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# ‘A shudder of terror’: HIV/AIDS nursing, oral history and the politics of emotion

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In July 1983, Australia announced its first (official) AIDS related death: a forty-three-year-old Melbourne man who died at Prince Henry hospital.[1] It was not until 1996 with the introduction of Highly Active Anti-retroviral therapy that there was effective treatment for the virus. Between 1983-1996, nurses were at the frontline of care. Whilst the medical profession floundered, desperately trying to catch up with the mysterious virus, nurses provided the intimate physical and emotional care desperately needed by people facing untimely and often painful deaths. This paper is based on oral testimony collected in 2017 from nurses who worked in Australian HIV wards and clinics during the crisis. It considers the testimony of three nurses, Tom, Jackie and Katharine*.[2] Paying close attention to the narratives of these three nurses enables a detailed investigation into how they negotiated complex and difficult emotions. In *An Archive of Feelings*, cultural theorist Ann Cvetkovich argues for a ‘reconsideration of the conventional distinctions between political and emotional life’, a blurring of the line between politics and emotion.[3] Barbara Rosenwein likewise draws attention to the dynamic connection between emotional and political life in *Emotional Communities in the Early Middle Ages*.[4] This paper will explore the ‘affective life of politics’ by considering how Tom’s, Jackie’s and Katharine’s memories of fear, discomfort and grief were inflected by the broader politics of the AIDS crisis, as well as their particular personal and geographic contexts.[5]

Jackie and Tom both worked in the HIV outpatient clinic at Sydney’s St Vincent’s hospital in Darlinghurst. Jackie is a straight woman and Tom is a gay man. St Vincent’s is in the heartland of gay Sydney, arguably the epicentre of Australia’s AIDS crisis.[6] Between 1983 and 1996, approximately six to seven thousand people died of AIDS related illnesses in Australia. Many of these people would have come through Jackie’s and Tom’s clinic.[7] Katharine worked in a very different context to Jackie and Tom. She nursed in an infectious diseases ward from 1987 at Princess Alexandra Hospital in Brisbane during Queensland’s notoriously conservative Bjelke-Petersen government. During interviews with each of these nurses, I found they had different ways of negotiating the difficult emotions associated with the AIDS crisis. Despite the risk that was associated with her work in the early days, Jackie was reluctant to discuss fear and anxiety. Conversely, Katharine was comfortable discussing the anxiety and fear that she sometimes experienced when nursing HIV and AIDS patients. Tom was comfortable talking about anxiety but not grief and sadness. He emphasised the joy and excitement of the period and relied on dry, dark humour to skate over the painful aspects of the period.

Examined side by side, these three distinct case studies provide insight into how our memories of emotion are mediated by the social and political environment of our everyday world and our personal political values. The different ways each interviewee negotiated difficult emotions was shaped, at least in part, by the complex political dynamics of the period and their particular personal and geographic contexts. Barbara Rosenwein defines emotional communities as ‘groups in which people adhere to the same norms of emotional expression and value – or devalue – the same or related emotions.’ Importantly, ‘More than one emotional community may exist – indeed normally does exist – contemporaneously.’[8] Jackie, Katharine and Tom each inhabited different emotional communities. Though both Jackie and Tom worked together in the same clinic at Sydney’s St Vincent’s hospital, Tom’s identity as a gay man living in the heart of Sydney’s gay community shaped what Cvetkovich might call his ‘affective experience’ of the crisis.[9] Similarly, though both Jackie and Katharine were heterosexual nurses working with HIV and AIDS patients, their distinct geographic contexts –Jackie in Sydney and Katharine in Queensland – saw them negotiate difficult emotions (such as fear) in different ways.

## Negotiating the politics of fear

The fear that surrounded the HIV virus was highly politicised.[10] The AIDS panic that erupted sporadically in Australian society throughout the 1980s and 1990s – from the moral outrage following the death of three Brisbane babies from a HIV positive blood transfusion

to the terrifying Grim Reaper advertisement – was inflected by homophobia and prejudice. Conservative media and politicians singled gay men out as agents of infection.[11] This set the stage for a significant increase in anti-gay hate crimes. In Sydney during the 1980s and 1990s, many gay men fell victim to vigilante gangs. The death toll from this period is only now becoming known, but at least 88 homicides have been identified as part of this swathe of gay hate crimes.[12] In this context, for nurses working with HIV and AIDS patients fear was a complex emotion to negotiate. While conservative Australia was fomenting panic over a gay swimming carnival at the Andrew Boy Charlton pool in Sydney, down the road at St Vincent's Hospital nurses were cleaning up HIV positive bodily fluids and dealing with used needles.[13] Particularly in the early days, nurses working at the coalface of the crisis in AIDS wards and clinics faced some danger of infection. Both Katharine and Jackie experienced moments of exposure to HIV positive blood: Jackie via a needle stick, Katharine when she covered her patient's open wound with her hands. They remembered these moments in very different ways. Importantly, it was not the objective level of risk associated with each incident that determined how it was remembered. Jackie did not recall feeling afraid but Katharine did, despite the much higher risk associated with a needle stick injury. Rather, I suggest that how they remembered these moments of exposure was mediated by the political and geographic contexts in which they were working.

When Jackie told me about her needlestick injury, she began by recalling how one of her colleague's became infected with HIV:

> And the other point is needlestick injuries and we did have a staff member, a female staff member – straight – I worked with her and she sustained a needlestick injury and within two weeks she'd had a very significant seroconversion illness, because at the time it happened she didn't think it was significant, but she seroconverted.

Q: So she was infected?

> Yep, she was infected from a needlestick injury so that was pretty hard for everyone. It was awful in fact, you know she was a great nurse. Yes – you know you had staff who got sick and died. Fortunately we only had one episode of a, um, needlestick injury that resulted in a seroconversion and HIV positivity [pause] but certainly as time went on it, you know, it changed everyone in our…. eye clinic that's right, because you know before we had so many antiretrovirals CMV [Cytomegalovirus] retinitis was rampant and the ophthalmologist who looked after all those guys he was just wonderful. He was another person – he was a married man, he had kids, and he had no qualms and he looked after all those patients with HIV retinitis and the patients loved him because he was so nice to them.[14]

Though Jackie admitted that the infection and death of her colleague was 'awful' she avoided using words like 'fear', 'afraid', 'scared'. She spoke in very general terms: it was 'pretty hard for everyone'.[15] She was also quick to deflect the conversation, moving abruptly from the story of her colleague's HIV infection to a description of the hospital's eye clinic. Here she highlights the respect that her heterosexual colleague, the ophthalmologist, showed towards HIV positive patients. Perhaps this is because, when Jackie raised the topic of her colleague's infection, she touched on some of the complex emotions that were part of the experience of AIDS nursing. That is, an understandable fear of exposure which, in a context where fear around HIV and AIDS was inflected with prejudice and ignorance, was something nurses like Jackie were (and perhaps still are) reluctant to acknowledge. She quickly deflected the needlestick infection to another, unrelated, story of an 'unprejudiced' medical practitioner. It was as if she was negating any suggestion of prejudice or fear in her memory of her colleague's injury and infection.

Following her segue to the eye clinic, Jackie returned almost immediately to the issue of needlestick injuries and revealed that she herself had experienced such an injury. She recalled:

> This particular time I remember 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 needlestick 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.[16]

When I asked her if the event frightened her, Jackie said: 'you know, I didn't think about it much at the time but certainly now, yes.' She commented that she looks back and thinks 'my god how lucky was I.'[17]

That Jackie did not recall feeling afraid at the time does seem surprising in this situation, certainly the reaction of her colleague suggests that there was an awareness of the risk involved in a needlestick. Jackie immediately ran her hand underwater and squeezed the wound and this indicates that she felt infection was a real possibility following the injury, especially given that the patient was 'end stage' – meaning a high viral load. Of course it's possible that Jackie simply cannot remember her fear. As Mark Cave points out, over time 'passions fade' and it can be difficult to recall emotions years after an incident.[18] Another possibility is that Jackie genuinely did not feel fear. After all, nurses at

St Vincent's Darlinghurst, the epicentre of the AIDS crisis, spent their days dealing with the HIV virus and its deadly effects. Perhaps for Jackie this moment of exposure was not outside the norm of her daily work life. Or perhaps Jackie's inability to recall fear reflects the changed status of an HIV diagnosis today. When stories are 'related in the present', how we remember and narrate them is shaped by this present.[19] Thanks to improved treatment, HIV is no longer a deadly virus in Australia, it is a chronic but manageable condition and perhaps Jackie's narration reflects this present medical reality. At the same time, it is worth noting that if this was the case, it was not something that inflected Katharine's memory of her own exposure.

Katharine (who worked in Brisbane under the politically conservative and homophobic Bjelke-Peterson government) remembered feeling fear and anxiety whilst working with people with HIV and AIDS:

> The only thing I can recall is a shudder of terror when someone said 'this is where you'll be working'. You know because I'd gone for a job and they said 'you'll be going to infectious diseases' and I said 'oh that sounds great' and then they said 'oh well you'll be looking after people with AIDS in there too' and I mean, I don't know anything, so I was fairly anxious I must admit…. And you know like I wasn't at that stage, I'd been back nursing since 1985 so I hadn't been back nursing a long time but I was happy and I was in the swing of things and this was quite challenging but it turned out being one of the best experiences of my life.[20]

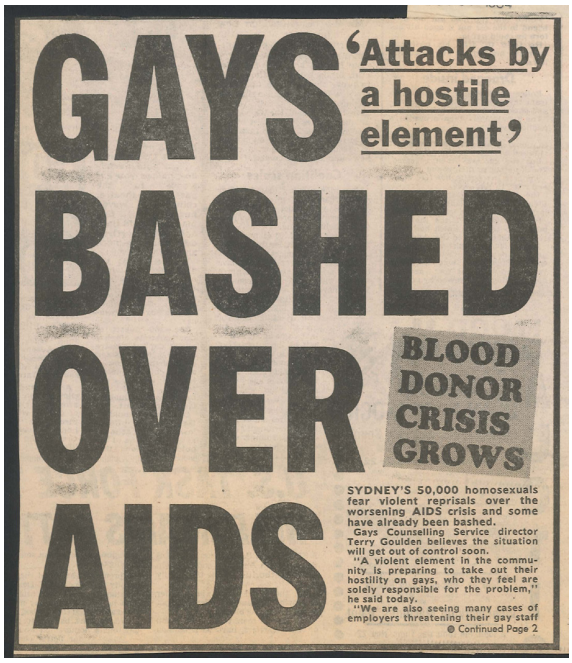
Katharine's 'shudder of terror' was quickly overcome, she went on to nurse many people with HIV and AIDS and had a long career in sexual health. But this was not the last time she felt anxious about her work. She recalled one moment in particular that left her uneasy. Like many of the nurses I spoke with, Katharine developed close relationships with her patients. She explained that this made it easy to overlook the possibility of contagion:

> Because you became so familiar with the individual patients…you had to remind yourself that, hey remember, you know, if there's bleeding…I remember once…it was a spontaneous thing and it was only because it was such a familiar person…I put my hand on something that was bleeding, he had a [pause] cannula and there was [pause] a problem and I didn't want anything to go wrong so without even grabbing a glove I put my hand over there.[21]

Katharine was happy to share this incident with me but I gained the impression that it had been a frightening moment. She recalled that 'it was only momentary', she quickly pulled her hand away. It made her 'stop and think.'[22] In Katharine's reflections, it became clear that she felt in that brief moment her actions had gone beyond ordinary care and concern. She recalled feeling afterwards that she had crossed a line: 'I had put to the back of my mind why he was really there and you know, boundaries are so important.'[23] Alessandro Portelli comments in *The Peculiarities of Oral History* that whether or not we maintain the orality of an oral source has bearing on its meaning.[24] Certainly, I found this to be true of Katharine's interview. It was only by listening to the recording that I noticed how her pauses became longer, her fluency and the volume of her voice changed, she became quieter when she discussed this encounter with the infected blood of her friend and patient.

It was clear to me that, for Katharine, this was a moment that was frightening at the time and that still provoked anxiety when remembered today. In truth, Katharine's encounter was not particularly dangerous. HIV cannot be transmitted through touch, even touching infected blood. By contrast a needlestick injury, like the one Jackie experienced, is relatively dangerous as it risks injecting the HIV virus directly into the blood stream. The transmission route of HIV was well established by 1985 and this information had been distributed to healthcare workers via pamphlets and fact sheets.[25] Even in Queensland, where information was restricted by the conservative state government, the Queensland Department of Health did distribute basic fact sheets about the virus.[26] It seems likely that both Katharine and Jackie would have known the relative risk of each encounter.

It was not, however, the 'riskiness' of these moments that shaped how these two nurses remembered these moments. Rather, it was the broader political and geographic contexts in which they worked. Michael Lambek argues that memory is a 'moral practice' and points out that 'if remembering is a moral and identity-building act, so to be sure, is forgetting'.[27] The narrative Jackie told of nursing during the AIDS crisis was of pragmatic, resourceful and non-judgemental nursing. It is a story inflected by the professional pride nurses were increasingly asserting following the industrial upsurge of the mid-1980s.[28] It was also a story of nursing in Sydney, the city where the gay community was largest and arguably the most organised.[29] The 1970s had seen the birth of gay liberation in Sydney, the emergence of a gay press, the development of gay political organisation and regular national homosexual conferences.[30] Inspired by New York's Stonewall Riots of 1969, the gay community came out of the closets and onto the streets to fight for the right to live and love without persecution. Most famously in Australia, Sydney's first gay and lesbian Mardi Gras in 1978 saw a protest and celebration during which gays and lesbians fought alongside each other against a homophobic police force and the prejudice of the media and justice system.


GAYS BASHED OVER AIDS

'Attacks by a hostile element'

BLOOD DONOR CRISIS GROWS

SYDNEY'S 50,000 homosexuals fear violent reprisals over the worsening AIDS crisis and some have already been bashed.
Gays Counselling Service director Terry Goulden believes the situation will get out of control soon.
"A violent element in the community is preparing to take out their hostility on gays, who they feel are solely responsible for the problem," he said today.
"We are also seeing many cases of employers threatening their gay staff
© Continued Page 2

'Gays bashed over AIDS', Daily Mirror (Sydney), 19 November 1984, p. 1. Courtesy the Australian Gay and Lesbian Archives.

The legacy of this activism saw the community highly organised and political when HIV arrived. Jennifer Power claims that '[t]he organised response of the gay community has been one of the most striking features of the HIV/AIDS epidemic in Australia.'[31] In other words, when gay men faced a health crisis that threatened their very existence, the gay community was able to draw on an existing tradition of activism and was ready to confront prejudice and discrimination.[32] HIV positive people took centre stage and demanded they be talked *to* rather than about; HIV positive people refused to be victims and asserted themselves as agentful patients who were fighting for their rights.[33] Rather than advocating abstinence, organisations like the AIDS Council of NSW (ACON) encouraged people to have sex safely and promoted positive images of gay identity and sexual practices.[34] This was the 'emotional community' in which Jackie found herself immersed, a place and a community that was rejecting the moral panic around AIDS, homosexuality and infection. In this context it is understandable that Jackie, a heterosexual woman who was working closely with the gay community, was reluctant to acknowledge that she experienced emotions like fear and anxiety.

For Katharine in Queensland, the political context was very different and this shaped how she experienced and recalled her own encounter with a patient's blood. The Bjelke-Peterson government was committed to maintaining the criminalisation of male homosexuality, they refused to pass on federal funding to the Queensland AIDS Council and to distribute the federal National Advisory Committee on AIDS (NACAIDS) safe sex information.[35] The street marches and demonstrations that were the backbone of the gay and lesbian movement in Sydney were banned in Bjelke-Peterson's Queensland. Moral panic reached fever pitch following the death of the four 'Brisbane babies' in 1984, and the unique political climate of 1980s Queensland made it difficult for the gay community to respond.[36] This is not to say that there was no response, rather that it was of a different quality to the confident, open challenge to fearmongering evident in Sydney. This may be why Katharine was happy to talk about her own fear and anxiety and why she felt that 'shudder of fear' when told she would be working with people with AIDS. Her 'affective response' or 'experience' was shaped by the broader politics of anxiety and prejudice that prevailed in Queensland at the time.[37] For Jackie in Sydney, fear and anxiety was 'devalued'. For Katharine, fear was a 'norm of emotional expression' within the 'emotional community' of Bjelke-Peterson's Queensland.[38]

## Rejecting the Reaper: Gay nurses and HIV/AIDS

The gay nurses I spoke to, even those who worked in Sydney, were more open than straight nurses to discussing their fears and anxiety around the virus. Tom, who worked at St Vincent's around the same time as Jackie, recalled his reluctance to share an ice-cream with his HIV positive friend:

> I had a close friend who I nursed while he seroconverted [seroconversion is the initial illness that is experienced following HIV infection]. I remember the first time we were walking on a beach together and we bought ice-creams and he offered me a lick of his ice-cream to see what the flavour was, as you routinely do, and I really thought about it before I took a lick of his ice-cream. And I knew, through all of my training and all of my knowledge, that there's no way I could get HIV from licking his ice-cream. But it was an emotional thing to overcome that, and in those early days when people felt like pariahs, when we didn't know what we were dealing with, that sort of stuff was really important.[39]

Tom, a member of the gay community, did not feel (as Jackie did) that he needed to distance himself from the prejudices of ordinary Australians. However, while Tom was noticeably more comfortable reflecting on his own anxieties and fears around the virus than Jackie, I did find him reluctant or reticent when discussing grief and sadness. It was not that Tom did not acknowledge that the crisis was difficult; he spoke about it at one point as 'our generation's world war'.[40] Rather, that he heavily emphasised life, happiness and humour, even when describing the sickness of a lover.

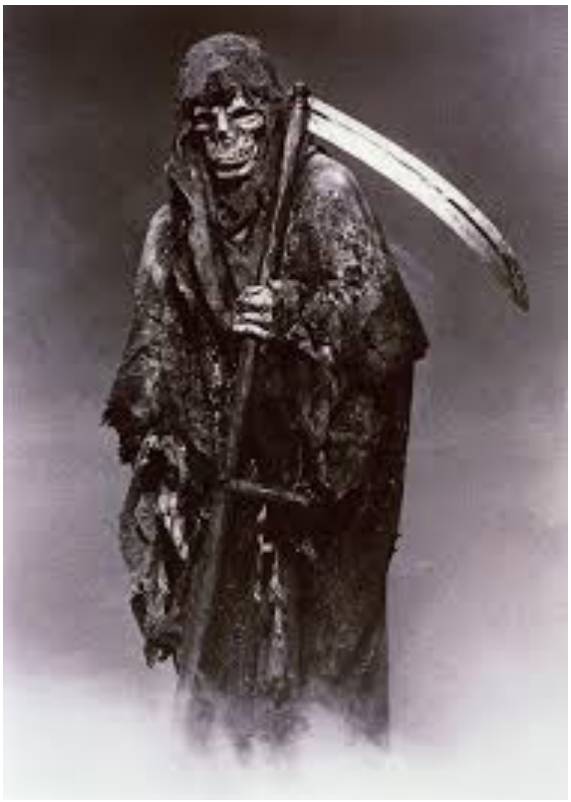
> I had an affair with a fellow who died, he was covered in KS [kaposi's sarcoma, an AIDS related cancer] at the end and quite demented,

> and he used to wear outrageous makeup and lipstick and beads and became quite eccentric at the end. But I can remember taking him to lunches and things with friends, with straight friends who would be quite confronted that there was this man who was a little demented with a lot of makeup on.[41]

In this story the sickness and approaching death of his lover is inflected with humour and a kind of camp sensibility. Tom employed this camp, funny and frank approach quite a lot when he talked about death. He remembered the early days of the crisis as a time when there were 'a lot of corpses on Oxford Street.'[42] Perhaps Tom struggled to remember or articulate the grief of the time or maybe it was simply too much to describe. It could be that Tom used dark humour as what Alistair Thomson might call 'a strategy of containment', a way of masking 'loss or pain'.[43] I interviewed him only once and perhaps we had not built sufficient trust for him to disclose those difficult emotions to me.

It is also possible that, for Tom, excitement and happiness *were* strong emotions he felt during these years. For Tom, as for many gay nurses, the AIDS crisis coincided with his youth. He was young, surrounded by other young gay people, doctors, nurse and activists; together they were fighting side by side for their community. It is easy to imagine the camaraderie, the sense of purpose and belonging that they must have felt. As community historian Paul Van Reyk notes in his examination of ward-based nursing at St Vincent's, 'the ward was not unremittingly grim. You could count on drag queens turning up in a flurry of feathers and sparkles to do an impromptu show.'[44] It seems likely that Tom's youth and community attachment shaped his experience of the AIDS crisis.

The way Tom negotiated his emotional memory of the period may also have been influenced by his political context. The association between gay sexual practices, identity and death was characteristic of the emergence of HIV and AIDS in the 1980s and 1990s. In *Policing Desire: Pornography, AIDS, and the Media*, Simon Watney notes that in popular consciousness AIDS makes 'the rectum a grave' and as a result 'the image of homosexuality is re-inscribed with connotations of contagion and disease.'[45] Though Watney's case study is AIDS in America, Australia was not immune from this association between gay life, sex and death. The infamous 'Grim Reaper' campaign is perhaps the most notorious example of this. Commissioned and broadcast by NACAIDS, the 1987 campaign saw the figure of the Grim Reaper, long associated with death in Western cultures, become synonymous with HIV/AIDS in Australia.[46] Bearing a scythe and bowling ball and adorned in a tattered black robe, the menacing figure was depicted bowling over 'ordinary Australians'. A terrifying voice-over delivered the government's warning to sexually active Australians: 'always wear a condom, always.' Alongside the authoritative safe-sex directive, the campaign carried a secondary message: AIDS was no longer a disease restricted to deviants—Dennis Altman's 'poofs, junkies, whores'[47]—it was coming for mainstream Australia.



'Grim Reaper' as appeared on national media in 1987, commissioned by NACAIDS.

In the opening frames of the advertisment, we see men, women and children—presumably representing the general community—being lowered, like skittles, on to a bowling alley. The menacing figure of the Grim Reaper is introduced and a voice explains: 'At first only gays and drug users were being killed by AIDS.' The Reaper's ball then bowls over men, women and children. In an image that evokes the industrial slaughter of the Holocaust, 'ordinary Australia' becomes a heap of bodies that is scraped off the floor of the bowling alley.[48] The implication of the NACAIDS campaign was that HIV/AIDS was horrifying, not so much because it killed gay men, haemophiliacs and drug users, but because of the threat it posed to others.

Many in the gay community objected on the grounds that the campaign positioned the lives of gays and IV drug users as less important than the men, women and children of mainstream Australia.[49] Not only did the advertisement present a hierarchy of guilty and innocent victims, as Deborah Lupton has pointed out, it also meant that the Grim Reaper – 'grotesque and medieval' with its associations of 'death, famine, plague and divine retribution' – became the definitive figure of AIDS in Australia and thus associated closely

with gay men.[50] In September 1990, the newsletter of the Western Australian AIDS Council *AIDSaction* reflected on the personal cost of the moral panic surrounding AIDS in an article titled 'Guilt: The Price of Pleasure':

> Those infected with HIV are subject to an adverse judgment on the part of society. When someone is diagnosed as HIV positive, they are suddenly confronted with the possibility of having to die prematurely. To further add to their anxiety, they find they are carriers of the disease which may alienate their friends, relatives and associates. They have become societies [*sic*] "new lepers"![51]

The gay community, however, refused to be defined by the grotesque figure of the Grim Reaper. Activist groups like AIDS Coalition To Unleash Power (ACT UP) brought defiance and anger from the streets of New York to Australian shores. Despite the efforts of conservative commentators and medical professionals, and in defiance of conservative politician and Christian minister Fred Nile's prayers for rain, Sydney's gay and lesbian Mardi Gras was not shut down by the AIDS crisis – the party continued, now with condoms.[52]

In the stories Tom told about the period, there was one moment when the impact of the Grim Reaper flashed through his testimony. Recalling bumping into patients at dinner parties and gay bars, Tom commented that he felt like 'nurse death sitting at the table'.[53] It was clear from Tom's tone in the interview that this description was inflected with his camp, tongue-in-cheek humour. Nevertheless, in this moment he positioned himself as a harbinger of death and disease. In some ways this moment only threw into relief his general reluctance to dwell on the darker emotions in his memories of the AIDS crisis. Tom predominantly emphasised joy and happiness in his recollections: it was, in his words, 'an extraordinary time'. As well as the clubs, the drugs and the sex, Tom described an incredible sense of purpose and fulfilment in his work. In the same way that the gay community refused to be defined by the vision of the reaper, Tom's emotional memory appears shaped in part by a political or moral inclination to tell a positive story of his community's resilience and a rejection of the association between gay life and death.

Mark Cave argues that 'Not only is emotion the key to understanding the actions and attitudes of interviewees, it is often the glue that holds the memory of events together.'[54] Certainly this was true for Katharine, her memory of the moment when she touched her patient's blood with her ungloved hand was clearly one that continues to affect her today. Through this story she conveyed the nature of the work she was doing and the close and intimate care that she gave her patients. In contrast, for Jackie and Tom, some memories of events held together well while some of the more difficult emotions we might associate with these events were notably absent. It seems that the sharply contested politics around fear and infection that was openly playing out in Sydney during the AIDS crisis helped shape the emotions that Jackie and Tom were willing or able to recall. Conversely, Katharine's experiences of fear are a testament to the very different political environment of 1980s Queensland, where fearmongering could not be challenged with parades and marches. These case studies demonstrate how the conventional distinction or delineation between politics and emotions is hard to draw.[55] For these three nurses, the emotions they experienced or felt able to express were shaped, at least in part, by the politics of the 'emotional community' they inhabited in the 1980s and 1990s.[56]

**This article has been peer reviewed.**

## Endnotes

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54 Cvetkovich, *An Archive of Feelings*, p. 10.

55 Rosenwein, *Emotional Communities*, p. 2.