy and advocacy circles about whether sufficient numbers of new GPs are taking up prescriber training to enable HIV care needs to be met in the coming years, in all the different parts of Australia¹⁴.

So at the end of 2007, I started to develop an idea for a grant application that proposed investigating some of these issues. With the leadership of Professor John de Wit, we recruited a flock of supportive research partners including Michael Kidd, from Flinders University, Robert Reynolds, an historian at Macquarie, and Sue Kippax, Emeritus Professor at the Social Policy Research Centre (UNSW), as well as representatives from the National Association of People Living with HIV/AIDS, the Australasian Society for HIV Medicine, the Royal Australian College of General Practitioners and the Australian Federation of AIDS Organisations. With their encouragement, as well as support from a number of GPs who currently work in HIV medicine, our grant application to the National Health and Medical Research Council was funded.

We are now heading into the final year of that project grant, and feeling hopeful that we can generate useful insights into the workforce experiences and challenges that currently face GPs who provide HIV care. I'm not going to take you through all the emerging findings from that study here but there are a few things about this grant that I would like to note before I move on. The first is that it is entirely qualitative in design (which is appropriate for research with a small number of clinicians, but nonetheless not at all typical of research funded by the NHMRC), the second is that we have Peter Canavan, an HIV advocate from NAPWA on our team of Chief Investigators (again, this is supportive of the rhetoric of consumer participation in health research but not at all common in the structure of most funded research teams), and finally our publications will include analyses that contribute to the more traditional domains of public health and health services research, but also those which engage with contemporary debates from the social sciences around the sociology of work and the professions, the discursive representation of the doctor role, and the changing cultural politics of HIV. And for all of that, I am particularly proud.

Our interviews with HIV doctors around Australia are still underway. The first question we have been asking them has been guaranteed to make them either laugh or shift uncomfortably in their seats. We asked: 'What do you think it means to be a doctor in Australia today?' I think it is quite revealing how many responded to that question by saying that they had never had the opportunity to think about it before, or at the very least, had never been asked. We then asked them a follow up question: 'And what then do you think it means to be an HIV doctor?' There was rarely any hesitation with this question. These clinicians were only too happy to explain what they love about this work, what drives them mad, what people don't understand, and what has changed their lives. And while we have much work to do in thinking about how to unpack all of this, the first of our analyses suggested that some of these factors are clinical, and others are professional, but many of these are explicitly political¹⁵. And so this is why it is going to be so essential for us to be informed by the social sciences in order to think through how doctors become engaged in HIV as an area of professional interest, and why the politics of that matters.

Conclusion

It has been a full generation since HIV was first detected in Australia, and it is still with us. The medicine has changed, dramatically and for the better. But it is nonetheless a full generation later, and HIV will still directly shape how I talk to my two young daughters about all of those issues and ideas that people and cultures and institutions have found so difficult to respond to in relation to HIV: sexual practice, sexual identity, gender relations, drug use, pleasure, stigma, difference. HIV still shapes how health

policy is made and how programs and organisations are funded and health systems designed and lives led, here in Australia as well as other parts of the world.

It is a full generation later, and we still need people to care about this issue, to think about how it could potentially affect them personally, or about how it already does affect others today. We still need lots of people who care in government, we still need lots of people who care in community, we still need lots of people who care in research: both clinical and social. And we still really need lots of GPs who care, who are interested in taking account of HIV in the ways they organise their approach to practice, how they make decisions about and conduct their work.

The doctors who do this work have played a significant role in responding to HIV, both in those now thankfully historic days of emergency and tragedy, and in our current times, responding to the needs of a sometimes hidden population, who are living their lives in communities across the full breadth of this country, and participating in cultures that span the full depth of our economic, educational, generational and ethnic diversity. These doctors are about as important a group of professionals as we get in our community, and I dearly hope their ranks will be continuously replenished with the kinds of engaged clinicians that typified the early response to HIV.

My own engagement in this field was largely due to a timely combination of serendipity and opportunity, but there is no doubt in my mind that it was also about the cultural and political meanings that HIV held for me at that time, and that have continued to generate an incredible amount of meaning for me as I have begun to build a research career. I hope to draw upon my sense of the significance and value of those meanings in developing the findings from our research with HIV GPs, and in considering what the social sciences might have to offer in finding new ways to think about and respond to this and related areas of health workforce shortage in the Australian setting.



Dr Christy Newman is a Senior Research Fellow at the National Centre in HIV Social Research where she has contributed to a wide range of research projects in HIV and blood borne viruses, general practice and primary health care, Aboriginal health and health in the media, since completing her PhD in 2004. Dr Newman is the recipient of the 2010 Paul Bourke Award for Early Career Research, an award established by the Academy of the Social Sciences in Australia in memory of a past Academy President, Professor Paul Francis Bourke (1938-1999).

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