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Recovering mothers' experiences of HIV/AIDS health activism in Edinburgh, 1983–2000

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> I am my own woman … I have overcome a lot of obstacles. … If you can't voice an opinion, make sure there is somebody who can do it for you or help you along the road.[1]
>
> Scottish HIV-positive mother, 1999

> When Clare feels sad about what HIV does to her mother, who is often tired and must have respite care for her illness, she eats jelly. 'I really like jelly,' she said. … Clare is one of the forgotten victims of a disease that came to Edinburgh in the early 1980s when the city was flooded with cheap heroin.[2]
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> Aileen Ballantyne, *Sunday Times* journalist, 1998

This chapter traces how healthcare workers and HIV-affected mothers responded to the AIDS crisis in Edinburgh in the last two decades of the twentieth century. In particular, it examines how women's health needs and needs as carers were met by the creation of new organisations and resources. It explores the ways the lives of HIV-positive mothers in Edinburgh were shaped by interdisciplinary collaborative HIV/AIDS care and activism born out of the daily fight for resources, information, space, and empathetic treatment for women and their families. Activism such as this was often indistinguishable from survival or best practice, occurring in the clinic and the home, in acts of care performed by medical practitioners and family members, and through the voicing and documenting of needs. This work can be traced through a wide variety of texts and archives, and was at the very least a backdrop for many women's experience of HIV and AIDS in Edinburgh.

To focus the analysis, I examine the creation of the Paediatric AIDS Resource Centre (PARC) in Edinburgh, alongside some of the items the centre published and disseminated, as well as other forms of activism the centre supported. PARC's activities were varied, from creating factual leaflets to facilitating training and publishing picture books, shaping mothers' experiences of HIV/AIDS activism both subtly – by training volunteers and broadening general HIV knowledge among the caring professions – and more directly by providing resources to them and their children. It is this textual history, alongside the words of HIV-affected mothers and the professionals who worked with them, that this chapter adds to the history of HIV/AIDS which has too often missed these stories. Following the example of those working with HIV-affected families at the time, I also pay particular attention to how the emotional needs of those affected by HIV were met, attending to the importance of familial bonds between mothers and children. I begin by sketching the landscape of care available to HIV-affected mothers in Edinburgh before PARC was founded, outlining the tone of media coverage, the medical and social care facilities which emerged, and the gap PARC was created to fill.

The chapter ends by examining some of the texts PARC created to facilitate conversations between HIV-affected parents and children after 'it dawned on social workers that [they] … might actually have a lot more children affected by HIV rather than infected by HIV'.[3] I demonstrate how PARC, in responding to a much-expressed need for resources, addressed the perpetual parenting question: what do we tell the children? Analysing PARC alongside the testimony of HIV-affected mothers and those that worked with them allows us to begin the work of recovering mother's experiences of HIV/AIDS, redressing a gap which has too long existed in the historiography.

The sources on which this chapter draws are diverse. For a variety of reasons, some of which are discussed below, the experiences of HIV-affected mothers living in Edinburgh in the 1980s and 1990s form an especially scattered archive. Their voices can be found in contemporary mainstream press, AIDS care newsletters, social work training manuals, medical journals, oral histories, picture books, and anthologies of their testimonies, to name but a few. As the contrasting quotations at the start of this chapter show, some texts present assertive statements from HIV-affected mothers and children, speaking to the networks of care that empowered them. In other contexts, their words appear only as bleak illustrations of profound tragedy, presented in service of an agenda which gave little space to their agency.

While each text offers a valuable glimpse of the lived experiences of HIV-affected motherhood, they all present their own difficulties in terms of their mediated nature and the power dynamics which coloured the disclosures they deliver. In some cases, mothers are spoken about rather than speak, their experiences described in aggregate or fictionalised. Other texts offer examples of the way disclosure of one's HIV status could be empowering, allowing access to much-needed resources or even acting as a form of activism itself. Indeed, disclosure of one's HIV status and the experiences which attended it were so important that some texts devoted pages, chapters, or entire volumes to this form of testimony. In many of the texts that I draw on below, however, the agency and motivations of the speaker are harder to discern. Social work manuals and childcare training texts contain letters, poems, and drawings which allowed HIV-affected and HIV-positive mothers and children to speak back to the health and social care community who worked to meet their needs. At the same time, the textual placement and case study presentation style used in such texts had the potential to turn such salvos into means rather than ends – experiences to learn from rather than sit with. As a historian I am unsure of, and uncomfortable with, the production context of such traces, and yet I want to give them space in the histories I tell, to return them to circulation rather than leaving them languishing unread in social work manuals that no one is using anymore. This is part of the recovery to which the title of this chapter speaks.

As thinking in HIV-related social work developed, workers began to use the term HIV-affected to refer to those 'infected or those who live in a family or community where … carers, relatives or peers have the virus, which will have emotional, social or economic consequences'.[4] As I have argued elsewhere, I use this term in part for its breadth and ambiguity, echoing the instructional social work texts which form part of my archive.[5] HIV-affected encompasses both service users and service providers, and, in the case of texts, producers and their audiences, acknowledging the complex production context of the texts under analysis. The ambiguous relationship between the producers of these texts and their audience is in part the product of the liminal space that health and social care workers who worked with HIV-affected people came to occupy in this period. The HIV/AIDS worker quickly became 'HIV-affected', experiencing 'courtesy stigma' as fears of casual transmission persisted, and they became emotionally compromised by the difficulties associated with their work.[6]

In focusing on mothers' experiences, there are stories which can and cannot be told. Children's needs do feature, but the voices of other key individuals in the lives of HIV-affected mothers have not found space here. Partners, parents, extended family, friends, and lovers all shaped the experiences of HIV-affected mothers, as did the myriad health and social care workers who engaged HIV-affected families. While this chapter acknowledges the ways that queer expertise in fighting for the rights and needs of HIV-affected people profoundly shaped the delivery of HIV care and education in Edinburgh, the voices of LGBTQ activists require more space than this chapter allows. These are histories we still need to write, and I offer this chapter as a starting point in larger project which will write the interconnected history of HIV-affected family life in Edinburgh.[7]

Early responses in the 'AIDS capital of Europe'

At the time of writing, most published histories of HIV/AIDS in the United Kingdom (UK) are largely inattentive to regional specificity, and England often stands in for all four nations.[8] Moreover, owing to the historiography's focus on media representations, policy-making, and gay men's activism, such work is particularly representative of events and experiences in the south of England and London especially, rather than offering a fuller national history of the impact of the virus.[9] Regional specificities are myriad, and in ignoring them we neglect the histories of those who fought on the local as well as the national scale to combat the spread of the virus and its social and its morbid effects. These differences occurred on the grand scale in terms of policy-making and tax spending, but are starker still when we consider differences along a more modest scale: the who, what, when, where, and how of service provision for HIV-affected people. As has been well documented, the 'Don't Aid AIDS' campaign filled television screens across the UK with tombstones, and doormats with 'Don't Die of Ignorance' pamphlets, in 1987. These striking gestures from a national government in search of a cost-effective solution to HIV/AIDS were by no means the most successful or most important assault on the problem in the UK. Indeed, in many ways these grand efforts were woefully deficient in the face of a new illness. Such attempts to halt the spread of HIV through mass education were lacking in details and left the needs of those already infected or affected by the virus largely unmet.

Scotland's experience of HIV/AIDS, while regionally and internationally inflected and influential, was demographically, culturally, and politically distinctive. For example, of those with HIV in Scotland by 1991, 63 per cent had contracted the virus through either heterosexual intercourse or needle sharing, versus 24 per cent for the UK as a whole.[10] Edinburgh, as a city, was disproportionately affected by the HIV/AIDS crisis in the early 1980–1990s, earning it the unhappy title of 'AIDS capital of Europe'.[11] Edinburgh's crisis followed a different pattern from that which was unfolding in London, with new infections predominantly occurring among intravenous (IV) drug users and heterosexuals.[12] While statistics from this period are problematic – recording sex and gender as a binary, sexuality as essentially heterosexual or *other*, and rarely recording ethnicity or age – there are some aspects of Edinburgh's HIV epidemiology we can glean. The retrospective testing of blood samples in 1985 (collected from IV drug users before the growing epidemic was recognised) indicated that between 1,000 and 1,500 IV drug users seroconverted in the city of Edinburgh between the summers of 1983 and 1984.[13] By 1985, 50 per cent of 'known' injecting drug users, meaning those engaged by social, medical, or criminal justice workers, were HIV-positive.[14] By 1987 Edinburgh accounted for 30 per cent of all cases of recorded HIV among women in the UK, and Edinburgh had the highest rate of recorded HIV cases in the UK overall.[15] By 1993, there were 500 'known' HIV-affected children with complex care needs in Edinburgh.[16]

Social workers working with HIV-affected people in the 1980s and 1990s stressed that all estimates were likely to be missing many HIV-affected families. What's more, the vagaries of the epidemiological statistics available failed to record a variety of forms of intersecting need, caused by some of the demographic specificities which shaped the experiences and health outcomes of HIV-affected people. Indeed, in 1991, social worker and expert on the familial dimensions of HIV/AIDS Naomi Honigsbaum charged the unclear collecting and reporting of statistics with creating a 'falsely optimistic view that infectivity in children is statistically insignificant'.[17] Children affected by – rather than infected *with* – HIV were even less likely to receive statistical acknowledgment. Parental status was not always asked of newly identified HIV-positive adults, and children with a non-parental close relationship to someone living with HIV or AIDS largely went unrecorded, with some children even going uncounted when it was the father, rather than the mother, who had the virus. These statistical deficiencies affected the distribution of funding for HIV-affected families, essentially hiding the social needs of those HIV-affected family members who did not fall under the purview of medical treatment or transmission prevention. Despite these quantitative difficulties, it is clear that in Edinburgh women and children were affected by, and in some cases infected with, HIV in higher numbers than elsewhere in the UK. As a result, Edinburgh became a hub of activism and expertise as the HIV-affected and those who cared for them scrambled to address previously unmet needs.

National education campaigns produced by the Health Education Council, Department of Health and Social Security (DHSS), and, later, the Health Education Authority across the late 1980s and early 1990s discouraged unprotected sex and IV drug use. However, the needs of those at risk because they were surviving through sex work, or already dependent on IV drugs, or those already positive or caring for someone positive also needed to be addressed. From 1985 to 1986 England's Central Office of Information ran the 'Heroin Screws You Up' campaign, deploying 'shock horror' tactics. This was matched in Scotland by the more optimistic Scottish Health Education Group campaign 'Choose Life, Not Drugs'.[18] Both were aimed at reducing IV drug use, but met criticism for failing to grasp the social deprivation which led many to become drug users, or the circumstances which resulted in persistent dependence.[19] Similarly, when the DHSS attempted to tackle AIDS with its foreboding 'Don't Aid AIDS' campaign, running from 1986 to 1988 and featuring the 'Don't Die of Ignorance' television advert balefully voiced by John Hurt, Lothian Health Board (LHB) offered Edinburgh's citizens their own health campaigns. LHB and the Lothian Regional Council HIV/AIDS team first ran the inclusive 'AIDS Concerns Us All' campaign, commenced on World AIDS Day 1988, then a few months later launched the similarly upbeat 'Take Care' campaign, begun with much fanfare on Valentine's Day 1989.[20]

While large-scale national and local government public health campaigns attempted to prevent new infections through a variety of media – from TV and radio to posters on buses – the high rates of HIV among women in Edinburgh meant the city rapidly became host to numerous charities and organisations focused on women and their families already affected by the virus. These organisations aimed to prevent new infections, but also strove to meet the emotional, medical, housing, care, and educational needs of those already living with the virus. It is the meeting of these needs that I examine below, foregrounding the specificity of women's experiences of HIV/AIDS in Edinburgh when the city's crisis was at its zenith.

Media-mediated motherhood

'This child has inherited Britain's most terrifying disease – from its mother', declared the tagline of a 1986 *Daily Mail* article titled 'My guilt when they said I'd given my baby AIDS'.[21] I begin by examining this lengthy article, which was featured in the paper's women's supplement *FeMail*, because it offers a typical example of the stigmatising representation of Edinburgh's AIDS crisis and HIV-affected motherhood in the 1980s.[22] Historians must pay attention to articles like this precisely because they are exactly the kind of problematic documents from which researchers might seek to recover mothers' voices. They offer, albeit in a highly mediated fashion, glimpses of some of the factors which shaped the experiences of women living with HIV in Edinburgh in this period, revealing the context which made the creation of PARC so necessary. Moreover, this kind of stigmatising representation formed the context for many of the empowering educational interventions made by HIV-affected mothers and those that loved and cared for them. It offers a flavour of how the reading public might have encountered Edinburgh's AIDS crisis and the mothers it affected. I critique it here to demonstrate the agency-stripping pessimism against which women fought, and to offer a little of the texture of the world built by a press intent on sensationalising AIDS to the detriment of those affected by it.

As I have argued elsewhere, following Steven Kruger, disease narratives and particularly those relating to pandemics allow 'an ordering of events', constructing a sense of 'meaning' or 'reality' which appears to have an authored coherence, 'as though its cause and ultimate reason … might be uncovered'.[23] This 'intentionality' in turn allows for 'moralized understandings', confining culpability and innocence to certain behaviours and characters.[24] Representations of AIDS, Kruger argues, can be divided into two interrelated major narratives: the macrocosmic and the microcosmic. The former is concerned with an 'epidemiological or population narrative', often following the 'historical trajectory of the epidemic' in search of an 'origin', then tracking the epidemic's 'progress', the 'spread of the disease', and finally the 'explosion of cases' within a particular population – an 'at-risk' group – which will finally, in the 'worst-case scenario', result in an 'apocalyptic spread of disease' wherein the virus breaches the boundaries of the 'risk groups', entering the 'general population'.[25] In the latter narrative, an individual's relation to the illness is represented, charting from the point at which contact with the virus is made to the positive test result, the development of symptoms, the AIDS diagnosis, and finally death. Within this microcosmic narrative of AIDS, '[p]assivity is imputed at all stages … except the initial stage, where, too often, a certain "culpable" activity is associated with the exposure to HIV'.[26] It is this latter narrative which the *Daily Mail* article follows.

The article states that 'innocent baby … little Jamie … is one of 29 babies to be infected in the womb because of a parent's drug abuse', firmly placing responsibility on his 'frail' mother and her 'drug addict husband'.[27] Jamie's mother Lorraine is then quoted in confirmation of this guilt: 'Every morning I wake up and blame myself … It makes me angry that Jamie has been the innocent victim of our drug abuse'.[28] Personal culpability for the spread of HIV thus established, the article moves from the intimate blame narrative between Lorraine, her husband, and their baby Jamie to take in the wider epidemic: 'Lorraine is just one of a growing number of Scottish heroin users who have made Edinburgh Britain's drug and AIDS capital.'[29] Edinburgh was first described as Europe's AIDS capital in 1986, in part because the epidemiological significance of its drug-using population was identified relatively early on in its AIDS epidemic, leading to vocal health workers and drug users calling for efforts to mitigate the crisis.[30]

In the *Daily Mail* article, we are told that:

> It is in Edinburgh that the most tragic maternity clinic in the county is to be found. Ward 7A at the Edinburgh City Hospital appears at first sight to be like any other post natal clinic, with the sound of babies' laughter filling the room, but over all lies a pervading sense of terror and guilt.[31]

Among those on the ward is Sylvia, twenty-three, who 'is plagued by infinite guilt for what she has done to her innocent child'.[32] Quoted in *FeMail*, she explained that 'Jonathan's birth was weird. All the doctors had goggles over their heads like space helmets. I supposed they were to protect them from my disease. It was the first time I had met people who were so terrified of AIDS.'[33] Sylvia then goes on to explain the conditions of her care, offering a familiar tale of the isolating experience of contact-free care in an atmosphere of fear: 'In hospital I felt like an outcast, eating off plastic plates and drinking out of plastic cups. I felt like a leper. I couldn't wait to leave hospital.'[34] At no point does the article furnish readers with the knowledge that HIV could not be casually transmitted by social contact, despite this having been established as early as 1983.[35]

The article allows Sylvia the opportunity to explain something of what it was to be an HIV-affected mother, although this is filtered through a veil of blame and hopelessness. 'I'm dreading the day he goes to school', Sylvia is quoted as saying,

> … and the day I have to tell him he has AIDS. How do you tell a wee boy that he has only a 50% chance of life? And how do you tell him that it is all the fault of Mum and Dad? I don't even know, I might not have to. In five years' time we might both be dead.[36]

Worries about how to disclose to children that they or their parents were living with HIV or AIDS were so common an experience that by the 1990s a variety of texts had been created to help HIV-affected parents make such disclosures, many published by PARC. For Sylvia, as one of the first identified HIV-positive mothers, such resources did not yet exist. The article offers a hint of hope for the future when it turns to the discussion of HIV/AIDS experts Drs Mok and Brettle and their work in the City Hospital's 'AIDS clinic'. They quote Mok's explanation that the

> general medical attitude to these mothers is full of gloom and despondency. They believe they have nothing to look forward to but death. For the first time we are offering them something positive. We tell them their future is in their hands.[37]

But this empowering message was merely employed by the *FeMail* article to create a sense of contrasting drama as rising hopes are dashed. It asks in response to Mok's hope, 'But for all their hard work, is their clinic really a success?', before ending with Sylvia's despairing words, 'when you think about it, there's not much they can really do. I will never stop feeling terrified and guilty. And whatever they say, I know it's more likely that I will die than live. What can you say to that?'[38] The gloomy end of the article belies its voyeuristic intent, eliciting sympathy in its general readers while painting AIDS as an isolating and devastating illness happening elsewhere. Although the *Daily Mail* showed little care for the disheartening effects of this kind of narrative, those involved with Edinburgh's paediatric AIDS clinic were working hard to bring an end to the isolation and fear the article described.

Taken on its own, the City Hospital's Paediatric AIDS clinic might not have felt like a success in the face of an illness which appeared to be overwhelming both individual patients and carers, as well as the health and social service sector more broadly. But the clinic was not on its own. Rather, it formed part of a network of emerging services intended to meet the health needs of HIV-affected mothers. These networks, and the actors like Mok who played pivotal roles within them, became the genesis for organisations such as small charities, support groups, campaign networks, or research groups. Indeed, the expertise which accumulated around the health practitioners and mothers at the City Hospital's AIDS clinic would eventually form the basis of PARC, an organisation working to create and disseminate empowering knowledge for HIV-affected mothers and those that worked with them.[39]

‘We had a mission’: Edinburgh’s emerging expertise around HIV-affected motherhood

From October 1985, consultant paediatrician Dr Jacqueline Mok had responsibility for monitoring and following up all babies born to HIV-positive women in the Lothian. During an oral history collected in 2018, Mok recalled that when she was asked to ‘look after these children born to mothers with HIV’ in the first HIV clinic dedicated to the care of children in the UK, she responded by questioning, ‘what do I know about that?’ Public health consultant Dr Helen Zealley, who had requested Mok take up the role, replied by pointing out that nobody else knew anything either.[40]

While HIV in children was recognised in 1982, knowledge on paediatric HIV, rather than AIDS, remained scarce in 1985.[41] Some doctors were still too scared to work with HIV-positive expectant mothers because, as Zealley explained, ‘there’s a lot of blood around when people deliver, people were terrified of blood’.[42] Mok herself joked that the request to set up an HIV clinic for mothers and babies was also to ‘risk your life and be infected’, and recollects being told by other doctors to ‘just keep your clinic down at the city hospital, we can’t have them at Sick Kids’, Edinburgh’s dedicated children’s hospital.[43] Despite this atmosphere of fear, uncertainty, and what Mok described as ‘gloom and doom’, over the next few years Mok was among a small number of health workers in the Lothian tasked with figuring out how to meet the needs of HIV-affected families.[44] Eventually Mok became both an expert in the care of HIV-affected mothers and children, and their educational needs, and in her role as co-director of PARC ensured that HIV-affected, as well as HIV-positive, mothers and children had access to the emotional and educational resources they wanted.

Trying to bridge the knowledge gap around HIV-positive mothers and babies, Mok travelled to New York, New Jersey, and Florida in 1985 to look at what had been set up for children there. However, she found that while expertise was developing globally, little was known about HIV-positive mothers and babies, rather than mothers and babies living with AIDS. Many mothers in Edinburgh were found to be HIV-positive but not yet ill, so the new services were focused on monitoring healthy mothers and babies, as well as treating AIDS. It is worth noting that those mothers who discovered their serostatus during pregnancy were generally advised, where medically and legally permissible, to terminate their pregnancy, in line with advice issued by the Royal College of Obstetricians and Gynaecologists in 1986.[45] Indeed, as one Scottish HIV-positive mother diagnosed at three months pregnant later recalled,

> the medical staff at the time, were very negative. They made me feel worthless really. ... Everyone expected me to get an abortion, medical staff, the whole lot. ... the way I was treated at the time made me feel worthless.[46]

Mothers were advised to terminate their pregnancies in part because it was believed, in the early years of the AIDS crisis, that pregnancy would accelerate the speed at which HIV-positive women developed AIDS, and that mother-to-baby transmission was around 50 to 80 per cent with the prognosis for paediatric AIDS very poor.[47] Despite this advice, many HIV-positive mothers continued their pregnancies and HIV-positive women continued to become pregnant, so the need for dedicated services in Edinburgh grew as the 1980s progressed.

Many HIV-positive mothers' experiences of birth were negatively affected by stigma, barrier nursing procedures, the uncertainty of mother-to-baby transmission rates, and the resultant pressure to terminate pregnancies. Frequently, HIV-positive mothers reflected on the continued feelings of guilt instilled in them by the media and the medical profession. Many also spoke of the anger they felt after experiencing poor treatment during birth. One mother who recalled a particularly traumatic birth described it, and the aftercare she received, as 'the worst four days I have ever experienced', and acknowledged a lasting sense of culpability after the birth: 'I felt really guilty. In my head I saw it as some form of abuse, because I didn't realise at the time that she [her baby] might lose the positive antibodies.'[48] Owing to these experiences, and other vulnerabilities common to HIV-positive mothers in Edinburgh, those working with HIV-affected families had to tread carefully and rebuild trust where it had been damaged. While ties between the voluntary, activist, and statutory sectors were key to achieving this, adaptation and research into what mothers actually wanted from health and social care services were also fundamental.

Postnatal and paediatric care took place inside and outside the hospital clinic, with home visits forming a key aspect of the care and monitoring which structured the first few months of HIV-positive mothers' and babies' lives after a new birth. At first Mok and Dr Ray Brettle (infectious disease consultant at the City Hospital with an interest in IV drug users' health) thought they should hold 'a family clinic' so that 'when the parents would come they would bring their children. But because the parents didn't come … the sort of family clinic became a mish mash of some clinic appointments and mainly home visits.'[49] Established in 1986, initially the paediatric counselling and screening clinic ran 'two sessions a week', but Mok explained that these 'became community based because sitting in my clinic at the City Hospital and expecting these very chaotic families to bring their children just didn't work'.[50] Indeed, less than 20 per cent of families used the Paediatric HIV Service outpatient clinic at Edinburgh City Hospital, with many preferring the home as both more 'convenient' and 'less distressing'.[51] Other families decided to keep the home 'a sanctuary of normality for the child, free from painful interventions', choosing instead to use a general practitioner (GP), health visitor clinic, or their child's nursery.[52] By allowing parents to choose the location of clinical encounters, as far as possible, much-needed trust could be built and the burden of surveillance lessened.

While locations differed, regimes of medical testing, surveillance, and treatment were fairly similar. When the European Collaborative Study (ECS) into paediatric HIV was initiated in 1985, Edinburgh was one of the first centres to join, quickly enrolling babies into the cohort study.[53] The standard testing protocol for babies included in the ECS was onerous. Each baby, as Mok explained,

> needed something like a follow-up at one week, three weeks, six weeks, and then six-weekly until six months, three-monthly until aged two years, and then six- to twelve-monthly. We also had to speak to the mothers in the antenatal period to seek their consent, to explain to them about the purpose of the study. Nobody actually withdrew consent. They were all very willing. They were very interested. Actually they were very thankful that somebody was interested in them and their children.[54]

As the numbers included in the cohort study grew, funding was sought from the Scottish Office to pay half of Mok's salary and to pay for a research fellow. The biweekly nurse-run hospital clinic sessions were replaced with a full-time health visitor to help facilitate home visits, or, as Mok put it with a little exasperation, 'we actually did home visits to actually make sure that we could actually see these children'.[55] From Mok's perspective, home visits were a laborious way of meeting the needs of difficult patients, who were challenging to work with even with this added intervention.

> Unfortunately there was some who would continue to use [drugs], and those were the ones that you never knew when you went to see them, if, you know, they would be awake, what state they would be in, whether they would be cooperative. [56]

Mok's perspective is that of a medical practitioner stepping outside the clinic to meet the needs of her patients and their families. However, her testimony acknowledges some of the reasons why HIV-affected families might have resisted interventions. The predominant route of infection for HIV-positive adults in contact with the family clinic was needle sharing, and so many of the families involved in the study had a history of poor relations with statutory services, which was often compounded by a difficult birth experience.[57] Moreover, the fear of children being taken into care often became a reality for those parents who were unable to recover from their addiction, prompting additional anxieties about dealing with authority figures such as health visitors. Other HIV-positive mothers found interventions frustratingly limited and the uncertainty around treatment exhausting. Writing in 1989 from Edinburgh's Brenda House rehabilitation centre, one HIV-positive mother offered the following angry poetic response to well-meaning medical advice, later included in a social work manual.

> … Tell me now will I die
> Well we have this brand new drug to try
> Would you like it now?
> Would you like it later?
> When you're being sick an' shittin' through a grater
> … Eat well, eat good they say
> On fuckin' what, 10p a day?[58]

As well as the intrusion of health workers and sometimes social workers into the home, the physical nature of tests also caused difficulties. Mok admitted that 'it was a lot of blood' being taken from small babies. While mothers were often 'very compliant … it was the fathers that we got the most flack from. … they either just left during the blood-letting, "oh I canea take this", you know, these great big men, or they would get really angry'.[59] Mok remembers being shouted at when attempts to take blood from babies failed. The pressure to get it right increased by the presence of distressed parents.

Despite these difficulties, by entering the home and offering consistent monitoring, which went beyond HIV testing, medical practitioners were able to build trust. Services run out of the City Hospital's HIV family clinic were adapted to bridge existing gaps in HIV-affected families' healthcare. Realising that 'these are families that never went for their screening appointments', clinic practitioners designed their intervention to be 'a one-stop shop'.

> [T]hey got the developmental screening and then I would take a clinical history to make sure they were okay, you can imagine the anxiety among a lot of these young women, any snuffle they might be on the phone to you, any contact with chicken pox, you know, they might be on the phone to ask for advice, they didn't go to the GPs. They always bypassed the GPs and they would come straight through to the paediatric clinic.[60]

Taking on the role of GP and providing home visits was often one of the more straightforward adaptations that Mok and her colleagues undertook. Much of the labour involved in meeting the needs of mothers and children affected by HIV was far from usual, especially in the early days. Oral histories from health and social care workers emphasise the way that obstructions created by stigma and the newness of their work often meant workers bridged gaps in services by taking on new roles. Workers also consistently acknowledge some level of courtesy stigma, with their family members fearing for their safety and the general public persistently concerned about contact transmission.[61]

In her oral history testimony, Mok reflected on the ways that she and the health visitor who joined her on home visits had to adapt. Fiona Mitchell, who later became integral to producing the children's books PARC published to meet the emotional and educational needs of HIV-affected children, ended up holding babies during blood lettings alongside her more usual health promotion role. According to Mok, 'she would just hold the baby, squeeze the arm, … whatever was necessary'.[62] Meanwhile Mok, when home visits ran long and she missed the bloods pick-up, found herself acting not only as paediatric HIV specialist and impromptu GP, but as delivery driver, running samples to hospital laboratories.[63] Reflecting on the varied and unpredictable nature of this work, Mok concluded: 'But it was fun. We had a mission. We knew what we were doing.'[64] As the needs of HIV-affected families changed, so too would the means by which Mok met her 'mission'. 'This was the realisation that we might not have enough infected children to keep me [Mok] busy … it dawned on social workers that we might actually have a lot more children affected by HIV rather than infected by HIV.'[65]

The genesis of PARC

Even before anyone realised that the needs of mothers and children might be different from anticipated, the 'innovative nature' of Lothian's response to HIV among mothers and babies meant Mok was in demand. Mok soon began to receive 'requests for information on all aspects of paediatric HIV (not purely clinical) from interested parties within the UK, Europe, and further afield'.[66] In July 1986 a study of mothers and babies with HIV similar to the ECS study was initiated in Zaire (now the Democratic Republic of Congo) involving fellow Edinburgh paediatrician Dr William Cutting. Owing to common interest, the two doctors had extensive contact, but it was not until 1988, when a needs assessment of HIV/AIDS in the Lothian was conducted, that the need for a more formal 'resource centre to handle data and information, to ensure the effective collection and dissemination to those requiring it' around paediatric AIDS was mooted.[67] In February 1991, PARC was officially established using short-term funding from UK children's charity Barnardo's and from the European Community. The centre was based at Edinburgh University's Department of Child Life and Health and received support from the university and LHB but, as was the case for many similar AIDS organisations, PARC never received long-term funding, instead relying on a variety of small grants, collaborations with other HIV organisations, and the labour of volunteers. Mok and Cutting both acted as directors, but their positions were unpaid.[68]

The explicit aim of PARC was to 'improve the care of children and families with HIV/AIDS by providing information for anyone involved in their welfare'. According to its profile in the Lothian HIV/AIDS newsletter *Meridian*, it achieved this by:

> Publishing and distributing information leaflets
> Responding to telephone, written and personal enquiries
> Organising training courses for groups of child carers
> Holding annual meetings giving a scientific update on HIV in women and children.[69]

To realise these ends, PARC helped facilitate and support the work of other organisations striving to meet the needs of HIV-affected families, enabling charitable and activist organisations to reach wider audiences. For parents affected by HIV, PARC collated together several leaflets written by Dr Mok with the aid of Fiona Mitchell to form 'a parent information pack'. The pack included 'Guidance Notes for Carers'; 'I am HIV+. What Does This Mean for My Child?'; 'My Child is HIV Infected – How Do You Know?'; 'My Child is HIV Infected – Where Do I Go from Here?'; 'My Child is HIV Infected – Signs and Symptoms'; and 'My Child is HIV Infected – What Treatments Are Available?'.[70]

Partially, PARC's leaflets aimed at HIV-positive parents functioned to prepare them for medical encounters inside and outside the home, securing ongoing consent for health interventions such as tests and treatments. However, because of the media's persistent interest in HIV-positive mothers and their babies, the leaflets also worked to redress misinformation and stigma, empowering HIV-affected families and attempting to instil hope. For example, the leaflet 'I am HIV+. What Does This Mean for My Child?' communicated scientific facts in simple terms, but also described one of the 'aims of follow up' as 'To reassure parents where possible that their child has no *signs or symptoms* of HIV infection [emphasis in original]'.[71] The green-and-white leaflet, decorated with teddy bears dressed as doctors, nurses, and patients, explained that '*All babies born to HIV positive mothers will at first be ANTIBODY*

POSITIVE [emphasis in original]', before reassuring parents that 'The city hospital has been following up on babies born to HIV positive mothers since 1985. So far around 10% of these babies are infected with HIV.'[72] After this important framing, the schedule of intense assessment required for babies born to HIV-positive mothers was then given, followed by a list of what such assessments would involve. The daunting future of intense scrutiny was somewhat softened by the leaflet explaining that:

> Approximately 90% of the children being followed up will lose their mother's antibodies around 12–18 months. When this happens we call the child
> *Presumed uninfected.*[73]

The leaflet ends by acknowledging the onerous nature of the medical scrutiny HIV-affected families were under, thanking parents for their cooperation, and reassuring parents that '*all information regarding you and your child will be treated in strictest confidence*' [emphasis in original].[74] Leaflets such as this acted as reference material, allowing HIV-positive mothers to process their diagnosis and the future regime of tests their baby would undergo in their own time, outside the clinical encounter. Within the clinical encounter, they provided a simple script for care practitioners to use, reassuring parents and persuading them to participate in cohort studies. Armed with the knowledge provided by doctors and leaflets such as this, women could more adequately plan for their future, anticipating the likely outcome of their baby being HIV-negative. These interventions had meaningful impacts for HIV-positive and HIV-affected mothers, redressing the hopelessness engendered by the media's representation of HIV. As one adoptive mother of an HIV-positive toddler explained, 'We had a doctor from the Fife Health Board out to counsel us on the virus and realised what the papers were printing on how you catch the virus was very wrong.'[75]

Alongside the creation of published material PARC maintained a large collection of resource materials on a 'wide range of topics relating to the care of children affected by and infected with HIV' and maintained two databases: 'a medical/scientific' database and one collating 'information on organisations and resources'.[76] The creation of these databases and the library of resources was made possible by the centre's keen maintenance of local, national, and international links, allowing it to benefit from, and exchange expertise on, both local and global scales. Thus, while PARC hosted the second International Conference on HIV in Children and Mothers in September 1993, which was opened by Diana, Princess of Wales and attended by over 500 delegates from all over the world, it also maintained more local collaborations. PARC was a member of the National Forum of AIDS and Children (a UK-wide group), the UK NGO AIDS Consortium, the Steering Group on Children and Families Infected and Affected by HIV/AIDS for Children in Scotland, Lothian AIDS Forum's Functional Group on Education and Prevention, and Lothian Information Workers' Network. These regional ties allowed PARC to draw on the expertise of organisations with Lothian knowledge, dealing sensitively with issues around drug use and sexuality by signposting the activist and voluntary organisations best able to help each HIV-affected family.

Though originally envisioned as an information centre, and a way to formalise the signposting and dissemination of HIV/AIDS information which had become informal aspects of Mok and Cuttings' jobs, the project soon took up a more proactive role. PARC began to organise training days aimed at those working with HIV-affected children. The adaptable and evolving biannual course 'Child Care Workers and HIV' was targeted at participants from 'statutory and voluntary sectors' and carers, and hoped to 'promote good practice in the care of children and families affected by HIV, by sharing experiences and expertise, and encouraging a multi-disciplinary approach'.[77] Through its links with regional, national, and international HIV/AIDS organisations, PARC was able to share a wide range of resources and experiences during these training sessions, while signposting other organisations which might be of use to participants and the HIV-affected families they worked with. For example, the one-day workshop PARC held in October 1991 hosted participants who were nurses, doctors, charity workers, council workers, social workers, and play specialists. Attendees were mainly from Edinburgh, Glasgow, London, and Manchester, but also Liverpool, Dundee, Aberdeen, Inverness, Mid Glamorgan, Essex, Carlisle, Carluke, and Wolverhampton.[78] Discussions ranged from confidentiality to bereavement and education, with the Lothian offered up as a case study of best practice.[79]

PARC was also proactive in its approach to meeting the needs of HIV-affected families. After a UK-wide needs assessment of service providers by PARC's coordinator Alison Angus in 1994, the centre sought funding to create resources not just for HIV-positive parents and the guardians of HIV-positive children, but for the HIV-affected children themselves. The UK needs assessment found that the greatest need was for 'information materials which can be used by the increasing numbers of children affected by HIV in families, who are faced with the loss of either, or both, parents'.[80] Three working groups were created to meet children's needs according to age, split between three and seven, eight and twelve, and thirteen and sixteen years, drawing on existing texts PARC had already collected in its library of resources.[81] In part these resources aimed to overcome the reticence of guardians around talking about HIV to their children, filling gaps in the education of HIV-affected children by empowering those that cared for them and the children themselves. Understanding what parents and guardians needed from PARC to facilitate such discussions and to create such targeted resources required the centre to actively assess the needs of mothers and children around HIV disclosure. This meant asking parents, and also children where possible, what they needed. It also meant facilitating the creation of resources by HIV-positive mothers themselves.

PARC, responding to parents' requests 'for books to help them open up' regarding HIV and 'for books that will help them explain how the virus works', produced or facilitated the publication and dissemination of several texts, both factual and fictional.[82] Among these was *It's clinic day*, a picture book by Ruth Stevens, an HIV-positive mother. The book follows a mother and child visiting an HIV clinic modelled on the City Hospital's clinic. By showing encounters with other HIV-affected children, interactions with the paediatrician and health visitor, and delivering simple information about HIV, the book modelled an ideal clinical visit and scripted the parental HIV disclosure for reticent parents.[83] PARC also published a series of picture books written by Fiona Mitchell and illustrated by Mark Mackensie-Smith, which followed Lucy and her mother. *Maybe another day* (1995) follows Lucy as she comes to terms with her mother's illness, realising it is not her fault.

The sequel, *Missing mum* (1996), shows Lucy learning that she will be cared for even when her mother has to attend hospital, and recognising that there are other adults she can trust with her fears. The year 1997 saw the publication of the final two picture books in the series, *Getting to know Sandra* and *Tell me again what happens*, which dealt with respite care and grief.[84] These simple and brightly illustrated books were designed with blank pages so that children could draw their feelings in reaction to the content and the similarities between Lucy's life and their own. Each text concentrated on Lucy's relationship with her mother and other caring adults, offering a textual aid for difficult conversations. PARC also collated an annotated bibliography of books in *What do we tell the children? Books to use with children affected by illness and bereavement* (1996), advising those working with HIV-affected children on how each text could best be deployed and warning adults to supervise children's use of HIV-related materials to prevent unnecessary fear.

In a similar vein to the Lucy series, PARC produced a large activity pack in a brightly illustrated 'attractive' ring-bound folder, *A resource pack for those working with children affected by parental illness* (1997).[85] Again, Mark Mackenzie-Smith provided the illustrations, ensuring a sense of continuity for HIV-affected families who had used the Lucy series. Comprised of short illustrated stories, worksheets, factsheets, and drawing and writing prompts, the pack concentrated on working through thoughts and feelings about the child's present and future. The pack was piloted by the staff and students from several local schools, as well as the hospice Brenda House, the family-focused drug dependency service the Riverside Project, and the children's charity Barnardo's, in an attempt to ensure it was appropriate.

As with the Lucy series, at its heart the pack was a tool for facilitating difficult conversations about HIV-affected family life, created as much for parents as it was for children. As the introduction explained, while parents

> may have difficulties coming to terms with their diagnosis, coping with illness or with fear of stigma … Children may become confused and fearful from lack of information or misinformation. Their questions may be ignored, answered inadequately or even untruthfully.[86]

While the pack acknowledged that some parents 'refuse to talk or allow others to talk to their children about their illness and its implications for the future', framing this as highly problematic, it also states unequivocally that 'Parents have a right to confidentiality. Children do not have a right to know their parent's diagnosis.'[87] However, because children attended hospital visits, hospices, and had contact with other HIV-related organisations, they were likely to pick up clues about the situation their family was in. Moreover, the pack argued, children 'have the right to participate in decisions concerning their future and to express views on all matters directly affecting them'.[88] The empowering intent of the pack was then clearly stated.

> With help, parents should be the ones to disclose any sensitive information and take responsibility for planning their children's future care. This pack is to help facilitate this process … to help start a dialogue within the family.[89]

The dialogic nature of the pack was in part encouraged by warnings that children 'should never be expected to attempt the work sheets on their own' but rather with an 'adult sympathetic to the child's needs in attendance', owing to the 'sensitive nature of the materials'.[90] For HIV-affected mothers, the pack offered a variety of sympathetic and carefully scripted routes to talk about HIV, AIDS, and death with their children, easing difficult conversations. Moreover, the very existence of the pack, and similar resources, reassured parents that while difficult, their experiences were not unique. Other HIV-affected families had weathered these difficult conversations and lived to tell the tale (in the form of PARC publications).

Conclusion

The lives of HIV-positive and HIV-affected mothers living in Edinburgh in the last two decades of the twentieth century were shaped by a wide variety of factors. Against a backdrop of media interest in Edinburgh's seemingly unusual demographic spread of HIV infection, mothers' experiences were rendered the stuff of newspaper melodrama and misinformation, engendering feelings of fear and guilt in those newly diagnosed. And yet, living in the 'AIDS capital of Europe' meant access to medical expertise and dedicated paediatric services which emerged relatively quickly at

Edinburgh City Hospital. While other cities' medical responses concentrated on the needs of patients with AIDS, the early recognition of a population living with HIV in Edinburgh created opportunities to differentiate and attend to the specific needs of those living with both HIV and AIDS. However, mothers' emotional and educational needs remained neglected by a national public health response aimed at preventing new infection rather than meeting the needs of those already living with the virus. Moreover, in the scramble to deal with the AIDS crisis, the needs of those affected by HIV, rather than infected with the virus, often remained invisible. This ellipsis has been echoed in the inattention the historiography pays to parenting bonds, and in part accounts for the absence of HIV-affected children from the historiography. Mothers' needs, and the needs of their children, were recognised by those that worked with them, but only received dedicated resources after the acute national crisis was brought under relative control.

PARC encapsulates aspects of the medical, educational, and emotional response to the needs of HIV-affected mothers in Edinburgh. Emerging from medical and social care expertise, PARC's ties with voluntary and activist organisations and its informal beginnings meant it was a reactive organisation which understood the needs of those it served. By analysing PARC's evolution from information hub to publisher, this chapter shines a light on just one organisation, albeit one with important reach, which shaped the lives of HIV-affected mothers in Edinburgh. In doing so, the chapter demonstrates that the recovery of histories which include the experiences of women and children affected by HIV is not only possible, but imperative. While the HIV/AIDS activism of HIV-affected mothers, and those that worked with them, was often low-key and hard to distinguish from the day-to-day of work or survival, it deserves its place in the historical record as much as any act of protest or direct action.

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Notes

1 This quote is from a collection of the experiences of HIV-affected and HIV-positive Scots compiled by Brid Cullen, a volunteer and later manager of Support on Addiction for Families in Edinburgh (SAFE). It is fairly typical of the assertive testimony which is often found in AIDS anthologies produced by AIDS activists and the voluntary sector. Brid Cullen, *Colours of hope and promise* (Glasgow: Wild Goose Publications, 1999).

2 This quote is demonstrative of the ways newspapers deployed the testimony of the HIV-affected and HIV-positive. Aileen Ballantyne, 'Learning to let mother go', *The Sunday Times*, 22 February 1998.

3 Interview with Jacqueline Mok and Helen Zealley on paediatric care for HIV-affected children and their families, by Louise Williams, 3 July 2018, Acc18/017, Lothian Health Services Archive.

4 Naomi Honigsbaum, *Children and families affected by HIV in Europe: the way forward* (London: The National Children's Bureau, 1994).

5 Hannah J. Elizabeth, '[Re]inventing childhood in the age of AIDS: the representation of HIV positive identities to children and adolescents in Britain, 1983–1997' (unpublished PhD thesis, University of Manchester, 2016).

6 Erving Goffman, *Stigma: notes on the management of spoiled identity* (London: Simon and Schuster, 2009), pp. 30–1; Ann Sutton, Sarah Morton, and David Johnson, 'Key issues in working with children and HIV', in *Children and HIV: supporting children and their families* (Edinburgh: The Stationery Office, 1996), p. 13; R. S. Barbour, 'The implications of HIV/AIDS for a range of workers in the Scottish context', *AIDS Care*, 7.4 (1 October 1995), 521–36. See also Chapter 4 in this collection, on the related idea of 'dirty work'.

7 This chapter is drawn from a much larger research project investigating how HIV-affected families were built and maintained through love, care, and activism between 1981 and 2016. My hope is that publications which address these other familial relationships will follow. https://wellcome.org/grant-funding/people-and-projects/grants-awarded/whats-love-got-do-it-building-and-maintaining-hiv (accessed 5 March 2022).

8 There are of course exceptions, including Virginia Berridge's attention to Scotland and its influence over English policy, in Virginia Berridge, *AIDS in the UK: the making of policy, 1981–1994* (Oxford; New York: Oxford University Press, 1996). This chapter, and the two chapters which precede it, will no doubt soon be joined by a flurry of important publications stemming from recent and ongoing research which seeks to uncover more regional histories of HIV/AIDS in the UK.

9 Matt Cook, '"Archives of feeling": The AIDS crisis in Britain 1987', *History Workshop Journal*, 83.1 (2017), 51–78.

10 Judith Bury, Val Morrison, and Sheena McLachlan, *Working with women and AIDS: medical, social, and counselling issues* (London: Psychology Press, 1992).

11 It is worth noting that other cities in and beyond Europe also earned this unhappy accolade, as discussed in the Introduction to this collection. Similar high infection rates among intravenous drug users in Switzerland earned Berne the same title, for example. Christine Toomey, 'Drug-haunted Berne makes fixing official', *The Sunday Times*, 2 July 1989, p. 20; Ballantyne, 'Learning to let mother go'.

12 Sheila M. Burns, Raymond P. Brettle, Sheila M. Gore, John F. Peutherer, and J. Roy Robertson, 'The epidemiology of HIV infection in Edinburgh related to the injecting of drugs: an historical perspective and new insight regarding the past incidence of HIV infection derived from retrospective HIV antibody testing of stored samples of serum', *Journal of Infection*, 32.1 (1996), 53–62.

13 J. R. Robertson, A. B. Bucknall, P. D. Welsby, J. J. Roberts, J. M. Inglis, J. F. Peutherer, et al., 'Epidemic of AIDS related virus (HTLV-III/LAV) infection among intravenous drug abusers', *British Medical Journal (Clinical Research Ed.)*, 292.6519 (1986), 527–9.

14 Bury, Morrison, and McLachlan, *Working with women and AIDS*, pp. 10–12.

15 *Ibid*.

16 *Ibid*.

17 Naomi Honigsbaum, *HIV, AIDS and children: a cause for concern* (London: National Children's Bureau, 1991), p. 8.

18 Alex Mold, 'Just say know: drug education and its publics in 1980s Britain', *The International Journal on Drug Policy*, 88 (2021), 103029.

19 Margaret Harker, 'Councils urged: do more in AIDS fight', *Edinburgh Evening News*, 8 August 1988, GD1/12/2/3 (313) AIDS press cuttings, Lothian Health Services Archive.

20 John Street, 'British government policy on AIDS: learning not to die of ignorance', *Parliamentary Affairs*, 41.4 (1988): 490–507; Colin Moore, 'Communicating prevention: the Scottish experience of health

education in the AIDS epidemic, 1981–1996' (unpublished master's thesis, Glasgow, University of Strathclyde, 2019), pp. 55–7.

21 Anne Barrowclough and Marie Scott, 'My guilt when they said I'd given my baby AIDS', *Daily Mail*, 27 October 1986, p. 12.

22 See, for example, William Daniels, 'Secret AIDS watch on a mother and baby', *Daily Mirror*, 21 December 1984, p. 2; Jill Palmer, 'AIDS baby nightmare: mum must wait to see if her baby will live', *Daily Mirror*, 20 February 1985, pp. 1–2; Jill Palmer, 'Wife get AIDS from husband's affair: death risk forces mum-to-be to have an abortion', *Daily Mirror*, 23 October 1986, p. 7; William Davies, 'Double curse of the aids plague city: the drugs were bad enough… now the addicts' needles are creating a horror on a unique scale behind Edinburgh's elegant façade', *Daily Mail*, 11 April 1986, p. 6.

23 Steven F. Kruger, *AIDS narratives: gender, sexuality, fiction and science*, 1st edn (New York: Routledge, 1997), p. 81; Elizabeth, '[Re]inventing childhood in the age of AIDS', pp. 48–9.

24 *Ibid.*

25 Kruger, *AIDS narratives*, pp. 75–6; Elizabeth, '[Re]inventing childhood in the age of AIDS', pp. 48–9.

26 Kruger, *AIDS narratives*, pp. 73–9.

27 Barrowclough and Scott, 'My guilt'.

28 *Ibid.*

29 *Ibid.*

30 C. McCarthy and P. D. Welsby, 'Edinburgh – the AIDS capital of Europe?', *Scottish Medical Journal*, 48.1 (2003), 3–5.

31 Barrowclough and Scott, 'My guilt'.

32 *Ibid.*

33 *Ibid.*

34 *Ibid.* For an in-depth look at nursing practices around HIV/AIDS, see Chapter 4 in this volume.

35 Centers of Disease Control, 'Current trends acquired immunodeficiency syndrome (AIDS) update – United States', *Morbidity and Mortality Weekly Report*, 32.24 (1983), 309–11.

36 Barrowclough and Scott, 'My guilt'.

37 *Ibid.*

38 *Ibid.*

39 Similar histories of integrated HIV/AIDS networks could be told by looking at the emergence of LGBTQ responses to HIV/AIDS in Edinburgh. Much of this history is yet to be written, but see, for health education and policy response, Moore, 'Communicating prevention'; Helen Coyle, 'A tale of one city: a history of HIV/AIDS policy-making in Edinburgh, 1982–1994' (unpublished PhD thesis, University of Edinburgh, 2008).

40 Zealley and Mok were interviewed together by Louise Williams of the Lothian Health Service Archive (LHSA) in 2018. As former colleagues, the conversation flowed freely and informally, with the two joking together and reminding one another of their past experiences with little input from Williams.

41 Jacqueline Mok and Sarah Cooper, 'The needs of children whose mothers have HIV infection', *Archives of Disease in Childhood*, 77.6 (1997), 483–7.

42 Williams, interview with Mok and Zealley on paediatric care.

43 *Ibid.*

44 *Ibid.*

45 Coyle, 'A tale of one city', pp. 118–20.

46 Cullen, *Colours of hope and promise*, p. 101.

47 Williams, interview with Mok and Zealley on paediatric care.

48 Cullen, *Colours of hope and promise*, pp. 101–6.

49 Williams, interview with Mok and Zealley on paediatric care.

50 Jacqueline Mok, R. A. Hague, P. L. Yap, F. D. Hargreaves, J. M. Inglis, J. M. Whitelaw, C. M. Steel, O. B. Eden, S. Rebus, J. F. Peutherer, 'Vertical transmission of HIV: a prospective study', *Archives of Disease in Childhood*, 64.8 (1989), 1140–5.

51 Jacqueline Mok and Fiona Mitchell, 'Communicating with parents and children about medical and nursing procedures', in *Children and HIV: supporting children and their families*, ed. by Sarah Morton and David Johnson (Edinburgh: Children in Scotland, 1996), p. 49.

52 *Ibid.*

53 The European Collaborative Study, 'Mother-to-child transmission of HIV infection: the European Collaborative Study', *The Lancet*, 2.8619 (1988), 1039–43.

54 Williams, interview with Mok and Zealley on paediatric care.

55 *Ibid.*

56 *Ibid.*

57 Mok and Cooper, 'The needs of children whose mothers have HIV infection', p. 483.

58 Honigsbaum, *HIV, AIDS and children*, p. 130.

59 Williams, interview with Mok and Zealley on paediatric care.

60 *Ibid.*

61 Cullen, *Colours of hope and promise*, pp. 78–86.

62 Williams, interview with Mok and Zealley on paediatric care.

63 *Ibid.*

64 *Ibid.*

65 *Ibid.*

66 'Paediatric AIDS Resource Centre (PARC)', *Meridian*, July 1994, GD/22/8/1, Lothian Health Services Archive.

67 *Ibid.*
68 *Ibid.*
69 *Ibid.*
70 *Ibid.*
71 PARC, 'I am HIV+. What Does This Mean for My Child?' (Edinburgh: PARC, 1991).
72 *Ibid.*
73 *Ibid.*, emphasis in original.
74 *Ibid.*
75 Extract from AIDS Bulletin, June 1988, published by Social Work Service Group, Scottish Education Department, quoted in Naomi Honigsbaum, *Living and working with HIV: training guidance for staff in the personal social services* (London: Central Council For Education and Training in Social Work, 1989), p. 63.
76 'Paediatric AIDS Resource Centre (PARC)', *Meridian*, July 1994, GD/22/8/1, Lothian Health Services Archive.
77 *Ibid.*
78 Jaqueline Mok, William A. M. Cutting, Lesley Reid, Joy Barlow, 'Child care workers and HIV' (Edinburgh: PARC, 1991), LHB45/1/4/9 (1:2) & LHB45/1/4/9 (2:2), Lothian Health Services Archive.
79 *Ibid.*
80 'Paediatric AIDS Resource Centre (PARC)', *Meridian*, July 1994, GD/22/8/1, Lothian Health Services Archive.
81 *Ibid.*
82 Kerstin B. Phillips, *What do we tell the children? Books to use with children affected by illness and bereavement* (Edinburgh: PARC, 1996).
83 Elizabeth, '[Re]inventing childhood in the age of AIDS', pp. 214–32.
84 Fiona Mitchell and Mark Mackenzie-Smith, *Tell me again what happens* (Edinburgh: PARC, 1997); Fiona Mitchell and Mark Mackenzie-Smith, *Getting to know Sandra* (Edinburgh: PARC, 1997).
85 PARC Working Group, *Activity pack: a resource pack for those working with children affected by parental illness* (Edinburgh: PARC, 1997).
86 *Ibid.*
87 *Ibid.*
88 *Ibid.*
89 *Ibid.*
90 *Ibid.*