

Critical Care: Australian Nurses and the HIV/AIDS Crisis

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In his 1993 memoir *Take Me to Paris, Johnny*, Australian historian John Foster recalls the fear and paranoia surrounding his HIV positive partner, Juan Céspedes, when he was admitted to hospital in the late 1980s. Foster describes how Céspedes's cleaning staff were afraid to touch his blankets. Meals were left to go cold outside his room. In one telling scene, Foster recalls the man from whom Céspedes hired a TV set refusing to enter the hospital room to pick up the weekly hire fee. Yet, in Foster's memoir, the actions of the nurses who care for Céspedes cut through this paranoia and prejudice. Though some nurses initially expressed anxiety about nursing an 'AIDS patient' for the first time, Foster describes how they rose to the challenge with courage and compassion. In one moving passage Foster describes the night nurse who called Céspedes 'Possum' and each evening before bed brought him an extra cup of coffee.

In many Australian AIDS memoirs, compassionate and dedicated nurses can be found bustling in and out of hospital rooms, yet their own stories are rarely told. To date, the only historical account of HIV nursing in Australia is the work of historian and activist Paul Van Reyk. Van Reyk documents the experience of nursing on Ward 17 South at Sydney's St Vincent's Hospital. It is a moving account of HIV nursing on a ward that played a central role in

Australian hospitalised AIDS care (Van Reyk, 2014). Van Reyk's work inspired my own investigation into the experience of Australian HIV nursing.

In 2017 I began research into the role of Australian nurses and nursing unionism during Australia's 'AIDS crisis', that is, the years between Australia's first HIV diagnosis in 1982, and the introduction of highly active anti-retroviral therapy in 1996. I have conducted nine interviews so far with HIV nurses, community activists and union leaders. For the nurses I interviewed, the years of the AIDS crisis were profoundly transformative. Like all those whose lives were touched by HIV, in the early days nurses found themselves stretched to their limits. The nurses I interviewed became their patients' counsellors, educators, friends, and sometimes, lovers. Nurses, and the unions that represented them, stood with the gay community against conservative doctors and surgeons to oppose regressive testing measures and they fought for their patients' rights.

Nurses: friends, social workers, lovers

The first case of AIDS was diagnosed at Sydney's St Vincent's hospital in 1982 (Ballard, 1989). Though it is difficult to know exact numbers, it is estimated that between six and seven thousand people died of AIDS-related illnesses in Australia

prior to the introduction of antiretroviral therapy in 1996 (Wilkinson and Dore, 2000). In Australia, as in the rest of the world, AIDS was associated with sections of the population deemed 'deviant' or marginal: gay men, injecting drug users and sex workers. As Dennis Altman suggests, from the outset AIDS was 'the most political of diseases' (Altman, 1992). Nurses who cared for AIDS patients in dedicated AIDS wards, outpatient clinics and sexual health clinics became embroiled in the complex political landscape created by the virus.

Though the Australian government's response to the virus was more pragmatic and compassionate than its conservative counterparts in the United States and the United Kingdom, the virus was still shrouded in fear and prejudice (Sendziuk, 2003). The association of HIV with sexual and social 'deviance' meant HIV positive people were regularly rejected by family and friends. Similarly, families and those who cared for HIV positive people were often treated as pariahs in their communities. Infamously, in Gosford on the NSW Central Coast, a three-year-old was banned from attending her local preschool after her positive HIV status was revealed (Sendziuk, 2003).

Yet, as I discovered in my interviews, when HIV positive people were rejected by their families, friends and communities, nurses stepped in to

provide physical and emotional support. Often this blurred the line between the personal and professional. One interviewee, Tom Carter, worked in a sexual health clinic in Victoria. He described taking patients home when their family and lovers rejected them. He recalled:

I had seven patients die at my house. My partner and I looked after them because their parents or their lovers had rejected them once they had been diagnosed with AIDS. The parents were either doing 'you're a sinner how evil are you' or they were phobic about catching something...there was lots and lots of stigma (Tom Carter, 14 June and 20 July 2017).

Nurses were often asked to negotiate complex and challenging social dynamics. Families sometimes struggled to understand what was happening to their loved ones. Many of the men dying of AIDS-related illnesses had not 'come out' to their families, some were married with children. Katharine, a nurse who worked with people with HIV and AIDS from 1987 in an infectious diseases ward in a large Brisbane hospital, suggested the challenges of the time resulted in many nurses seeking further training to acquire counselling skills. She commented "you just didn't have that real skill of communicating at that level of grief or in situations where people are struggling to understand 'what's happening to my brother or my husband?'" (Katharine, 5 May 2017).

Of course, not all nurses that I spoke with worked in wards. Many of those who worked with HIV positive people worked in community sexual health clinics. These nurses not only worked within clinics, they organised dynamic outreach programs. One of the nurses I interviewed, Wendy, worked out of a small sexual health clinic in central Melbourne. Wendy is a heterosexual woman and had little to no contact with the LGBTIQ community prior to the AIDS crisis. Yet, by the mid-1980s Wendy was a regular at inner-city gay baths and

saunas where she would provide free testing and, in her words, offer 'a little bit of education' about safe sex practices. This was, as Wendy put it 'ground breaking stuff':

Here I am, I'm a heterosexual female in all this and I thought this is probably not going to go down very well...but I was allowed into the saunas, I took blood one night a week.

Wendy recalled the first few times she set up in a sauna:

As the guys started coming in I got to be the talk of the saunas...they said oh goodness there's a lady in there but she's ok, she'll have a talk to you. (Wendy, interview 7 July 2017).

She gained the trust of the sauna's patrons, providing free testing to many of them. Some men declined the test but would approach her regularly for a chat. Nurses like Wendy took on duties and responsibilities we might associate more with health promotion, or social work, than nursing. Yet, they were able to bridge these two roles with competency and compassion. Wendy was able to take blood, have a chat, and provide sexual health advice, all in the space of a single evening.

A significant proportion of HIV/AIDS nurses were gay men and women. As Van Reyk explains, gay men and lesbians were drawn to HIV/AIDS nursing out of a desire to 'take care of their own' (Van Reyk, 2014). For many gay and lesbian nurses HIV/AIDS nursing was an opportunity to work in a queer-friendly environment. The nurses who Van Reyk interviewed from St Vincent's remembered finding a sense of community and purpose that brought them immense joy and fulfillment, even in the most difficult of times. Yet, for gay nurses the AIDS crisis also represented a challenging collision between the two worlds they occupied, their professional and personal lives. One gay nurse I interviewed, Toby*, described feeling like 'Nurse Death':

I can remember being at dinner parties, going into gay bars and there'd be a barman or people on staff who I would have taken their blood or done their T-cells in the morning or people sitting at a dinner party who I was supposed to be meeting for the first time and they'd look at me and I'd be Nurse Death sitting at the table...I'd have to pretend I'd never seen them before.

Perhaps most confronting for Toby was when the line between sexual partner and patient was blurred. He remembered 'lovers and ex-lovers rocking up to clinic'. He felt this made his work particularly challenging. Comparing himself to one of his close colleagues, a straight woman, he reflected:

At the end of her day she went back to her heterosexual world...in some ways it was much easier for her to compartmentalise what she was doing professionally whereas I was living it (Toby, 20 April 2017).

Nursing on the frontline: negotiating risks, fighting for patient rights

Nurses in HIV/AIDS wards and clinics not only had to navigate complicated social and political landscapes, they also had to negotiate the health risks posed by the virus itself and the anxiety associated with this risk. For example, Josephine*, who worked in the out-patient clinic at St Vincent's hospital in Sydney spoke about acquiring a needle stick injury in the early days of the epidemic:

I remember this particular time taking a butterfly needle out of a patient and I knew he was very unwell, very end stage. I don't know how it happened but I got a needle stick injury and I remember it was into my thumb and I remember [my colleague] saying to me quick squeeze it and just keep running your hand under the tap which I did so I really milked it straight away as soon as it happened...and I look back and think

* Pseudonym used

my god how lucky was I (Josephine, 20 June 2017).

What was everyday work for nurses like Josephine was exceptional by any other standard: their patients were dying of a disease that was both new and deadly. Nurses had to confront the daily possibility of exposure to the virus. Moreover, because their patients were immune-compromised and thus vulnerable to opportunistic infections and viruses, they also had to negotiate exposure to diseases like tuberculosis. In these circumstances, many doctors, surgeons and the organisations that represented them responded to HIV with fear and paranoia. Van Reyk points out that even though it was nurses, in close and continuous contact with patients who faced the highest risk of exposure, it was surgeons who were campaigning for '5,000 spaceman-like protective suits' and the right to refuse surgery to HIV positive patients. Nurses, by contrast responded with pragmatism and compassion and fought for an approach to infection control based on 'universal precautions'. Universal precaution involves assuming all patients, blood products and bodily fluids are potentially infectious. In this way nurses were able to ensure safe working practices and, importantly, it meant that people with HIV and people from HIV-associated groups, namely gay men, were not discriminated against or singled out for 'special' treatment (Kermode 1992).

Today universal precautions are common practice in hospitals in Australia and around the world. However, in Australia in the 1980s, nurses and their unions fought a political battle with surgeons and doctors for this practice, opposing the 'test and contain' approach advocated by the Australian Medical Association and Australian Association of Surgeons at the time (Sendziuk, 2003; Power, 2011). With HIV testing widely available from 1985, a debate raged within the gay community and amongst healthcare professionals around the efficacy and ethics of testing. Though many gay men did get tested, numbers of prominent community

spokespeople and activists argued against testing. They did not trust the anonymity of test results and feared how they might be used. It is not surprising the gay community was nervous to trust the government, given that homosexuality was still criminalised in some Australian jurisdictions or had only very recently been decriminalised when HIV arrived in Australia.

Unfortunately, many of the community's worst fears were realised in 1985 when the NSW state government, with the backing of the Australian Medical Association and Australian Association of Surgeons, attempted to implement legislation making it compulsory for doctors to alert the government when they found someone HIV positive and to supply their name and personal details, essentially creating an HIV positive register (Power, 2011).

Nurses and their unions stood alongside the gay community in opposition to this proposal (Fela, 2018). In August 1985 the New South Wales Nurses and Midwives Association published their 'AIDS' policy in its periodical, *The Lamp*. Significantly, the policy enshrined union opposition to the state government's proposed legislation, stating that the New South Wales Nurses and Midwives Association 'opposes the implementation of a national register of AIDS antibody positive persons' (Ridgway, 1985). In many ways, this was thanks to two progressive women in the leadership of the NSWNA, Bronwyn Ridgway and Jenny Haines. Ridgway, the assistant secretary of the NSWNA, was particularly committed to defending the rights of people with HIV; she saw nursing unionism as crucial to this task:

There was the fear and loathing and homophobia and all of that. We were hoping that we would get to people's minds, health carers' minds, in a compassionate way to be ahead of what ended up being...well, an epidemic. (Ridgway, interview 22 May 2017).

Nurses had voted Ridgway and Haines into the leadership of the NSWNA in a climate of growing industrial militancy and confidence. In the early to mid-

1980s nurses across the country were increasingly using industrial means to fight for their rights and to reject their subordinate role in the hospital hierarchy. Most famously, in Victoria, nurses went on strike for fifty days in 1986 to win better pay and conditions (Colson 2001).

The vocal activism of the gay community, combined with the opposition of nurses and their unions, meant the compulsory notification legislation proposed by the government was unfeasible. Instead, an anonymised system of free testing was introduced, an important step. In the early days of epidemic, it was difficult for many gay men to see the point of doing an HIV test when there was no treatment. As new drugs like azidothymidine (AZT) were introduced, testing became increasingly important because early detection was linked to improved health outcomes. It was crucial that affected communities felt confident in the privacy of the testing system, as it meant people were more likely to be tested.

It was not only through the formal machinations of their unions that HIV nurses took a stand for patients' rights. As Katharine put it to me, 'I found I became quite a defender'. When I asked what she meant by being a 'defender' Katharine explained that it meant being able to:

stand up for people, be an advocate you know if people start to say discriminatory comments and stuff like that you find yourself without even thinking about it saying 'do you really know what you are talking about?'

Likewise, Wendy* told me she and her co-worker decided early on that in the sexual health clinic where they nursed, they would avoid recording names or other personal details of their patients in order to protect their identities. She told her colleague: "I'm not writing people's details in this, I'm writing 'conversation' or 'long discussion' or 'long chat' and that was all we wrote."

* Pseudonym used.

For Wendy and her colleagues, this decision to protect patients' rights arose out of the conditions they were working in, and in response to their observations of the political context. Wendy remembered that 'they were always talking about locking people up or putting them on French Island' [in Victoria's Western Port Bay] and that the unofficial confidentiality procedures she and her colleagues invented were, "I dunno, a premonition that things were going to go awkward." Wendy's fears proved well-founded: in the mid-1980s police came to her clinic and demanded patient files. Wendy and her colleagues are unsure to this day why the police wanted the files, but the nurses refused to hand them over. The police left and came back again, but still Wendy and her colleagues refused to surrender them. The police never obtained the files. That Wendy and her colleagues were willing to defy the police rather than compromise patient privacy is an indication of the courage and strength of conviction that guided nurses in their approach to their patients' rights. Perhaps it was also a reflection of the broader industrial context, a context in which across the country nurses were standing up for their rights and striking. It seems likely this collective spirit of defiance might have found its way into the small sexual health clinic staffed by Wendy and her colleagues and given them the courage and confidence to stand up to the police.

I spent the last few months of 2017 analysing and re-reading the interviews that I had conducted with nurses like Wendy. This was also the time in which the marriage equality postal survey occurred. The survey saw close media and public scrutiny of deeply personal aspects of LGBTIQ+ life: it put lives and relationships on trial in a way that echoed some of the homophobia of the AIDS crisis. In this difficult time, I found great solace in the nurses that I had the privilege to interview. When HIV wreaked havoc, these nurses came to the community's aid. Nurses went to enormous lengths to ease the suffering of those who were sick and dying. They stood in solidarity with those living with HIV and AIDS and were prepared to face down authorities in order to defend their patient's rights. Amid the political

ugliness of the postal survey, they reminded me every day of the capacity for compassion and courage, even in the most challenging circumstances.

Sources

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