

Nursing a plague: nurses'
perspectives on their work during
the United Kingdom HIV/AIDS crisis,
1981–96

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One evening shortly before Christmas 1984, David Ruffell began to feel 'very peculiar'. Walking around his local grocery store, he 'felt so ill [he] thought [he] was dying'. Thinking that he might have a venereal disease, he visited the Genito-Urinary Medicine Clinic in Hammersmith, London. The doctor at the clinic took one look at David and said, 'My God, you look absolutely awful', and immediately sent him for an X-ray. Upon reviewing the X-rays, he took hold of David's hand and told him, 'You're quite seriously ill. I'll be perfectly blunt: you've probably got a rare type of pneumonia called pneumocystis, which is connected with the AIDS problem. Until we can do a biopsy on your lung, we're going to admit you to Charing Cross Hospital immediately to treat you for that pneumonia.'¹

At the hospital David waited alone behind curtains in the emergency department. No one would go near him. He shouted for a glass of water and a nurse responded by checking with the doctor first. She returned with the water but was wearing a mask and rubber gloves. David was eventually taken up to the ward and nurses placed him in isolation with a sign on the door that read 'Important: Barrier Nursing' and others saying 'Bio Hazard'. He was nursed in isolation for two weeks and 'never saw anybody unless they had a mask, gown and rubber gloves on'.² By Christmas 1987, three years after his initial diagnosis, David reported that he was 'very much alive'. He had taken up painting and was working

on a series of pictures collectively entitled *Diagnosed AIDS*. To David, death from AIDS was ‘a million miles away’. He did not have ‘time to die. Bedsides, [he wanted] to learn how to play the steel drums next.’ David Ruffell died on 5 July 1989. He was forty-nine years old.³

The United Kingdom’s (UK) acute HIV/AIDS crisis emerged in 1981 and continued until 1996, when the evidence base for anti-retroviral medication was confirmed and concepts of HIV/AIDS began to shift from untreatable terminal illness to manageable chronic disease.⁴ By 1996, over 12,000 people had died from an AIDS-related illness in the UK. These years, before effective anti-retroviral medication became widely available, were filled with suffering.⁵ Many of those who delivered front-line care during this time were greatly affected by their experiences, the resonances of which linger on for them today. Their insightful and revealing memories deserve a prominent place in our accounts of the era.

This chapter draws on new oral histories of nurses who cared for people living with HIV/AIDS (PWHAs), the loved ones of people who died of AIDS-related illnesses, and people who were diagnosed as HIV-positive between 1981 and 1996. Nurses working at the height of the HIV/AIDS crisis felt themselves to be fighting a ‘plague’, and to present their stories today is to illuminate a difficult time in the recent history of nursing. After describing our sources and reviewing the atmosphere surrounding HIV/AIDS in the UK in the 1980s, we explore the early difficulties and guidelines surrounding HIV/AIDS nursing in the UK. In describing the personal draw that HIV/AIDS care had for some nurses, particularly those who identified as ‘queer’,⁶ we show how HIV/AIDS wards often became safe queer spaces, full of humour and campness. These spaces were welcomed by members of the queer community, but may have induced discomfort for some non-queer PWHAs. We frame the work involved in nursing PWHAs as ‘dirty work’, a term first coined by sociologist Everett C. Hughes.⁷ Nurses undertaking this work were marred by their regular interactions with stigmatised individuals, and we discuss this in relation to Erving Goffman’s concept of ‘courtesy stigma’, where those closely linked to people from stigmatised groups also acquire stigma.⁸ Despite this – and perhaps sometimes because of it – many nurses worked to create a home-like environment on hospital wards for PWHAs, and to craft new ways of caring

that involved collaboration with ‘experts by experience’,⁹ and a willingness to bend the rules. Nurses were faced with new kinds of decisions about what was permissible in these times of crisis. These experiences had a profound impact upon their lives, both professionally and personally.

Sources

Personal testimonials provide complex and nuanced accounts of HIV/AIDS, which can challenge ‘sweeping or oversimplified cultural memories of this period’ as a time only of extreme sadness, for example.¹⁰ They also provide access to the experiences and views of hitherto marginalised individuals and communities, and can let us explore hidden or taboo subjects.¹¹ Historian John D’Emilo argues that these sources have the ‘power to enrich, deepen and expand enormously’ the history of sexuality,¹² and numerous scholars have similarly highlighted their value for suggesting new and nuanced histories of nursing.¹³

Face-to-face semi-structured oral history interviews were conducted by the lead author with twenty-two nurses who had cared for PWHA in various care settings across the UK, as well as seven loved ones of people who died of an AIDS-related illness, and four people who were diagnosed as HIV-positive in the 1980s. These interviews were audio-recorded and then transcribed, for ease of analysis and interpretation.¹⁴ Participants were recruited via advertisements in the nursing press, the bulletins of HIV/AIDS organisations, and flyers advertising the project in sexual health clinics. Initial participants then put us in contact with other individuals. Participants were given a choice of where they would like to be interviewed, and most chose to be interviewed in their own home. In line with the views and practice of leading oral historian Penny Summerfield, all participants have been given pseudonyms here. As Summerfield has argued, this offers some protection for interviewees from the ultimate manifestation of the power inequity in the oral history relationship, namely, ‘the historian’s interpretation and reconstruction in the public form of print of intimate aspects of their lives’.¹⁵

There is a danger with this type of history, which pays close attention to individuals’ attitudes and values regarding a sensitive

issue, that interviewees and particularly the former nurses would tell us what they thought we wanted to hear. The fact that the interviews were conducted by a registered nurse (RN) may have helped to put former-nurse interviewees at ease and encouraged greater honesty, in that the interviewer was able to identify and empathise with elements of their story. He was in some respects an 'insider' in relation to the nurses he interviewed.¹⁶ At the same time, there may have been elements of their practice that they did not feel able to reveal or admit to today, for fear that their past professional conduct would be judged in a negative way.

Summerfield argues that people do not simply remember what happened to them, but make sense of the subject matter by interpreting it through the contemporary language and concepts available to them. Therefore, the historian needs to understand not only the narrative offered, but also the meanings invested in it and their discursive origins.¹⁷ Similarly, Simon Szreter and Kate Fisher note that personal testimonies are subjected to 'selection, omission, distortion and retrospection' and that these narratives are influenced with layers of 'cultural consciousness ... communal conventions, idealisation and nostalgia'.¹⁸ Nevertheless, they go on to argue that dialogue with the present should be seen as productive rather than distorting.¹⁹ This is the approach we have adopted here, recognising that these interviews are not an exact representation of past events, but are in conversation with a present in which attitudes and ideas about HIV/AIDS have changed.

This project is based on testimonies from a small number of nurses who volunteered to be interviewed, most of whom had been working on specialist HIV wards. Thus, they are not representative of all nurses during the HIV/AIDS crisis. They are likely to be those who became particularly closely involved and invested in HIV work; other nurses will have had different experiences and behaved differently.

First encounters: nursing care of PWHAs, 1981–7

Community groups such as the London Lesbian and Gay Switchboard and the Terry Higgins Trust (THT) were mobilised by volunteers and led early piecemeal responses to the HIV/

AIDS crisis.²⁰ As discussed and described by historians including Virginia Berridge and Matt Cook, it was not until 1986 that the UK government became more robust and proactive in its reaction to this intensifying problem.²¹ There emerged, as Berridge has described, a sense of wartime emergency.²² That year, the secretary of state for health and social security, Norman Fowler, set up a cross-departmental unit to coordinate government attempts at ‘crisis management’. Beginning in November 1986, and despite substantial Cabinet opposition and a distinct lack of enthusiasm from the Conservative prime minister, Margaret Thatcher, £20 million was spent on a major national public health campaign known by its tagline ‘Don’t Die of Ignorance’. This included television and billboard advertisements, and a leaflet posted to every household in the country.²³ In one television advert, a volcano erupted under a darkened sky and images of cascading rocks gave way to shots of a tombstone being chiselled, as the actor John Hurt gave a portentous voiceover.

There is now a danger that has become a threat to us all. It is a deadly disease and there is no known cure. The virus can be passed during sexual intercourse with an infected person. Anyone can get it, man or woman. So far, it’s been confined to small groups, but it’s spreading, so protect yourself and read this leaflet when it arrives. If you ignore AIDS, it could be the death of you, so don’t die of ignorance.²⁴

As proliferating news reports about HIV/AIDS uncovered and fanned public alarm (and prejudice), the government’s own campaign also drew on tactics of shock and fear. By the end of 1986, such highly emotive ways of communicating had become the norm in much public discourse about HIV/AIDS in the UK. Intermingled with this were anxieties about the supposed collapse of traditional homes and families, about race and immigration, and even about the long-promised nuclear apocalypse. These adverts aired only a few months after talks on reducing nuclear arms had collapsed at the Reykjavík Summit between Ronald Reagan and Mikhail Gorbachev, and a year after the Chernobyl nuclear power station disaster had given a glimpse of what nuclear fallout would mean for the world.²⁵ HIV/AIDS became, in one news headline, ‘a moral Chernobyl’:²⁶ one more disaster that the ills of the age seemed to have brought forth.

Internal government polling after the campaign revealed that 84 per cent of those asked felt confident that the campaign had educated them enough to avoid the risk of contracting HIV. In later years, this campaign would be hailed as a great success.²⁷ The UK government response to HIV/AIDS largely avoided the coercive measures that characterised, for example, official reactions in Sweden, Cuba, and the USA, including travel restrictions, forced disclosure, and quarantining.²⁸ Nevertheless, the broader context of fear was powerful and sustained. Some were uneasy about taking communion at church and chose to dip the wafer rather than drink directly from the cup. Others took their own scissors and combs to hairdressers. Flashpoints for fear included prisons, dentists, and blood transfusions, and hospitals in particular became a source of worry.²⁹

Owing to the limited knowledge about routes of transmission, and the perceived risk of infection to other immune-compromised patients, PWhA admitted to National Health Service (NHS) hospitals were initially placed in isolation on general medical wards. This lack of knowledge, underscored by fear and ignorance, meant that patients were often poorly treated and subjected to theatrical shows of infection control, as recalled and described by Archibald Major. Archibald was an enrolled nurse on a surgical ward in 1983 and remembered a patient who came in with a breast abscess who was also living with AIDS. When the porters arrived to take him to theatre, 'they were completely gowned up. They had disposable trousers over their ordinary trousers; they'd got gowns on, three pairs of gloves, masks and visors.'³⁰ Walter Fredrick, whose partner died of an AIDS-related illness in 1984, remembered sitting with him in isolation: 'a hand would come round the door with food on it and it would just be dumped on the floor'.³¹ Meanwhile, Christian Cowley recalled the 'repulsion and homophobia' that some physicians and nurses directed towards him and his partner, who died from an AIDS-related illness.³²

As early as February 1985, professional nursing association and union the Royal College of Nursing (RCN) recognised that 'AIDS has highlighted serious deficiencies in the ability of some nurses to meet the psychosocial needs of their patients' and published a set of guidelines to remedy this entitled *The psychological support of the patient with AIDS*.³³ These guidelines acknowledged that caring for

PWHA would be challenging over the coming years, and that basic nurse education had, in most cases, failed to help nurses understand lifestyles different from their own. The guidelines stated that it was 'essential that nurses should be aware of their own feelings with regard to homosexuality, bi-sexuality or drug addiction before entering a situation where a patient may feel the need to discuss his life', since a nurse's 'initial and on-going attitudes may greatly affect the psychological outcome for these patients'. Nurses were encouraged to respect the personal and intimate relationships that PWHA had, and to be prepared to provide the person's significant other with the same information that they would normally only give an official next of kin. The RCN guidelines also emphasised that psychosocial care extended to include 'holistic' care, for not just the patient but also their loved ones. Nurses needed to provide emotional and psychological support to patients and their loved ones, from the moment of diagnosis through to palliative care and its related emotional difficulties. The guidelines explicitly stated that this 'care would need to be of a higher standard than previously seen due to the competing confidentiality issues and the emotionally charged nature of the diagnosis and concomitant work'.

Overall, this guidance placed a significant emphasis on the softer nursing skills that seemed necessary to care for this particular group. Christine Hallett has argued that responding to the emotions of patients and their loved ones is one of the 'arts' of nursing which have long been a central and unique aspect of nurses' work,³⁴ and many nurses later reflected on drawing upon these skills in the early days of HIV/AIDS. 'Suddenly here we were involved with the care of these critically ill patients, and nothing was working', remembered one interviewee. 'It felt like all we could do was make them comfortable and support their and their partner's emotions.'³⁵ Myrtle Cleator recalled the tension between official guidelines and providing the kind of care that felt necessary. With reference to a person in the final stages of AIDS, whom she had nursed in 1983, she noted that 'in those very early days the protocol was to "gown up" from head to toe every time you went into the room, even if you were just going in for a chat'. After giving her patient a bed bath and taking off her gloves, mask, and apron, she was about to leave the room when she noticed that he was crying. She 'walked over and gently wiped the tears from his eyes. I knew I should have

put another pair of gloves on, but I just couldn't help myself.³⁶ Recollections of difficult or emotional experiences such as these may have been disclosed as a result of the relationship of trust that was built up between the interview participants and the interviewer.³⁷ Conversely, though, this relationship could have been counterproductive in some cases, leaving individuals less willing to share memories that placed individuals or the nursing profession as a whole in a less positive light.

As hospitalisation and death rates rose, the NHS found itself ill-equipped to deal with the escalating crisis both organisationally and emotionally, as nursing student projects from that time indicate.³⁸ Responding to these emergent difficulties, the Charing Cross Hospital in London set up a Nursing Advisory Committee on the Care of Patients with AIDS in 1985, chaired by Robert Pratt, senior tutor of the hospital's School of Nursing. In April that year the committee published *AIDS: Towards a strategy of care*, which set out policy and procedure for nursing care of patients with HIV/AIDS at Charing Cross. The policy was evidently written in order to standardise the care of PWHA, and to quell anxieties among the Charing Cross care team. 'It is *not* necessary to put on aprons and gloves simply to go into the room to talk to the patient, take in a cup of tea or a meal tray', the policy stated. 'It is perfectly safe to touch patients without wearing gloves.' However, the policy still required PWHA to be nursed in isolation, with a 'Barrier Nursing' poster hung on the door, while the use of disposable utensils and crockery was also mandatory.³⁹ This no doubt derived from the belief, widespread at the time, that HIV could 'possibly be contracted by exposure to saliva'.⁴⁰

The policy at Charing Cross emphasised the physical safety of staff and patients, and lacked discussion or guidance about how to meet the psychosocial needs of PWHA and their loved ones. Emanating from one hospital, it also indicated a paucity of national guidelines governing the care of PWHA at this time and the potential for great variation in levels of care between different hospitals around the country. Interviewees also noted regional variation; those who moved from rural locations to big cities like London and Manchester remembered receiving care from more dynamic, knowledgeable, and inclusive healthcare practitioners in urban centres.

'Looking after our own'

By the end of 1987, around 2,500 people were known to be HIV-positive in the UK, and over half of the 610 people known to have already died from AIDS-related illnesses had perished in this year alone. A significant step towards the professionalisation of the medical and nursing response to the crisis came with the widely publicised opening of Broderip Ward at London's Middlesex Hospital in April 1987: the first ward in the country dedicated to HIV/AIDS care. It was opened by Diana, Princess of Wales, who shook hands during the ceremony with nine patients without wearing protective clothing or gloves. In an interview with London newspaper the *Evening Standard*, an HIV-positive nurse who worked on the ward noted that this gave 'royal approval' to the fact that it was impossible to become infected through social contact.⁴¹ Similar wards as well as community-based HIV/AIDS care services soon followed at sites across the UK in the late 1980s and early 1990s.

Within these services, nursing care began to change. This was partly to do with the increased knowledge and confidence signalled by the Princess of Wales' behaviour, but also flowed from those who worked there. Many of the nurses who elected to practice in these settings identified as queer and felt a sense of responsibility to their community, friends, and partners. Interviews suggested that support was forthcoming from across the queer community, with HIV/AIDS acting as a catalyst for this disparate and sometimes divided demographic to unite. Cecil Fenwick, whose partner died of an AIDS related illness in 1995, mused on this.

The gay community changed, and we banded together. As opposed to being separate and polarised, and always looking out for sex. It was more like, 'we need to get together and look after each other.' If this guy from wherever doesn't have any family and he's sick, we need to support him: buy him groceries, wash his dishes. It became like watching out for your neighbours or your friends.⁴²

Similarly, Cressida White, a nurse who identifies as a lesbian, reflected on her motivations for nursing those with HIV/AIDS at this time. 'I suppose it was about looking after our own', she said. 'It's peculiar really because, for whatever reason, it isn't common

for gay men and lesbians to mix. It was like that before the onset of HIV and AIDS and it's like that again now really. But, during the 1980s and early 1990s, gay men and lesbians really came together. I think it drew out the caring nature of our community.⁴³

Others choosing to work in HIV/AIDS wards were heterosexual men and women whose loved ones had HIV/AIDS, or who simply perceived this as an exceptional health crisis to which they felt compelled to contribute their nursing skills. Some initially drifted into this area of practice through temporary agency shifts, but chose to work full-time in the field when they witnessed and experienced the dynamism and compassion of nursing care in this context. 'To jump into this body of nursing that was about respect, kindness, and gentleness towards these patients and their loved ones was just unbelievable, mind-blowing', one remembered.⁴⁴ Nurses also spoke about colleagues sometimes becoming patients; some nurses were HIV-positive themselves and were embraced by staff and patients alike in these environments. With a variety of motivations, these nurses created distinctive settings for delivering care and were at times symbols of continuity and compassion to their patients in rapidly changing and inauspicious times.

Many interviewees reflected on the high proportion of queer nurses who worked on HIV wards and the resultant humour and 'campness'.⁴⁵ Nurse Gertrude Fell, a trans woman, recalled that 'the ward was outrageous. The Charge Nurse used to have these gold lamé slippers that he would wear especially for the ward round.'⁴⁶ In her book *Dear Fatty*, comedian Dawn French described the HIV ward where a friend was nursed and died as 'the campest place in London', where there were 'nurses in drag and a cocktail trolley at 6pm'.⁴⁷ Meanwhile, Otto Best, who was diagnosed as HIV-positive in 1989, remembered 'a female nurse taking my blood and a male nurse in the corner doing whatever he was doing. She put the needle in, and I said, "Oh, you did that ever so well I shall have to give you a little prick award." To which the male nurse in the corner replied, "Nobody wants to win that, dear!"'⁴⁸ The queer humour that accompanied much HIV/AIDS nursing exemplifies Mary Douglas' account of jokes as 'a victorious tilting of uncontrol against control ... the levelling of hierarchy, the triumph of intimacy over formality, of unofficial values over official ones'.⁴⁹ Removing hierarchies between nurse and patient, generating intimacy, and promoting new values were a key part of nursing on these wards.

Nurses and PWA often spoke in their testimonies about the humour on these wards, emphasising that it was fun to be there despite the brutality of the condition. Participants were very keen to emphasise that this period ‘wasn’t all doom and gloom. There were as many laughs as there were tears.’⁵⁰ Although Farley Faragher, who was diagnosed as HIV-positive in 1985, ‘felt like the Sword of Damocles was constantly hanging over my head’, this necessarily changed the way he and many other HIV-affected people began to live their lives. He said, ‘I realised that I only had a year or two more to live probably, so why not go out with a bang?’⁵¹ ‘You know’, recalled Meredith Frampton, ‘we had a lot of fun on the ward. There was a lot [of] mischief. We made it fun.’⁵² Humour has also been recognised as a means by which healthcare workers rearrange their work, release tension, and create emotional alliances with their teams.⁵³ On HIV/AIDS wards, humour could release tension from the emotional labour of witnessing and coping with the atrocious daily realities of HIV/AIDS, and could create alliances between patients and nurses.

These alliances were also encouraged by a shared sense of community. Queer nurses described wanting to help because they felt that it was part of their duty to help others in their community. ‘I just had to do something’, said one. ‘I couldn’t sit back and watch as this vile syndrome wiped out my community.’⁵⁴ The proliferation of queer nurses requesting to work with PWA saw many citing a preference to ‘take care of their own’.⁵⁵ Others were drawn to the field of HIV/AIDS nursing because they knew how difficult it was to be queer at the time, with increased stigma for a perceived role in proliferating HIV/AIDS. Perhaps most infamously in this vein were the comments of James Anderson, the chief constable of Greater Manchester, who remarked in 1986 that homosexuals, drug addicts, and prostitutes who had HIV/AIDS were ‘swirling in a human cesspit of their own making’.⁵⁶ There was an increase in hate crimes directed towards gay men and ‘jokes’ that took their association with AIDS for granted; GAY and AIDS became crude acronyms – ‘got AIDS yet?’ or ‘arse-injected death sentence’.⁵⁷ Queer women were not immune from this; at the start of the HIV/AIDS crisis in the UK, lesbians were assumed in some quarters to be ‘high-risk’ as well, and some were barred from donating blood as a result.⁵⁸ Experiences of homophobia in public and in medical settings were one factor that encouraged many queer women to provide nursing care to those with HIV/AIDS.⁵⁹



Figure 4.1 Sean Pert (left) and his friend Darren, taken when they lived together in Manchester, circa 1993/4. Darren died on 27 June 1996. He was twenty-seven years old.

PWHA and their loved ones spoke of the positive impact that queer nurses had on their care. When Sean Pert reflected on the nursing care his best friend Darren received (see Figure 4.1) before his death from an AIDS-related illness in 1996, he noted that ‘Gay nurses were a godsend. I was just like, “Oh, thank god, we’ve got a gay nurse.” There was a kind of unwritten understanding and compassion between us.’⁶⁰

Although most patients on HIV/AIDS wards in the UK during this period were white, gay men, this was not the whole picture. Women consistently made up a minority of those diagnosed with HIV/AIDS, and towards the mid-1990s wards started to admit more Black people. In 1997, official statistics recorded over 400 Black individuals with AIDS in the UK; a majority of these were from ‘presumed heterosexually acquired HIV infection’.⁶¹ As described elsewhere in this collection, the epidemic also affected large numbers of injecting drug users, particularly in the cities of Liverpool, Edinburgh, and London. The experiences on the wards of those who did not identify as gay, who may have faced other forms of marginalisation or

discrimination on the basis of gender, race, or drug use, have yet to be explored. As nurse George Jefferson reflected, 'I did occasionally think, would straight patients feel as comfortable in this environment as gay people? This was a small bit, but I was aware of it ... I understand why, up to a point', he concluded, 'because it's kind of reversing something that has been really awful for such a long time. We really want to make sure gay people are getting an amazing service and et cetera et cetera, but we also need to acknowledge there are a lot of straight people that are HIV-positive. Will they feel as comfortable in this environment? Most did', he thought, but 'some didn't'.⁶²

Experts by experience and collaborative nursing

Against the often melodramatic backdrop of discussions or depictions of HIV/AIDS in the media in the 1980s, the relentless march of the disease emboldened some patients to self-organise, to speak up, and to speak out.⁶³ Virginia Berridge has analysed 'the rise of the patient' and the many HIV/AIDS activist organisations formed in the UK in the 1980s and 1990s, looking at patients gaining power through organisations set up to champion their cause.⁶⁴ These organisations were enormously influential in terms of shifting the power dynamics within medicine away from paternalism and towards collaboration. Here, we consider how this played out on the individual level, and its impact upon nursing.

Until the mid-1990s, HIV/AIDS was so devastating and puzzling that it was often those who had the most acute and personal lived experience with it, in the form of their own diagnoses, who were most knowledgeable. Patients were often as well-read and as up-to-date on treatment options and prognoses as their medical teams, meaning they sought recognition and collaboration with their nurses. Otto Best, who was diagnosed as HIV-positive in 1989, typifies this.

A lot of us were young and we had awareness about what the ballgame was, and how fast things were moving. Many of our learning curves were almost the same as the nurses'. The style of nursing us was a shared relationship of a participating nature. You couldn't play the autocratic 'I'm the nurse, you're the patient' stuff, it didn't work. It was essentially a shared nursing experience.⁶⁵

Moys Gillespie, a nurse who worked on an HIV/AIDS ward in the 1990s, reflected that she had learnt a great deal about HIV/AIDS treatments directly from PWHA, offering further confirmation of a newfound parity between nurses and patients; both groups stood together in the face of this crisis – not in abject, helpless suffering, but rather as equals at the cutting edge of medical advances. ‘The guys taught you’, Gillespie remembered. ‘They knew their meds back to front. You’d take the drug trolley around (and there’d be lots and lots), but the guys would say to you “I need that and that.” That was my first example of patients taking control of their own health in terms of questioning. It took a little bit of getting used to, but I thought it was amazing.’⁶⁶ This level of knowledge and ability among some PWHA to express their concerns and choices fed into the shaping of the care environment. Elias Pound, who was diagnosed as HIV-positive in 1988, describes this characteristic from his point of view: ‘We were not a group of people who said, “Oh, would you please give us better care?” We demanded it!’⁶⁷ Aloysius Murphy used the same phrasing, remembering in positive terms the distinctive environment on the HIV/AIDS ward in which his partner had received care and the quality of nursing, adding that ‘I think the patients demanded this’.⁶⁸

The rise of the expert by experience was arguably connected to a broader rhetoric of personal empowerment, developed from challenges to medical paternalism which began in the 1960s. The anti-psychiatry movement, for example, or the broader critique of medicine laid down in Ivan Illich’s (in)famous 1974 book *Medical nemesis*, sought to challenge and disrupt the power of the medical professional and the medical establishment.⁶⁹ The phenomenon of the expert by experience HIV/AIDS patient also had antecedents in the fight for gay rights of the 1970s. Fights for gay rights, anti-psychiatry, and challenges to medical authority all involved activism, and activism of course plays a large role in histories of HIV/AIDS. In the context of nursing, we see not just an expert patient but an activist patient.

This was not the grand-scale HIV/AIDS activism we may expect but, rather, small-scale efforts to change knowledge, attitudes, and norms by influencing and teaching healthcare practitioners so that the experiences of PWHA in the future would be better. Elizabeth

Quayle, who had nursed PWHA in a hospice, expressed this idea and reflected on the PWHA that she nursed, offering her own interpretation for the genesis of the activist patient and the daily struggle they faced on the ward.

These people were really up against it. I also think that they were used to 'bucking the norm', so they've been used to pushing against establishment ... That's what came across to me, and they were now very confident in doing that ... So, there was a lot of 'we don't do that. We don't like that.' And you could feel the challenge in their eyes.⁷⁰

Some patients therefore sought and captured power within their healthcare experiences, through a combination of expert knowledge and an ability to challenge medical authority and to demand a certain quality of life in hospital.⁷¹ Nurses also had to be willing to learn from their patients. Shortly after starting on an HIV/AIDS ward, Marie Kelly recalled sitting on the bed of a patient who had been newly diagnosed with AIDS. He was telling her about all the different types of sex he had and asking about the risks involved. 'I felt so naïve', Marie said. 'I'd never even heard of "S&M", let alone what it entailed! I remember thinking "I've got a lot to learn!"'⁷² Where patients could express themselves and nurses were prepared to listen and learn, care could become more collaborative.

This experience was far from universal. PWHA in prisons, for one, did not have the same sense of agency. Prisons often exacerbated the concerns of PWHA that not enough was being done to help them. John Campbell felt that he knew more than his 'nurses' in prison, having correctly identified that most were not RNs but correctional officers with six weeks of medical training.⁷³ An internal report quoted people in prison stating that the prison doctor 'frightens me because he gives me such poor explanations of what's going on', or that the medical advice received about HIV/AIDS in prison always contradicted that of the THT, leaving PWHA extremely worried.⁷⁴ PWHA in prison were aware that they were sequestered from the NHS, from RNs, from developing medical knowledge about HIV/AIDS, and from voluntary organisations like the THT; they were one example of PWHA whose circumstances severely compromised their ability to become experts, and who did not experience the collaborative care that was praised elsewhere.

Nursing and 'dirty work'

Nurses often reflected on the strain of the labour involved in nursing PWHAs. All the nurses that we interviewed spoke of the intensive physiological and psychological nursing care that was required, and the difficulties that this entailed. Everett Hughes first coined the term 'dirty work' in 1951 and developed it further in 1958; he used it to conceptualise occupations considered socially, morally, or physically degrading or disgusting.⁷⁵ Nurse and researcher Catherine Prebble, in her discussion of psychiatric nursing as 'dirty work', has clarified that these occupations are not inherently dirty, but rather they carry an idea of 'dirtiness'.⁷⁶ Members of a group who carry out 'dirty work' come to personify the work itself, and therefore become 'dirty workers'.⁷⁷

This can usefully be applied to nursing PWHAs. Physically, nurses for PWHAs were intimately involved with the often unpleasant aspects of bodily function: elimination, pain, washing, and handfeeding. Annie Crebin recalled how 'thin and frail' the PWHAs that she nursed in the 1980s and 1990s were: 'young men were literally skin and bones in bed. We had to turn them regularly to stop pressure sores, but each turn caused them excruciating pain.'⁷⁸ Patients' beds would often need changing up to five or six times a night because of night sweats or cryptosporidium diarrhoea. Freda Rutter remembered this in vivid detail, saying that there 'was literally litres and litres of brown water pouring out of these people. And the night sweats; it was like you'd poured a bucket of water onto their bed. They were sopping.'⁷⁹ Many had difficulty eating and drinking owing to oesophageal candidiasis, which was 'literally coming out of their mouths and round their face'.⁸⁰

Socially, nurses were also marred by their regular interactions with these stigmatised individuals, described by Erving Goffman as 'courtesy stigma'.⁸¹ Nurses for PWHAs were expected to provide succour and care for a highly stigmatised group, experiencing severe psychological and physiological distress – a duty that society demanded, but also reviled. A poignant example of courtesy stigma was that many nurses decided to keep their place of work confidential from friends and family, believing that it could give rise to panic, suspicion, and unwanted questioning. Indeed, when Martha Munro told her father that she was going to work on an HIV/AIDS

ward he was unequivocal in his condemnation of her choice, asking ‘Why the hell would you put yourself at risk for a bunch of queers? It’s their own fault they’ve got this disease – it serves ’em right – let ’em rot I say!’⁸²

Some nurses encountered hostility from other hospital staff,⁸³ creating a sense of segregation. Bertha Brown recalled feeling isolated from and stigmatised by colleagues in other departments of the hospital. ‘I can remember being in the canteen with colleagues from the HIV ward, and getting a sense of people looking and not wanting to sit with us.’⁸⁴ Sarah Shimmon shared a similar memory, saying that ‘I felt we were completely isolated and didn’t really mix with other people much in hospital. There was a sense we were slightly apart.’⁸⁵ Consequently, many nurses reported that the HIV/AIDS wards where they worked had less surveillance compared to other wards within the hospital. ‘We were pretty much left to our own devices’, remembered one. ‘People were scared to come onto the ward, so they just left us to it.’⁸⁶ As the next section discusses, this independence from mainstream hospital oversight and activity was not without some advantages.

Testing boundaries and ‘care-crafting’

The stigma that was attached to HIV/AIDS care providers fostered environments where nurses, often free from direct managerial oversight, could dictate care and shift boundaries with much greater ease. Nurses recounted the ways in which the type of care they provided on HIV/AIDS wards was different from that which they had provided in other care settings. Nurses described watching out for the nurse administrator while patients smoked forbidden cigarettes or when pets were brought onto the ward to comfort their dying companion. Couples would lie in bed together behind closed doors or curtains, with no questions asked as to the extent of their intimacy. One nurse took a patient for a ride on the back of a motorbike a few days before the patient died, because it was something that the patient had always wanted to do. Other nurses discreetly palmed clean needles for intravenous drug users.⁸⁷ In this way, nurses collaborated in different ways with their patients, creating new kinds of nursing environments and care. For some, this work was itself a form of activism. ‘We took a stand’, remembered

one interviewee: 'we were activists at a time when support from our leaders and colleagues was mainly absent'.⁸⁸

Nurses remembered becoming aware of the necessity for these environments to be inclusive and welcoming. Jane Bruton had been the sister on an HIV/AIDS ward and spoke of creating a home-like environment that was 'a place of warmth, safety and love'.⁸⁹ Marsha Bausch similarly reflected on the contrast between the HIV/AIDS ward she worked on and other wards in the hospital.

At one point the ward had to move to another ward because they were going to repaint it. They split the ward in half and the other half was a surgical ward, which was run by somebody who'd been in the army – a military charge nurse. The patients were woken up at 6am – full blaring lights went on, drugs were given out and people were left standing 'white and wobbly'. We just had a curtain separating the two halves of the ward. So, in our half of the ward, it would be dark and peaceful, and there might be some sort of earth music playing, with scented candles and aromatherapy. As the patients woke up one by one, we would individually offer them breakfast. We'd make them toast or cornflakes, whatever they wanted. We'd always wait for them to wake up. We'd make sure that they had their drugs, but then let them go back to sleep, if they wanted. It was so marked, the contrast between the wards.⁹⁰

Aloysius Murphy, whose partner died from an AIDS-related illness in 1987, agreed that the HIV/AIDS ward where his partner was nursed and died was 'unlike any other ward. It had an amazing energy, strength, and vitality. Nurses were liberal and vibrant in their care'.⁹¹

As we analysed and interpreted these testimonies, it became apparent that there were times when these memories were more important as an indication of personal development and meaning than as a source of empirical data. Peter Pain, for example, when recalling his time working on the HIV/AIDS ward, stated that 'it was a special chapter of my life ... as I reflect on that time, I always remember the blazing sun streaming through the big windows on the ward and how bright and beaming it made the ward look'.⁹² His memory of sunny weather was not a factual account of endless sunshine, but a way of conveying his happy memories of the time spent working on this ward. This offers a way to understand the subjective experiences shared in interviews and the numerous

constructed identities that they connote, especially in relation to the meanings that these nurses later placed on their work caring for PWHAs. Indeed, Elizabeth Kennedy argues that to supplement the authenticity of the data, historians must learn in this way from the subjective nature of oral history interviews.⁹³

Being liberal and vibrant, as already indicated, could mean breaking the rules – or, rather, creating new ones for this unprecedented situation. This required thinking beyond standard training and policy. Paaie Clague explained that nurses on HIV/AIDS wards ‘had to be really imaginative in our care and work outside the box. On many occasions, this meant we broke the “rules”, which was brilliant. That said, looking back, there were no rules; we didn’t have rules because we didn’t know what the rules were. We’d never done it before.’ The guiding principle in this context was

being human with people, not just being the Nurse. Sometimes we made unorthodox and, on reflection, quite bold clinical judgements and decisions, which nurses on other wards would have probably balked at. That makes it sound like it was unprofessional; it wasn’t – there was a great deal professionalism. We just did just whatever we could to enhance their stay and reduce their fear and suffering. And I can honestly say that every decision we made felt completely like it was the right thing to do.⁹⁴

Paaie’s testimony suggests that the care of PWHAs necessitated new ways of thinking, requiring imagination and confidence. It also required self-reflection and a willingness to question; as Margaret Kidd remembered, ‘[e]very decision you made you looked at and asked why’.⁹⁵

The particularities of HIV/AIDS also meant that nurses had to navigate new and challenging formulations of medical ethics regarding confidentiality. Breaches of confidentiality could include indirect disclosures of an HIV/AIDS diagnosis; for example, a patient’s cadaver wrapped in a body bag would indicate that they had died of an AIDS-related illness, as other deceased patients were not subjected to such robust infection-control measures. There was the worry of a ‘double coming-out’, since for a man to reveal to friends and family that he had HIV/AIDS would also imply or confirm that he was homosexual. HIV-related stigma was also present within communities that were marginalised on the basis of sexuality

or race and ethnicity, and revealing an HIV diagnosis could prompt ostracisation and isolation.⁹⁶ On the specialist HIV/AIDS ward in Edinburgh, where HIV/AIDS was prevalent among those injecting drugs, Elizabeth Quayle recalled that nurses had to be mindful of keeping patients' identities secret in case they were known to one another through drug debts, which could lead to violence on the ward.⁹⁷

Hugo Pearl, an RN in charge of an HIV/AIDS ward in the early 1990s, described in detail one example of the decision-making that nurses engaged in, across often undesignated ethical terrain. His story is worth quoting in full.

This patient comes around the corner from his bed. And he's dressed head-to-toe in leather, carrying a little leather cap. I said, 'And where the hell are you going?' It was like ten o'clock at night. He said, 'I just thought I'd pop out for a drink.' I went, 'Sweet cheeks, I've got a list of medication as long as my arm to get through you. You know what you're like, it'll be an eight-hour thing.' He said, 'I just wanted to go out for a quick drink, I'm sick of being cooped up in here.' And I went, 'I want you back in here in an hour, all right? Where are you going?' He told me where he was going, I can't remember what club or pub, or wherever he was going. And off he trots. I told no one he had left. He signed no release forms, nothing! He was just, 'Thanks love!' and off he trotted. At about one or two in the morning, I get a call from the front hall who said: 'I've got a couple of fellas down here and one of them says he's a patient on your ward.' I thought: 'Oh thank God he's back. Someone's obviously brought him back.' And so, I said to the guy on the phone: 'All right, just send him up.' So, he walks down the ward, it's pitch-black. He's still dressed in leather, chaps, you know, the whole box and dice. He leaned up against the nursing station as pissed as a rat, and he said to me: 'Can my friend stay?' And I said: 'It's not a bloody hostel, dolly. It's a hospital with beds, they're all single.' And he said: 'Aw, he's missed his last bus.' I looked up the top of the ward and there's this guy stood there smiling like a Cheshire cat. He said, 'He can't sleep in the street.' And I thought 'well, that just beggars belief. I'm sorry, you go out, you're a patient on a HIV unit, and you pick up some trade and bring 'em back.' So, I said: 'All right, he can stay.' So, we pulled the curtains round, got him into bed, and you know, the other guy got into bed as well. And I said 'If I hear anything going on behind this screen then I'll be in here every five minutes. This drip better not be stopped

either!’ And I plugged that in and I said: ‘You, smart ass, you will be out of this ward by 6:30 when the buses start because when the day staff come in and find what’s going on, I’m for the chop, not you, all right? So, don’t mess with me, do as you’re told!’ Anyway, I don’t know what went on in there, but sure enough he’d left by 6:30.⁹⁸

There is a knowingness in the telling of this riotous yarn; it is funny and presents itself like a kind of queer pantomime, with closed curtains, costumes, and Hugo’s reprimands and threats to burst in on the pair, even though he was clearly a fairly willing accomplice. It depicts a hospital ward unlike most others, in which patients’ wishes were respected no matter how unconventional, and where humour was never far away.

While Hugo’s clinical judgement and decision-making lay beyond the boundaries of what would have been deemed acceptable by professional codes of conduct (then or now), his actions on that night enabled a one-night stand to blossom into a loving relationship. The visitor who had missed his bus became the patient’s boyfriend, and was with him by his side until he died. Hugo was care-crafting to allow his patient to retain a quality of life that he had lost, not just because of the psychological and physiological effects of the disease, but also because of the ‘social death’ that followed. Social death saw many who were already in an out-group shunned by society, struggling to remain connected to a community.⁹⁹ Letting a patient leave the ward on that night allowed a man living with AIDS a rare moment of re-entry into a social realm that had seemed off-limits.

Previous research has categorised rule-breaking and subterfuge on the part of nurses as ‘responsible subversion’.¹⁰⁰ Our findings complement but complicate this, spotlighting the emotional component to this in the case of HIV/AIDS. The Denver Principles, written in 1983 by AIDS activities in the USA to help guide the care and treatment of PWHA, advocated that healthcare professionals should ‘get in touch with their feelings (e.g., fears, anxieties, hopes, etc.) about AIDS and not simply deal with AIDS intellectually’.¹⁰¹ For many nurses, these feelings were complex; as discussed above, many were drawn to working on HIV/AIDS wards for very personal reasons. Deeply felt emotions mediated the everyday lives of many gay men, including gay nurses such as Hugo, during the HIV/AIDS crisis. This is evident in the personal testimonials from



Figure 4.2 David (lying down) and Eric (sitting) at their home in Boston, MA, 1986. Photograph reprinted with permission by Sage Sohler from her series 'At Home with Themselves: Same-Sex Couples in 1980s America'.

the USA; David, photographed with his partner Eric in Figure 4.2, recalled that he 'hated everyone when [he] found out his [partner] Eric had AIDS, including Eric. I mean, I was angry at him for getting this disease. Angry at myself for being gay, angry for having those feelings of anger.'¹⁰² Luc Ferrier, a nurse who worked on an HIV/AIDS ward in the 1990s and who is also an HIV-positive gay man, described how his social life centred on attending the wakes of friends who had died, where he 'cried and cried until I thought I couldn't cry anymore, then I cried some more'.¹⁰³ Matt Cook has explored emotions in the British context, finding that many gay men felt they had to hide the grief, anger, frustration, anxiety, and shame experienced in the context of 'serial loss and anti-gay backlash trading in blame and fear'.¹⁰⁴ Hugo's responsible subversion may well have been a reaction to this, in that it allowed grief and frustration to be set aside in favour of humour and defiance. This subversion became a celebration of queer joy and virility in the face of death.

Conclusion

The unique nature of the nursing work involved in caring for PWHAs in the 1980s and 1990s had a lasting impact on the nurses that we interviewed. Many said that it had transformed them, not only professionally but also personally. For many of the nurses we interviewed, these memories were so powerful that they reportedly felt like they had occurred only moments ago. Nurses reported that they were still in contact with their colleagues from those years, and that the strong emotional bonds with their peers that developed had not diminished. The impact of this work was treasured, and the period was understood as a time of intense joy and intense sadness, of humanity experienced to the fullest, stripped of façade and pretence. Nurse Hattie Price became emotional as she reflected on what it meant to her to remember this aspect of her nursing career.

It was a special part of my life. It sounds odd, but some of the most joyful memories I have are working on [the HIV/AIDS] ward. It made me who I am now, and it taught me how to be a brilliant nurse. It changed my view on the world, particularly working in an environment that I was the minority, the other [becoming emotional]. It was a ridiculously amazing experience that defined the rest of my life.¹⁰⁵

This chapter contributes to the history of nursing in the UK by highlighting these experiences during the HIV/AIDS crisis of the 1980s and early 1990s, and the ways in which the care of individuals belonging to stigmatised groups was crafted. It reveals the personal draw that HIV/AIDS care had for some, particularly for nurses who identified as queer, and the distinctive nursing environment that was created, in which humour played a prominent role. It also adds to our understanding of the emergence of the expert by experience; assertive PWHAs became experts and took control of their own care, prompting nurses to collaborate with them. In this context, nurses made bold decisions about what actions were permissible in times of crisis.

Nurses caring for PWHAs in the 1980s and early 1990s worked through a long and difficult period, when there were limited biomedical solutions on hand. The unpredictable physical, psychological, and social harms inflicted by HIV/AIDS threatened to overwhelm life on the wards, and placed a heavy burden on nursing

professionals who themselves suffered ‘courtesy stigma’ and had to grapple with complex emotions. In this most difficult of moments, nurses found richness in their work with PWHA by drawing on their ‘artistic’ nursing skills to craft the best care possible. Displaying compassion, creativity, and fortitude, many nurses in the UK joined forces with their patients to forge ahead with collaborative care, and deserve a place in HIV/AIDS history.

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Notes

- 1 David Ruffell, *Walking after midnight: gay men’s life stories* (London: Routledge, 1989), pp. 95–108.
- 2 *Ibid.*, p. 102.
- 3 *Ibid.*, p. 109.
- 4 See, for example, Matt Cook, ‘AIDS, mass observation and the fate of the permissive turn’, *Journal of the History of Sexuality*, 26 (2017), 239–72; Simon Garfield, *The end of innocence: Britain in the time of AIDS* (London: Faber & Faber, 1994).
- 5 See, for example, Colin Clews, *Gay in the 80s: from fighting for our rights to fighting for our lives* (London: Troubador Publishing, 2017); Craig Hanlon-Smith, ‘His story, her story, it’s all our stories’, *GSCENE Gay Magazine*, 7 January 2016, p. 37.

- 6 We have used the term ‘queer’ in this chapter to reflect queer in its broadest sense, not to collapse people together, but to mean those considered queer in whatever (gendered or sexualised) ways.
- 7 Everett C. Hughes, *Men and their work* (Glencoe, CA: Forgotten Books, 1958); Everett C. Hughes, ‘Work and the self’, *Social psychology at the crossroads*, ed. by John H. Rohrer and Muzafer Sherif (New York: Books for Libraries Press, 1951), pp. 313–23.
- 8 The phrase ‘courtesy stigma’ was used by Erving Goffman in *Stigma: notes on the management of spoiled identity* (Harmondsworth: Touchstone Press, 1963).
- 9 An expert by experience (EbE) is someone who is able to articulate lessons and suggestions from their own ‘lived’ experience of health challenges. Their expertise is based on their own individual experiences, enabling them to speak with authenticity. EbEs can also be in a unique position to connect to others with similar experiences, bringing a wider range of ‘lived’ experience views to partnership working.
- 10 Matt Cook, ‘“Archives of feeling”: the AIDS crisis in Britain 1987’, *History Workshop Journal*, 83 (2017), 57.
- 11 See, for example, Tommy Dickinson, *‘Curing queers’: mental nurses and their patients, 1935–74* (Manchester: Manchester University Press, 2015).
- 12 John D’Emilio, ‘Afterword: if I knew then...’, in *Bodies of evidence: the practice of queer oral history*, ed. by Nan A. Boyd and Horacio N. Roque Ramirez (Oxford: Oxford University Press, 2012), p. 269.
- 13 See, for example, Geertje Boschma, ‘Community mental health nursing in Alberta, Canada: an oral history’, *Nursing History Review*, 20 (2012), 103–35; Jane Brooks, *Negotiating nursing: British Army sisters and soldiers in the Second World War* (Manchester: Manchester University Press, 2018); Peter Nolan, ‘Psychiatric nursing past and present: the nurses’ viewpoint’ (PhD dissertation, University of Bath, 1989).
- 14 Anna Green, ‘Unpacking the stories’, in *Remembering: writing oral history*, ed. by Anna Green and Megan Hutching (Auckland: Auckland University Press, 2004), p. 11.
- 15 Penny Summerfield, *Reconstructing women’s wartime lives* (Manchester: Manchester University Press, 1998), p. 27.
- 16 Catherine Prebble, a registered mental health nurse, believed she was an ‘insider’ when interviewing mental health nurses, mainly due to perceptions of a shared stigma by association with mental illness and shared insight into feeling misunderstood by other nurses and by the public. Catherine M. Prebble, ‘Ordinary men and uncommon women: a history of psychiatric nursing in New Zealand public mental

- hospitals, 1939–1972’ (PhD dissertation, University of Auckland, 2007), p. 23.
- 17 Penny Summerfield, ‘Culture and composure: creating narratives of the gendered self in oral history interviews’, *Cultural and Social History*, 1 (2004), 69.
 - 18 Simon Szreter and Kate Fisher, *Sex before the sexual revolution: intimate life in England, 1918–1963* (Cambridge: Cambridge University Press, 2010), p. 51.
 - 19 *Ibid.*, p. 11.
 - 20 The Terry (now Terrence) Higgins Trust is a UK charity that campaigns on and provides services relating to HIV/AIDS and sexual health. It was established in 1982 and was the first British charity to support people living with HIV/AIDS.
 - 21 Virginia Berridge, *AIDS in the UK: the making of policy 1981–1994* (Oxford: Oxford University Press, 1996); Cook, ‘Archives of feeling’. See also Garfield, *The end of innocence*; Norman Fowler, *AIDS: don’t die of prejudice* (London: Biteback Publishing Ltd, 2014).
 - 22 Berridge, *AIDS in the UK*, pp. 6–7.
 - 23 See Chapter 2 in this volume for a detailed analysis of the television advert and leaflet that circulated in Italy at around the same time, and Chapter 5 for the alternative route followed in Wales.
 - 24 These public information films are available online at the British Film Institute’s YouTube channel: www.youtube.com/watch?v=yVggWZuFApI and www.youtube.com/watch?v=iroty5zwOVw (accessed 25 October 2021).
 - 25 Nuclear dangers were thoroughly etched into public consciousness; films such as *Threads* (1984) memorably depicted the extreme medical, economic, social, and environmental consequences of nuclear war on the city of Sheffield in northern England. *Threads* (dir. Mick Jackson; London: British Broadcasting Corporation, Nine Network, 1984), DVD; *The 80s with Dominic Sandbrook* (dir. Alex Leith; London: British Broadcasting Corporation, 2017), DVD; Cook, ‘Archives of feeling’, p. 57.
 - 26 Quoted in Cook, ‘Archives of feeling’, p. 60.
 - 27 Fowler, *AIDS: Don’t die of prejudice*, p. 27; Jon Kelly, ‘HIV/AIDS: why were the campaigns successful in the West?’ *British Broadcasting Corporation News Magazine*, 28 November 2011, p. 6.
 - 28 Steve Connor and Sharon Kingman, *The search for the virus* (Harmondsworth: Penguin, 1989), pp. 6–11; Matt Cook, ‘AIDS, mass observation, and the fate of the permissive turn’, *Journal of the History of Sexuality*, 26.2 (2017), 244.

- 29 Berridge, *AIDS in the UK*; George Severs, 'The Church of England's response to the HIV/AIDS epidemic, c. 1982–2000' (master's thesis, University of Cambridge, 2017); Cook, 'Archives of feeling', p. 61.
- 30 Interview with Archibald Major, 22 February 2017.
- 31 Interview with Walter Fredrick, 18 April 2017.
- 32 Interview with Christian Cowley, 13 April 2017.
- 33 Royal College of Nursing, *The psychological support of the patient with AIDS* (February 1985). The RCN was also active in lobbying Parliament to pass an official declaration of the rights of people with HIV/AIDS in 1992. See Royal College of Nursing Archive (Edinburgh), *The Royal College of Nursing Council minutes: The UK declaration of the rights of people with HIV & AIDS* (RCN 20.2–3), February 1992.
- 34 Christine E. Hallett, 'Nursing: the lost art?', lecture at the University of Tromsø. Available online at <https://mediasite.uit.no/Mediasite/Play/152d249a450941f9bf6b770cf9ba30581d> (accessed 25 October 2021).
- 35 Interview with Polly O'Sullivan, 26 April 2017.
- 36 Interview with Myrtle Cleator, 8 August 2017.
- 37 See, for example, Szreter and Fisher, *Sex before the sexual revolution*, p. 6.
- 38 See, for example, Fiona Huntsman, 'An aid for AIDS' (final-year project, Middlesex Hospital School of Nursing, 1984); Elizabeth A. Cave, 'Equipped to care? Awareness of AIDS and HIV amongst student nurses' (final-year project, Middlesex Hospital School of Nursing, 1985).
- 39 Robert J. Pratt, *AIDS: towards a strategy of care* (London: Charing Cross Hospital Nursing Advisory Committee on the Care of Patients with AIDS, 1985). Emphasis in original.
- 40 Huntsman, 'An aid for AIDS', p. 60.
- 41 Quoted in Garfield, *The end of innocence*, p. 280.
- 42 Interview with Cecil Fenwick, 7 April 2017.
- 43 Interview with Cressida White, 4 August 2017.
- 44 Interview with Meredith Frampton, 13 February 2017.
- 45 Campness is used here to mean 'a characteristically gay way of handling the products of a culture through irony, exaggeration, trivialization, theatricalization and an ambivalent making fun out of the serious and respectable'. Richard Dyer, *The culture of queers* (London: Bloomsbury Publishing, 2002), p. 250.
- 46 Gertrude Fell, interviewed 26 January 2017.
- 47 Dawn French, *Dear Fatty* (London: Random House, 2009), p. 347.

- 48 Interview with Otto Best, 26 April 2017.
- 49 Mary Douglas, *Implicit meanings: selected essays in anthropology*, 2nd edn (London: Routledge, 1999). See also Hannah J. Elizabeth, 'Love carefully and without "over-bearing fears": the persuasive power of authenticity in late 1980s British AIDS education material for adolescents', *Social History of Medicine*, 34.4 (2021), 1317–42.
- 50 Interview with Ethel Caine, 6 September 2017.
- 51 Interview with Farley Faragher, 22 March 2017.
- 52 Interview with Meredith Frampton, 13 February 2017.
- 53 Carmen Moran and Margaret Massam, 'An evaluation of humour in emergency work', *The Australian Journal of Disaster and Trauma Studies*, 3 (1997), 176–9.
- 54 Interview with Emily Skillicorne, 16 June 2017.
- 55 Van Reyk, 'Life during wartime: nursing on the frontline at Ward 17 South at St Vincent's Hospital', *HIV Australia*, 12.1 (2014), 38–42 (at 39).
- 56 Fowler, *AIDS: don't die of prejudice*, p. 18.
- 57 See, for example, Clews, *Gay in the 80s*; Cook, 'Archives of feeling', p. 63.
- 58 See, for example, Julie Fish, 'Our health, our say: towards a feminist perspective of lesbian health psychology', *Feminism and Psychology*, 19.4 (2009), 437–53.
- 59 For a discussion of queer women's support of gay men during the HIV/AIDS crisis see 'His story, her story, it's all our stories', p. 37.
- 60 Interview with Farley Faragher, 7 April 2017.
- 61 Kevin M. De Cock and Nicola Low, 'HIV and AIDS, other sexually transmitted diseases, and tuberculosis in ethnic minorities in United Kingdom: is surveillance serving its purpose?', *British Medical Journal*, 314 (1997), 1747–51, tables 2 and 3.
- 62 Interview with George Jefferson, 14 August 2017.
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- 65 Interview with Otto Best, 26 April 2017.
- 66 Reyk, 'Life during wartime'.

- 67 Interview with Elias Pound, 7 March 2017.
- 68 Interview with Aloysius Murphy, 4 February 2017.
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- 71 Cave, 'Equipped to care', p. 55.
- 72 Interview with Marie Kelly, 22 February 2017.
- 73 Garfield, *The end of innocence*, p. 199.
- 74 David Miller and Len Curran, *The second sentence: the experience and needs of prisoners with HIV in HM Prison System, England and Wales* (London: HM Prison Service, 1991), p. 19.
- 75 Hughes, *Men and their work*; 'Work and the self'.
- 76 Prebble, 'Ordinary men and uncommon women', pp. 199–200.
- 77 Blake E. Ashforth and Glen E. Kreiner, "'How can they do it?' Dirty work and the challenge of constricting a positive identity', *Academy of Management Review*, 24 (1999), 413–34.
- 78 Interview with Annie Crebbin, 2 October 2017.
- 79 Interview with Freda Rutter, 15 February 2017.
- 80 Interview with Elias Pound, 7 March 2017.
- 81 Goffman, *Stigma*.
- 82 Interview with Martha Munro, 17 February 2017.
- 83 This is discussed in the context of Ireland in Martin S. McNamara, Gerard M. Fealy, and Ruth Geraghty, 'Cultures of control: a historical analysis of the development of infection control nursing in Ireland', *Nursing History Review*, 21.1 (2013), 55–75 (at 65).
- 84 Interview with Bertha Brown, 6 May 2017.
- 85 Interview with Sarah Shimmion, 25 January 2017.
- 86 Interview with Freda Rutter, 15 February 2017.
- 87 Reyk, 'Life during wartime', p. 40.
- 88 Interview with Peter Pain, 20 March 2017.
- 89 Gideon Mendel, *The ward* (London: Trolley Books, 2017), p. 20.
- 90 Interview with Marsha Bausch, 13 March 2017.
- 91 Interview with Aloysius Murphy, 4 February 2017.
- 92 Interview with Peter Pain, 20 March 2017.
- 93 Elizabeth Lapovsky Kennedy, 'Telling tales: oral history and the construction of pre-Stonewall lesbian history', in *The oral history reader*, ed. by Robert Perks and Alistair Thomson, 2nd edn (New York and London: Routledge, 2006), p. 281.
- 94 Interview with Paaie Clague, 1 February 2017.
- 95 Interview with Margaret Kidd, 19 July 2017.

- 96 Catherine Dodds, 'HIV-related stigma in England: experiences of gay men and heterosexual African migrants living with HIV', *Journal of Community & Applied Social Psychology*, 16 (2006), 472–80.
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- 98 Interview with Hugo Pearl, 24 March 2017.
- 99 See, for example, Joe Wright, '“Only your calamity”: the beginnings of activism by and for people with AIDS', *American Journal of Public Health*, 103 (2013), 1789.
- 100 See, for example, Dickinson, *Curing queers*, pp. 179–99; Sally Hutchinson, 'Responsible subversion: a study of rule-bending among nurses', *Scholarly Inquiry for Nursing Practice: An International Journal*, 4 (1990), 3–17; Sally Hutchinson, 'Nurses and bending the rules', *Creative Nursing*, 4 (2004), 4–8.
- 101 Bobbi Campbell, 'Second National AIDS Forum', *San Francisco Sentinel*, 23 May 1983, p. 4. Robert 'Bobbi' Boyle Campbell, Jr. (28 January 1952–15 August 1984) was a public health nurse, the sixteenth person in San Francisco to be diagnosed with Kaposi's sarcoma (KS: a proxy for an AIDS diagnosis at the time), and the first to come out publicly as someone living with HIV/AIDS. He wrote regular articles in the *San Francisco Sentinel*, recounting his experiences and posting photos of his KS lesions to educate others. He also helped to write the first San Francisco safer-sex manual.
- 102 Quoted in Sage Sophier, *At home with themselves: same-sex couples in 1980s America* (Boston, MA: Spotted Books, 2014).
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- 105 Interview with Hattie Price, 8 March 2017.