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Surviving an epidemic: Australian GPs on caring for people with HIV and AIDS in the early years

Background

Although general practitioners (GPs) play a central role in responding to human immunodeficiency virus (HIV) in Australia, the social history of their contribution in the early years has remained largely untold.

Methods

In-depth interviews were conducted with 21 GPs who provided HIV care between 1982 and 1996. De-identified transcripts were broadly coded in NVivo, then analysed for themes regarding GP experiences during the early years.

Results

Participants recalled a time of death, fear and prejudice, with large numbers of patients diagnosed with and dying from a highly stigmatised disease. An enduring emotional legacy resulted, with GPs developing survival strategies such as better managing relationships with patients, seeking mental health support and reducing working hours.

Discussion

These GPs represent the first generation of GPs in Australia caring for people with HIV. Understanding their experiences can inform and inspire the next generation, who inherit a much brighter future for HIV care.

Keywords

HIV; AIDS; general practice; history of medicine

Australian general practitioners (GPs) have provided care for people with acquired immunodeficiency syndrome (AIDS) – now called people living with human immunodeficiency virus (HIV) (PLHIV) – from the first diagnoses in 1982.¹ Each of the six national HIV strategies, between 1989² and 2010,³ have described GPs as central to the diagnosis, management and treatment of HIV. The rollout of effective antiretroviral therapy (ART) in the mid- to late nineties transformed HIV into a chronic manageable illness, leading primary care to be increasingly viewed as central to HIV health service delivery globally.⁴ Approximately 123 GPs are currently accredited to prescribe ART in Australia,⁵ and play an important role in caring for the almost 25 000 Australians living with diagnosed HIV infection, 90% of whom are men.⁶ However, the limited research available on the role of GPs prior to the introduction of ART suggests that while most were willing to screen and educate patients about HIV, many were reluctant to maintain a therapeutic relationship after diagnosis.⁷

A number of 'AIDS doctor' memoirs were published in the 1990s recalling experiences of the early years,⁸ but the stories of the Australian GPs who were willing to provide ongoing HIV care have remained largely untold. General practitioners feature in the first person accounts of Australian PLHIV⁹ and medical specialists who worked in the area¹⁰ as well as in socio-historical research on the early years,¹¹ but only

a few such accounts have been authored by GPs themselves. A short piece was published in AFP in 2004, describing experiences of 'working in an inner-city, 'queer' general practice'¹² and in that same year, restricted access recordings of interviews with four GPs were archived in the National Library of Australia as part of an oral history project on the 'Australian response to AIDS'.¹³ These provided insights into the enormous strain experienced by the GPs working at the 'coalface', their role as advocates in pushing for early treatment access and the support they provided to patients living with and dying from a highly stigmatised disease.

Our national study was the first to record first-person accounts of GPs involved in providing HIV care in different settings across Australia. While we were originally interested in understanding the contemporary rewards and challenges of this work, as well as pathways into this field,⁵ it became clear that the experiences of the early years GPs were distinctive. This paper therefore aims to give voice to that first generation of Australian GPs providing care to PLHIV, seeking to document their shared experiences and the effects of engaging with this field, and to capture the enduring insights gained in surviving an epidemic.

Methods

The HIV General Practice Workforce Project recorded the views and experiences of clinicians providing general practice-based HIV care in different caseload and geographical settings across Australia. The methods have been described in detail elsewhere.^{5,14} This paper reports on interviews conducted with GPs with first-hand experience in providing HIV care.

Of the 44 GP participants, 21 had commenced providing HIV care prior to 1996, when more effective treatment combinations began to be made widely available. This paper is focused on those 21 participants who represent the early years of HIV care.

Semi-structured, in-depth interviews were recorded between September 2010 and October 2011. Written consent was obtained for 11 face-to-face interviews, and verbal consent for 10 phone interviews, following a structured protocol. Participants were offered \$150 reimbursement. Interviews were audio recorded, transcribed and checked, then de-identified to protect confidentiality.

The National Research and Evaluation Ethics Committee of the Royal Australian College of General Practitioners and the Human Research Ethics Committees of participating universities granted ethical approval.

De-identified transcripts were analysed thematically using NVivo software, identifying patterns and variations in the data through an iterative process of constant comparison and revision.¹⁵ A preliminary coding frame was developed, and refined among the research team, in consultation with members of the expert committee.

For this paper, a second round of analysis was conducted, focusing on the experiences of GPs involved from the early years. Three major thematic categories were identified, and are described below.

Results

Participants included 13 men and eight women, most aged in their fifties (n=15), five in their forties and one in their sixties. Around half (n=10) commenced providing HIV care between 1982–1990 and the other half (n=11) between 1991–1996. Seventeen were active prescribers of HIV medications at the time of interview, while the other four had allowed their prescriber rights to lapse. The majority were based in urban areas (n=16), with five in regional areas.

Participants were based in all states and territories except Western Australian and the Northern Territory. Almost all identified with an Anglo, Caucasian or European cultural heritage. Although not asked, half (n=11) self-disclosed as gay and another three as heterosexual.

Death, fear and prejudice: GP experiences of providing HIV care through the early years

Supporting our previous research,⁵ most of these early years GPs described becoming involved in providing HIV care because of a social imperative to support peers in the gay community or serve those in need, an intellectual interest in sexual health or related fields, or working in clinics and communities where HIV first became prevalent in Australia.

Whatever their motivations, these GPs described feeling overwhelmed and powerless in diagnosing new infections and providing ongoing care when there was little to offer in the way of effective treatment. The number and age of people dying from AIDS, and the kind of deaths they were experiencing, contributed to what was described as a horrific epidemic:

‘When the antibody test first became available ... patient after patient you were telling them that they were HTLV3 positive. Sixty a week ... And it was a death sentence, they had six months to live ... Person after person after person was positive. And ... we had nothing to offer. We knew nothing.’ [Current GP prescriber 3]

‘People in their twenties and thirties were dying, which was a really, quite difficult scenario ... you [could] make a diagnosis, but you couldn’t give people really anything substantial for it ... you could always do something in terms of helping the symptoms, but ultimately you couldn’t [save them].’ [Current GP prescriber 10]

‘People had [all] sort of AIDS spectrum diseases ... sarcomas all over them ... rupturing and terribly disfigured. And people who were blind from CMV ... Some horrific deaths ... You know, sort of gastrointestinal KS, bleeding everywhere.’ [Current GP prescriber 24]

‘There were so many ... talented people, from conductors to famous artists ... [And] to see these people that you had seen, five to ten years earlier in their public profile ... now reduced to wasted bodies and contemplating death at a ... relatively young age.’ [Current GP prescriber 27]

A second feature was a blurring of boundaries, including a pervasive fear and confusion about

who would be affected next, caring for friends and colleagues as well as patients, and sacrificing personal lives to support those dying in their homes:

‘Before the hospice opened you’d have a really gruelling day and then ... spend [your] evenings driving around the suburbs, looking at people who were on their deathbeds at home for months and months ... and months. It was awful. And ... they’d be dying and the boyfriend and friends who were looking after them were kind of thinking, ‘Well, I’m only 6 months away from that myself.’ [Current GP prescriber 11]

‘There was a lot of home visits. And there was a lot of people who, you know, we’d always have the roll call of deaths and there’d be a lot of people who died ... ‘in control to the last minute’ ... There were all these euphemisms for ‘killed themselves’ ... There were quite a few last suppers ... where they’d invite all their friends around and their doctor ... You’d all sit there and they’d be propped up, you know, all forty kilograms of them and they’d die a few days later.’ [Current GP prescriber 27]

A third feature relates to the prejudices associated with HIV and AIDS at that time. Many GPs described witnessing discriminatory attitudes and having to challenge the views of some professional colleagues while also protecting confidentiality:

‘It was so stigmatised ... people were terrified ... I would see my patients out and about socially, and I had to be careful to be introduced to them and not to be seen to be talking to them because everybody knew what I did.’ [Current GP prescriber 24]

‘There was also the frustrations of ... getting other health care workers involved, getting biopsies, getting blood taken, getting surgeons to operate on them, that sort of thing ... So the death and that prejudice was what I recall.’ [Current GP prescriber 2]

‘[I]t was really incumbent on the GP to try and fight for them, I suppose, against what supposed experts in other areas like orthopaedics or surgery or so on felt ... [They] said, ‘Well, if this guy’s got HIV and he’s immune suppressed, he’s going to die anyway. There’s nothing anyone can do for him so why should it be a priority to treat his

appendix or to treat his piles, or whatever?"
[Previous GP prescriber 2]

An enduring emotional legacy: The effects on GPs of providing HIV care through the early years

Participants often evoked metaphors of war in describing the scale and impact of HIV, and the effects on the GPs involved in providing care:

'And it really was ... like a war ... You're just in crisis mode all the time. You'd be out every night looking after sick patients. You'd be getting phone calls all night. You'd spend all day trying to get people into hospital, driving people to hospital yourself. Doing home visits in the daytime ... like you just were on the go all the time and, you know, that went on for a number of years.' [Current GP prescriber 29]
'It's like a war, you know, having hundreds of people die in a short period of time. It was so bleary and horrible. But we were just wrecks and I don't think we all realised at the time how depressed we all were because we were just so overworked.' [Current GP prescriber 11]

In these and other extracts, concern is expressed for the mental health of these doctors, both through the early years and as an enduring legacy:

'[I]f you compared it to any practice in Australia now ... You'd be looking and saying, 'There's something wrong here.' Someone aged between, in their twenties or thirties, dying every week. And so that was very challenging. And, you know, it has an effect on the mental health and wellbeing of the people who are providing care and support as well, especially as it accumulates over time.' [Previous GP prescriber 4]
'I think I suffered, like lots of my generation. We were swamped by HIV. We got depressed ... I went very much from being a real social butterfly to being swamped with work and having no time ... And then when that need went away, I was happy not socialising ... I don't see that as a problem but ... I have colleagues who are much more home bound than I am or less sociable. And I think that's because whatever damage happened in that time, they haven't had people around them to force them to overcome [it].' [Current GP prescriber 11]

'It was certainly difficult in those days and some of the doctors left the field, others committed suicide. I know I burnt out for a period of time so I think people coped with it in different ways.' [Current GP prescriber 10]

Others expressed ambivalence about recalling those experiences. For example, the following quotes are from an interview with a GP who subsequently chose to leave general practice:

'I look back with mixed feelings. I suppose, one, with gratitude that I was able to be there at that time and to actually, I hope, do some good. And the second is with a lot of sadness ... I did try and write down the names of everyone I knew who had been a patient of mine who'd died ... And I kind of gave up after about a hundred and fifty because it sort of seemed so macabre. But amongst those were colleagues, you know, other doctors. And at least three other doctors that I knew very well died, and two of them I looked after. And lots of friends, people who had been really good friends of mine, who succumbed ... I found I didn't really actually have a life outside of my practice and HIV medicine. And it became all-consuming and there wasn't any kind of relief from it. And ... it was partly my own fault in that I was also willingly involved in committee work and in advocacy work ... to improve conditions for people with HIV. But it also meant that there really wasn't any relief ... And I suppose you eventually, after some years, come to a realisation that you can't actually keep going like that.' [Previous GP prescriber 2]

Survival strategies: How GPs sustained their engagement throughout and beyond the early years

Among GPs who remained engaged with HIV care over time, particular strategies were identified as having made that possible. This included drawing strength from relationships with patients, or in contrast, keeping oneself at a distance:

'What's actually kept me here, it's the patients ... True, I have my life outside here, which is far more important ... But you wouldn't have stuck around all these years unless ... you were really getting something out of it. And the patients make it. I won't

say they're friends ... But I've been invited to grandchildren's birthday parties, of people who are HIV ... and [I felt] privileged to be there.' [Current GP prescriber 3]

'Although I would know a person who is positive and their close friends who are caring for them, and their home and their dogs and cats, and things like that, I ... certainly wouldn't have got involved on a level that I get involved now. Because I knew that ... They were going to die and it was a matter of when they were going to die ... I don't think it was a conscious decision. I think it was just something that happened.' [Current GP prescriber 16]

While some were willing to seek assistance from mental health professionals, this was not necessarily straightforward for participants:

'[We] had a psychiatrist ... so there were self-help things ... offered ... lots of people came for the first meeting ... but the numbers dwindled really quickly ... [D]octors think, "I'm not suicidal so I don't need anything like that." Or, "You only need that if you're weak." And that was my attitude then, too. And I think that's got a lot to do with being male ... And doctors, you know, we're supposed to be in control.' [Current GP prescriber 11]
'I got to a point probably 4 years ago now where I just left, I walked out ... And that's when I acquired a psychiatrist. And it's made a big difference ... Because, of course, even if you try to talk to colleagues away from this practice, like we all have doctors, most have, you know, other doctor friends, they don't get the ... issues that you have to deal with.' [Current GP prescriber 29]

Many GPs talked about reducing hours spent in providing HIV care as a way to manage the emotional impact of this work, while others ultimately left the field:

'I suppose I really escaped [to another area of general practice] because although the work was similar, it was, it meant I was working ordinary working hours and I didn't have to provide care for patients after hours.' [Previous GP prescriber 2]
'I didn't want to see patients more than three days a week and I thought it was good psychologically for me ... And that was because ... we saw [that colleagues] ...

[who] tried to be all things to all people just burnt out. And they would leave and then come back and leave, and come back, or leave medicine altogether ... [So] I think that's why there are a few of us in this practice who have been doing it for more than twenty years, because we don't do it every day.' [Current GP prescriber 11]

'I think the issue of balance is really important for every GP: it doesn't matter what area of medicine you're working in, everybody needs to ensure that you do have balance between your professional life and your personal life. I mean that's part of building your own resilience so that you can continue to be an effective clinician over time. If you don't look after your own health and wellbeing, eventually you're going to reach the point where you're not going to be any good to anyone because you're going to become sick and incapacitated, and unable to keep practising.' [Previous GP prescriber 4]

Discussion

Our analysis captures the significant and distinctive experiences described by GPs involved in providing care to PLHIV and AIDS during the early years of the Australian response. Their accounts provide important insights into what motivated and sustained GPs in surviving this epidemic. The first generation of GPs caring for PLHIV witnessed a traumatic loss of life and had to challenge fears and prejudices in both the community and the profession in a time of little understanding of HIV transmission and prevention, or indeed, the best way to care for those affected. Not only were the physical aspects of dying from AIDS difficult to witness, but there was an enduring emotional legacy for GPs in supporting countless young people as they were 'contemplating death'. The doctors who identified as gay or homosexual were particularly aware that many of their peers, friends and partners potentially faced a similar fate, as they might themselves.

These experiences had a range of distressing effects, and for some GPs it became too much to bear, particularly those who experienced little relief from the all-consuming nature of the work. Those who did continue in the field described strategies such as protecting themselves from getting too involved with patients, or in contrast, drawing

strength from that involvement. Seeking help from mental health professionals was potentially fraught, but the decision to soldier on could have long-term consequences. Working part-time was a consistent theme, but some did choose to leave the field. As noted in the data, achieving a work-life balance is essential for all GPs. However, given the historically unique conditions of the early years of the HIV epidemic, the strategies these GPs developed to sustain their engagement over time should be encouraging to all clinicians regarding their potential to survive and even thrive through the most difficult of circumstances.

As there has been little other research conducted on GPs providing HIV care, the body of literature most relevant here is that which explores professional motivations to provide care to marginalised or underserved groups. United States research has shown that despite structural constraints, most physicians feel they have a duty to 'serve the underserved', and will overcome considerable barriers to 'actualize this service ideal'.¹⁶ Family physicians who rate highly the 'universalist' value of enhancing and protecting the wellbeing of all people are most likely to provide care to indigent patients.¹⁷ The choice to pursue general practice as a career has also been consistently associated with having a 'social orientation'.¹⁸ However, particular special interest¹⁹ areas within general practice may still be viewed as more challenging than others, increasing the need to understand clinician engagement with these sub-fields.

A small body of Australian research has investigated the motivations of GPs who work in Aboriginal health, refugee health, mental health and drug and alcohol medicine.^{20,21} While GPs working in these areas seem consistently driven by social ideals,²¹ this does not obscure the complexities they face. Some of the strategies GPs use to sustain their engagement have been confirmed by our findings, including working part-time and taking 'time out from their work in disadvantaged areas when they recognised that they were close to burning out'.²¹ In addition, respect for patients has been described as a primary mechanism for building professional resilience in challenging areas.²¹ What seems distinctive about GP accounts of the early years of HIV is their sense of working on the frontlines of a national crisis. Indeed, the heroism that these

GPs demonstrated in sustaining this role, providing care when others refused, at risk to themselves and their professional reputations, is both inspiring and humbling. Future research could explore the role that female doctors played in responding to an epidemic primarily affecting men, as well as the particular complexities faced by gay male doctors in caring for their own communities.

HIV has become a remarkably different health condition today. With the assistance of ART, those who are newly diagnosed can now expect to live a full and long life,²² and there are suggestions treatment can also reduce the number of new infections.²³ Nonetheless, new HIV diagnoses recorded annually have been consistently increasing in number for more than a decade⁶ and some estimates suggest up to 30% of infections are yet to be diagnosed.²⁴ The expert delivery of ART and other forms of HIV care will require more GPs to become engaged with HIV medicine in all parts of Australia.²⁵ We hope these accounts of the early years of HIV care offer new insights and help to inspire the next generation of Australian GPs to continue this work into the future.

Implications for general practice

- GPs have always played a central role in HIV care, but there have been few published accounts of those who worked on the frontlines of the epidemic in the early years.
- The heroism that these GPs demonstrated in providing care when others refused, demonstrates the strength and resilience that clinicians can draw upon in even the most extreme of public health emergencies.
- Recognising and learning from the experiences of the first generation of GPs providing HIV care can offer new ways to engage the interest of the next generation.

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