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ARTICLE

The contaminated blood scandal in England: exploring the social harms experienced by infected and affected individuals

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Abstract
During the 1970s and 1980s, over 30,000 people in the UK were infected with HIV and/or hepatitis C because of treatment with blood and blood products for conditions such as haemophilia or through blood transfusion. We used the social harms perspective to understand the experiences of those affected. We conducted in-depth interviews with 41 infected people and 11 family members and analysed the data according to five dimensions of social harm: physical harms, psychological harms, cultural harms, economic harms, and harms of misrecognition. We found that people were harmed by the medical system, the social context that perpetuated stigma and shame against them, and successive governments being largely unwilling to address the many health, social, and economic impacts of infection on families. What stood out were the many reports of harms of misrecognition, which were often experienced as more irreconcilable than the circumstances of infection itself. They were also harms that have been largely ignored.
While patient safety encompasses a broad field of work, much of the research focuses on physical harm and medical error. The social harms lens can provide important insights into patient safety incidents as it can help explain the complexity of the different dimensions of harm that individuals and their families experience.

Keywords: Contaminated blood; HIV; Hepatitis C; Social harms

Introduction

During the 1970s and 1980s, up to 33,000 people in the United Kingdom were infected with HIV and/or hepatitis C because of treatment with National Health Service (NHS) blood and blood products for conditions such as haemophilia or through blood transfusion (Infected Blood Inquiry, 2022a). By 2019, at least 2,900 infected people had died, and people are still dying. The number of affected partners, children, or parents, many of whom were bereaved, remains unknown. Many infected people and their families suffered serious long-term harms (Infected Blood Inquiry, 2023c). The UK government gradually made available some financial and other support from 1988; yet, it was only in 2018 that the national government-backed Infected Blood Inquiry was launched to investigate the circumstances that led to individuals becoming infected because of receiving NHS blood and blood products and to assess the many resultant and continuing impacts on infected people and their families (Box).

Box. Contaminated Blood Scandal in the UK

From the late 1970s through to the early 1990s, tens of thousands of people, mostly in high-income countries – including Australia, Canada, France, Germany, Ireland, Italy, Japan, the UK, and the USA – received blood or blood products that carried significant risk of infection with HIV and/or hepatitis C. Supplied from pooled donations (mostly from 'high-risk' donors in the USA), people continued to receive these products despite increasing evidence of the risks involved (Feldman & Bayer, 1999).

In the UK, up to 1,250 people living with bleeding disorders, including 380 children, were infected with HIV, and between 2,400 and 5,000 people were infected with hepatitis C. A further 26,800 people were infected with hepatitis C following blood transfusion (Infected Blood Inquiry, 2023b). Many people were co-infected with HIV and hepatitis C or/and hepatitis B. Some infected people passed HIV infection on to their partners. Fewer than 250 of the people with bleeding disorders known to have been infected with HIV are still alive.

The response of successive UK governments to what has become known as the Contaminated or Infected Blood Scandal has been described as a lack of willingness to act. Two initial inquiries into the scandal failed to fully investigate the extent or causes of the harms: the Archer Independent Inquiry set up in 2007 (Archer et al., 2009) and the 2015 Scottish Public Inquiry into Hepatitis C/HIV-acquired infection (The Penrose Inquiry, 2015). In July 2017, over 400 infected and affected people brought a group legal action against the Government, seeking compensation for infected people with bleeding disorders and their families. Later that month, the UK Government announced the establishment of what became the Infected Blood Inquiry.

The issues investigated by the Inquiry included how much the UK government, blood services, other NHS services, and medical practitioners knew about the risks of infection, whether sufficient and adequate information was provided to patients and families, and if there had been a 'cover-up' (Infected Blood Inquiry, Infected Blood Inquiry, 2024a). In its final report published in May 2024, the Inquiry documented that infected and affected people experienced serious long-term mental, physical, social, and economic impacts, while spending decades being denied recognition of harm and refused adequate compensation. Only on publication of the Inquiry's report did the UK Government issue a formal apology for these events (Prime Minister's Office, 2024).

In December 2024, the Government documented the actions that had been taken in response to the Inquiry's recommendations (Cabinet Office, 2024). This included setting up a compensation scheme to be delivered by a newly established Infected Blood Compensation Authority (IBCA), with a funding commitment of £11.8 billion (Paymaster General, 2024). However, continued delays and a perceived lack of transparency in implementing the compensation scheme have recently prompted the gathering of additional evidence and hearings by the Inquiry: *'The decision to hold hearings . . . reflects the gravity of the concerns expressed consistently, and repeatedly, to the Inquiry. . . . People infected and affected do not have time on their side. Our goal is . . . to address the concerns, and help [the authorities] gain the trust of those who have had to wait many decades for recognition and compensation'* (Infected Blood Inquiry, 2025). At the time of writing, the Inquiry continued to gather evidence.

Although referred to as the 'biggest treatment disaster in the UK National Health Service history' (Archer et al., 2009) (p. 103), harms caused by the contaminated blood scandal appear not to have received systematic attention in the patient safety literature beyond the implications for blood safety systems (Lancet HIV, 2015, Weinberg et al., 2002) and transfusion medicine (Goodnough et al., 1999). A few studies explored medico-legal consequences with a main focus on contaminated blood scandals in France (Kazarian, 2019) and Canada (Orsini, 2007).

Traditional conceptions of patient safety are not adequate to understand the harms experienced by those affected by contaminated blood (whom we refer to as 'infected and affected people' hereafter), although it should be noted that these conceptions are not intended to address the experience of harm. For example, the World Health Organization (WHO) defines patient safety as 'the absence of preventable harm to a patient and reduction of risk of unnecessary harm associated with health care to an acceptable minimum' (World Health Organization, 2023). As Mitchell et al. (2023) have observed, patient safety discussions have an implicit focus on physical injury to patients, frequently caused by technical error. While there is increasing recognition of the 'non-physical' consequences of medical errors, including emotional, psychological, social, and financial harms, these tend to be less systematically studied (Ottosen et al., 2021, Sokol-Hessner et al., 2019, Vincent, 2003, Gallagher et al., 2003).

Ottosen et al. (2021) investigated the long-term effects reported by patients and family members who experienced adverse medical events. They distinguished experience of primary (physical and/or emotional) harm resulting from the event itself, and secondary harm as the consequence of how the event was dealt with by the institution where it occurred, including (further) physical, psychological, financial and social impacts. Secondary harm as conceptualised by Ottosen et al. is akin to the notion of 'compounded harm', which may arise when human considerations of trust and relationships in the context of safety incidents are inadequately addressed (Wailling et al., 2022).

While these conceptualisations are helpful, they primarily focus on discrete harmful events and may not adequately capture the sustained, indeed cumulative, harms that people affected by contaminated blood experienced. We here use a 'social harms' lens to more comprehensively assess the different forms of harm experienced by those affected by the contaminated blood scandal in the UK. Developed within critical criminology, this approach highlights the structural context of social problems and considers how states or large corporations cause various forms of harm in society (Hillyard and Tombs, 2007). Social harm reflects 'the relations, processes, flows, practices, discourse, actions and inactions that constitute the fabric of our society which serve to compromise the fulfilment of human needs and in doing so result in identifiable harms' (Pemberton, 2016) (Chapter 2, p. 11). This is relevant in the context of the contaminated blood scandal, which the Infected Blood Inquiry described as 'systemic, collective and individual failures to deal ethically, appropriately, and quickly, with the risk of infections being transmitted in blood, with the infections when the risk materialised, and with the consequences for thousands of families' (Infected Blood Inquiry, 2024a) (p. 2). The analyses presented here are a starting point for further debate about the use and usefulness of the social harms perspective in the context of patient safety.

Methods

We draw on in-depth interviews conducted as part of a wider study that sought to assess the nature and scope of the need for psychological support for individuals and their families affected by NHS-supplied infected blood and blood products and the requirements for psychological support to meet these needs (Cyhlarova et al., 2023).

Public and patient engagement

This study was conducted from August 2022 to August 2023, when the Infected Blood Inquiry was inviting witness statements from and held public hearings involving infected or affected people. We were alert to the added burden that our study might place on participants as it would require them to reflect on their experiences as survivors and/or bereaved family members in the context of the wider Inquiry. We consulted organisations providing support to infected and affected people, including the British Red Cross, Haemophilia Society, Haemophilia & Bleeding Disorders Counselling Association, Hepatitis C Trust, and Terrence Higgins Trust, to help shape the study. These organisations provided feedback on research materials (information sheet, interview topic guide), which we incorporated. They also acted as facilitators to engage infected and affected people to participate in the study.

Participant recruitment

We recruited infected and affected people through two routes. First, we consulted the British Red Cross, the Hepatitis C Trust, and the Terrence Higgins Trust, who advertised our study to their newsletter subscribers, or by word of mouth, inviting potentially interested people to contact the research team (December 2022-January 2023). Thirty-six infected individuals or family members expressed interest via this route and 24 were interviewed between January and May 2023.

Second, we drew on the 2022-23 Service Satisfaction Survey of infected people and their dependents who received financial support from the England Infected Blood Support Scheme (EIBSS) at that time (NHS Business Services Authority, 2023). The survey included an option for respondents to participate in research on psychological support and to provide their contact details to the research team. A total of 366 EIBSS survey respondents indicated their willingness to participate in further research (20% of EIBSS survey respondents). Of these, we contacted a purposive sample, seeking to capture a range of socio-demographic backgrounds (age, gender, region of residence, ethnic group). Of 63 survey respondents invited, 28 agreed to be interviewed during April and May 2023.

Data collection

Interviews used a semi-structured topic guide developed through consultations with experts and support organisations, and explored participants' experiences of the contaminated blood scandal and the impact it has had on their wellbeing, along with views on and experiences of counselling, psychological and other types of support. We also collected broad demographic information. Most interviews were conducted using the video platforms Zoom or MS Teams ($n = 31$), followed by in-person interviews ($n = 11$); the remaining 9 interviews were conducted via telephone. One interview involved two participants (a couple). Interviews lasted an average of just under 60 minutes (range 41 to 73 minutes). Written consent for participation and having the interview recorded was confirmed verbally at the beginning of the interview. Participation in interviews was entirely voluntary, and participants were able to request the interview or the recording to be stopped at any time; no such request was made. Participants were offered £35 in compensation for their time (gift voucher or cash payment); travel costs were reimbursed where relevant.

Analysis

Interview recordings were transcribed and anonymised. Data were organised and managed in Nvivo and coded by EW with assistance from the study team. The initial coding structure was based on our research questions and objectives. These codes were supplemented, refined, and recategorised within the parent-child node structure after an initial stage of inductive coding, followed by axial coding to examine the relationship between in-vivo codes. The initial analysis primarily followed a thematic approach while also drawing on grounded theory approaches, including constant comparison and analysis of deviant cases (Thorogood and Green, 2018).

For the present analysis, we reorganised relevant existent child nodes in line with five categories of social harms described by Tombs (2019): (i) *physical harms*, such as death, hospitalisation, other (longer-term) effects, exacerbation of existing conditions (e.g., chronic disease); (ii) *psychological harms*, including direct trauma and trauma associated with grief at loss of loved ones and survivor guilt, suicidal intentions, self-harm, depression and/or anxiety; (iii) *cultural harms*, relating to 'harms produced by having the ways of living to which [people] are accustomed or acculturated either disturbed or .... removed' (p. 72); (iv) *economic harms* at individual, organisational or societal levels; and (v) *harms of misrecognition*, ranging from lack of respect for human dignity and integrity to systematic contempt, including the constant struggle to be heard. With regard to economic harms, we only assessed individual-level harms, although there are clearly broader societal impacts, for example, from family breakdown, education and/or employment disruption to lost productivity, alongside costs associated with treatment of the health consequences of infection (Infected Blood Inquiry, 2023a).

Ethical approval

Ethical approval was granted by the Observational/Interventions Research Ethics Committee at the London School of Hygiene & Tropical Medicine (Ref: 28215). Written and verbal consent were sought before interviews, and participants were reminded that they could stop at any time. This reminder was reiterated by interviewers when participants appeared upset or distressed by the conversation.

Findings

We interviewed 52 people: 41 infected individuals and 11 affected family members (10 bereaved). Most participants were female (62%), aged 51 years and over (77%), and identified as White British (71%). We report findings according to five categories of harm: physical, psychological, cultural, economic, and misrecognition, using quotes to further illustrate particular points. Participant numbers starting with a '1' refer to infected people, those starting with a '2' to affected people.

Physical harms

Most of the infected people we interviewed described living with long-term health conditions associated with their infection(s) and their treatments, which had life-changing impacts on their wellbeing.

The vast majority of those interviewed had contracted hepatitis C and many of the long-term impacts we document here relate to hepatitis C infection. There were reports of how infection had complicated the treatment of pre-existing conditions and exacerbated other health conditions. Treatment of hepatitis C involving interferon/ribavirin became available in the 1990s and was frequently mentioned as especially challenging, because of the side effects. People described their experience of treatment as *'horrendous . . . . absolutely awful'* [126] and feeling *'sick as a dog'* [134]. One spouse reported that interferon treatment had not been an option because of their partner's renal failure (*'there's 50:50 chance that it's going to knacker your kidney transplant. And that was just too big a risk'*). The infection finally successfully cleared once direct-acting antivirals became available by the mid-2010s, albeit with significant side effects (*'I thought he was a goner at that point because his body just seemed to be struggling to cope with the drugs'* [206]).

Several participants had developed cancers or other long-term health conditions because of their infection(s). This was often the case for people infected with hepatitis C but who were only diagnosed much later.

> *Didn't find out until 2016. Well, been at the hospital so much in the last few years before then, got diagnosed with a lot of autoimmune things that I've now been told are triggered by it. I had cancer because of it. So, yes, that was a bit of a shock. I had treatment in 2017, but yes, it's completely utterly and shattered my life.* [105]

Some who had received hepatitis C treatment had successfully cleared the virus, but several had already suffered advanced liver damage which, by that time, was no longer curable (*'I look back and just think, 'Need he have bothered having that treatment?''* [206]).

Among those infected with HIV, there was appreciation of how treatment had meant surviving, in particular, by those with haemophilia who had seen many of their contemporaries dying. But treatment with azidothymidine came at a cost of other long-term health problems such as osteoporosis, neuropathy and other long-term impacts.

> *But, I mean, I don't want to get too melodramatic, but it has cancelled out all the good things that have happened, for me, in terms of HIV. Like, all the [medications] eventually have*

> *controlled my condition, given me a future but that future is now full of pain and immobility because of a single side-effect caused 20-odd [years ago]... The only thing going for it is it doesn't begin with H because everything else in my problem list begins with H, this one begins with P for peripheral neuropathy.* [116]

Psychological harms

The impacts on people's emotional states that were predominant across the interviews were: grief and loss; guilt; depression, fear, and anxiety. About half of the study participants explicitly mentioned that they had experienced trauma and most described incidents that caused them significant distress when discussing their current state of wellbeing.

Direct trauma

Indicators of trauma were evident in most interviews with infected people. Some experiences related to the infection itself and treatment side effects, while others related to being told they were likely to die as a result of their infection(s). Many coped by suppressing their feelings. Some participants described their trauma in general terms of being infected and then coping with the consequences, while others reported specific traumatic events.

> *But because I was pregnant at the time, I was sort of coerced if you like into terminating my pregnancy at seven months. So I had to go through labour, I was put in a separate room to everybody else. People were covered in masks. Sort of like what you see when you see Ebola now.* [102]

For some, trauma responses were an ongoing problem, often related to or triggered by encounters with health care (*'the sound of my feet on the tiled floor echoing back from the wall'* [114]). In one instance, a participant who had been infected through transfusion following a post-partum haemorrhage described her experience witnessing her daughter giving birth.

> *I was surprised at how quickly I was back into the, 'This is me 30, whatever it was, years ago. This is how it happened', and thinking – and I just couldn't be involved. [...] I just wanted to go home, even though it should have been all very lovely and been a lovely delivery and all the rest of it. But, yes, just sitting there thinking, 'No, that's it. I want to go home now. Can't cope with this'.* [129]

Many participants expressed rage and anger at what happened to them and the catastrophic impact that receiving contaminated blood or blood products was having on their lives. Some reported becoming aggressive and having *'violent outbursts'* [129] that often came from out of nowhere, scaring family members, including children.

> *[I]f I had a knife in my hand and a chopping board, I'd be stabbing the chopping board. And it was very, very concerning to me, because it was very, very out of character, totally out of the blue. And I felt like I was endangering myself and potentially anybody else who might have been around me.* [109]

Grief

Trauma associated with grief was a common experience. Grief related directly to mourning those who died because of their infection including friends, siblings, partners, parents, and grandparents. There were also many accounts of grief about loss of their future, including relationships and children, education, careers, jobs, and livelihoods. We return to some of these later.

Perhaps the theme spoken about with the deepest sadness was the impact that infection had within families, particularly parents and children, with expressions of grief about loss of lives that could have been (‘*my oldest son said - I didn’t live, we existed. [sobs]*’ [103]). Parents spoke with profound regret and despair about not being able to be the parent they wanted to be and knowing that their children were denied the childhood they could have had, had they not been unwell (‘*I was the worst mother under the sun. [....] I wasn’t there for them*’ [107]), with at times distressing consequences, such as children being taken into care (‘*[my son] had to be fostered out when he was six months old, this was due to [the parent’s] cancer and the chemotherapy*’ [113]).

Some people talked about their sadness about not having been able to have children and the impact that this had on their relationships with partners. We noted above the experience of one woman who felt pressured into having a termination of pregnancy on medical advice. Another woman whose partner had been infected with HIV described not being offered sufficient support or advice when considering the implications for having children.

> *It was sheer utter, you know, brutal negligence really. Instead of kind of like sitting and talking and saying, ‘Well you know, what support do you need? Are you actually fertile? Do you know what you do? Do you know when you’re supposed to have sex’, you know. You know, it’s like that, you know, just the basics, so it was awful.* [101]

People talked about lost periods in their lives (‘*We grieve for ourselves*’ [120]). Some felt that they had lost years to illness or treatment. People infected with HIV described being told not to expect to live long and so not to aspire to careers or make long-term plans (‘*[W]hat’s the point of having a career when you’re going to be dead*’ [135]). Others reported a gradual realisation that they had always assumed they would die young because of their infection (‘*I hadn’t made any plans because I assumed that wasn’t going to be an issue*’ [129]).

Guilt

Expressions of guilt took a variety of forms. People with haemophilia recounted parents feeling suicidal with guilt over the suffering they felt responsible for, while participants who had been infected as children described feelings of guilt because of the perceived impact their infection had on their parents. Where mothers contracted infection through transfusions linked to their birth, children expressed feeling guilty and ashamed for ‘causing’ their mother’s infection.

Other forms of guilt that were expressed by some were feelings of survivor’s guilt, for having ‘*a future*’ [116], or minimising their own profound suffering, since ‘others had it worse’ (‘*I mean I’m thinking, Jesus man, I’m playing with sweets here by comparison to where she is*’ [130]). Some participants also reported feeling guilty for using services or for receiving financial compensation (referring to interim compensation payments made to infected individuals and bereaved partners registered with the UK infected blood support schemes in October 2022 (Infected Blood Inquiry, 2022b)), when people with more severe health conditions may need the money more urgently.

Depression, anxiety, and fear

People’s mental health suffered as a result of the infected blood scandal, with many participants reporting having either diagnosed clinical depression or more general feelings of sadness. Anxiety, fear, worry, and uncertainty were also commonly expressed by study participants.

> *My husband’s on antidepressants. The amount of grief he’s had because he’s had to give up work to help look after me and help me do things, help with the children and psychologically, it’s affected him. It’s taken away his job, it’s taken his pride.* [105]

At their worst, feelings of depression, being overwhelmed, and of having no agency or control prompted suicidal feelings, ideations, or attempts; often this was related to the treatment of hepatitis.

Fear of treatment not working was commonly expressed. This was in part because of the debilitating side effects, but also because of fear of possible resultant complications or recurrent infections.

> *I was on treatment for about 18 months, partly because I was too scared to stop it, because I've heard and I've researched that it comes back, that it can come back. [. . .] I'd been told to stop taking it [. . .] [a]nd I continued to take it off my own volition. And it made me so ill I could hardly walk. I was shaking. I couldn't function. I couldn't talk to my family. I couldn't do anything.* [126]

There were also wider worries and fear of infecting others, and uncertainty about the risks. Many of those infected with hepatitis C told us that they had been given very strong warnings about taking precautions when they were informed about infection in the 1980s and 1990s, and which had created '*a sort of deep-seated restraint on getting involved with other people*' [137]. Misperceptions of risk of infection pervaded peoples' lives, with constant worry of infecting others undermining relationships with loved ones ('*I have a fear of going too near the grand-children*' [134]).

> *And one time my mum, even my mum, I had a drink of coffee there, she just put the cup in the sink and put bleach in it. Sorry, she said, put the cup in the sink I'll bleach it later. That's my own mum.* [141]

Some people avoided using services such as dentists or barbers. One woman with heavy menstrual periods reported being '*paranoid*' and bringing bleach to work in case any blood spilled.

Cultural harms

Cultural harms reported by participants were mostly linked to stigma and discrimination associated with infection and the related impacts on their lives and career aspirations. In some cases, people had to move house and their social networks were disrupted ('*when they found out we got painted AIDS across the door*' [121]). One participant, who had '*graffiti put on the back of [her] house*', described how discrimination ('*kids getting picked on*') had led her daughter to get a criminal record from being '*always in fights because of [her mother's infection] . . . She can't have a life because of that criminal record*' [141].

Cultural harms were closely intertwined with feelings of grief and loss of what could have been, as described above. This was often expressed in terms of careers not experienced or potential not achieved, or, in one case, not following a 'regular' path.

> *So, that's something which I – that transition was hard and took me a long, long time, and even now I'm sort of – I'm not aimless, I'm sort of – but it's [the] thing about I've never wanted a career. I've not adapted to social norms because that wasn't how my life was projected.* [135]

In some cases, changed careers had substantial financial consequences in terms of loss of future income, and although people did accept their situation, the underlying sadness about lost opportunities was often palpable.

Commonly, the ability to trust others had been compromised by receiving contaminated blood; this led many participants to feeling profound isolation.

> *I was very, very careful about who I told but even so some close friends were also quite shocking really, and again teachers, you wouldn't believe. I'm still shocked now that they thought that we were unclean and didn't want to associate with us, and kept their children away from us.* [208]

Many never or very rarely disclosed their infection, sometimes creating awkward interactions in people's private and professional lives. For example, one man was shamed by a colleague for not wanting to participate in a blood donation drive at work, for *'not want[ing] to help people'* [134], while desperately trying to get out of the situation. One other participant described how the instructor of a first aid course they were attending referred to people with hepatitis C as *'dirty, disgusting'* people [131]. When others were forced or felt they had to disclose their diagnosis, they often felt that they needed to explain their situation (*'You never say it's because of the way I lived, you always want to clear yourself because you don't want people to think badly of you'* [137]). There were accounts of supervisors telling colleagues about individuals' illness and being 'ghosted', dismissed, or forced out of work. One person recalled needing to bring his own cup to the pub so that he, and his friend who had been infected with HIV through receiving contaminated blood, would not infect other patrons.

These experiences led some participants to express a great need for secrecy about their experience, which, at best, undermined social relationships or, worse, destroyed them.

> *And then everything that came up at the [Infected Blood Inquiry], just hearing again and again and again layers upon layers of hell and having to live in secrecy, having to keep everybody at arms' length, having to literally cut myself off from so much because I can't share for the risk and especially the risk where my son was concerned.* [111]

Even years after being infected, some of the respondents we spoke with chose to give anonymous statements to the Inquiry, *'because I couldn't bring myself to put my name on something that was out there attached to the hepatitis'* [129].

Economic harms

Economic harms experienced by infected and affected people often occurred because of difficulties related to education or work. Participants reported not completing or leaving education early, and not achieving what they might have otherwise ('*It hit me mid-career, and the consequence, the potential financial loss if enormous. And looking back to the 1990s I was not able to do, was not able to perform and deliver what I could have done*' [140]). Several participants lost their jobs and careers, often on grounds of poor health, although this was at times driven by open discrimination.

> *I would have been still in my good job. I had a really good job, which I enjoyed. [. . .] Done that for 15 years . . . until one of the guys started to hint, "Oh, he's got AIDS," [. . .] And then because I had so much time off because of hospital appointments and that, I had to lie sort of thing . . . And then in the end I told one of my bosses. The next thing I know I've been called in and basically fired.* [121]

The financial consequences could be severe (*'They retired me on health grounds . . . and I've been living of [benefits] ever since'* [121]), in some cases resulting in inability to pay off mortgages or losing the family home altogether. While the economic impacts of infection were devastating in themselves, the associated personal losses could be even more profound.

> *Yes, so with every emotion I'd gone through, then I lost my job. Bless them, they was very good, they left my job open for about seven months; in fact, they'd gone over the allotted time. But I couldn't give a date I was going back, I didn't know if I was going to be alive the next week, the*

> *way my mind was racing. And it was at that, my very lowest point there, that I'd considered taking my own life.* [120]

Many participants commented on the interim compensation payments made available to infected people and bereaved partners in October 2022, and the anticipated additional compensation payment following the publication of Infected Blood Inquiry final report in May 2024 (Infected Blood Compensation Authority, 2024). There was common recognition that this would not make up for the loss, hurt, and grief that people have experienced.

Many participants expressed mixed feelings about compensation payments, thinking of it as 'blood money', and while some saw it as a way to support (and 'pay back') their children for lost childhoods, others expressed great uncertainty about how to think about it and use it. In several cases, lump-sum payments made to infected people as part of the government support schemes or the interim compensation payments caused further harm as no support was offered to help recipients deal with the sudden influx of large amounts of money.

> *Well, like I say, back to that first [government] payment, that £20,000, I pretty much blew that in a year in a purple haze [. . .] [It was like] 'Here you are. Have that' [. . .] 'OK, cheers. Thanks'. So, yes, I wasn't living at home. So, yes, lived in a flat with a load of mates. So yes. money wasn't spent wisely, put it that way.* [118]

Harms of misrecognition

Accounts of harms of misrecognition tended to dominate our interviews, and they were deeply interconnected with many of the psychological and cultural harms described above.

Lack of respect for human dignity and integrity

Nearly half of the participants reported feeling mistreated or abused by and/or distrustful of health care staff and the NHS more widely. Distrust of those in medical roles was particularly common ('*[Doctors are] supposed to be the ones who look after you, not the ones who make you worse*' [117]). We also heard expression of strong feelings of betrayal at being infected through health care procedures, especially upon learning later that the risks were known at the time. This hurt was sometimes described as more difficult to comprehend than the circumstances of the infection itself.

> *Because you have an innate trust in these organisations that, you know, you go into a medical situation, you believe everything that you should have is sterilised, is clean, is good for you, is going to make you better. And it wasn't the case at all.* [103]

Instances of lack of respect for human dignity ranged from health care professionals performing diagnostic tests without people's knowledge or consent and of diagnoses being withheld. A common experience was finding out about the diagnosis by accident or being told about it in unprofessional ways.

> *Some doctor [came] in and goes, 'Oh, who are you?' and so I said who I am, and he goes, 'Oh, you're the kid with [hepatitis C.]' And I went, 'No. I'm here for the test to find out if I've got it'. And then he shut the door and bolted very quickly.* [117]

Not being given (adequate) information was common. One respondent reported that their parents were told that they had been exposed to '*non A, non B hepatitis*' without any other information, which the parents interpreted to mean that their child had neither hepatitis A nor B. It was only later that they understood that 'non A, non B' was the name of a disease which their child did have.

Information communicated to patients was, at times, so sparse that infected people were also not told when their treatment had been successful or that they had cleared their infection. Participants commonly reported receiving no meaningful support, in some cases simply being handed a leaflet about their infection only.

> *And after I just sat in silence. [The GP] downloaded some sheets and he said, 'Take those home and read them. It's about hepatitis C and HIV', and I said, 'Does that mean I've got both? Does that mean I've got hepatitis C, I've also got HIV?' He says, 'As far as we know, we don't think so', and I said, 'Well, I'd like to know'. Anyway, that really was the final thing before going off to the local hospital to be treated by a specialist consultant.* [119]

A repeated account was being diagnosed and sent away, which often resulted in devastating consequences. One woman reported that neither she nor her husband received any sort of psychological counselling or practical information about trying to conceive after he was diagnosed with HIV. She later contracted HIV from him.

Contempt

Many participants reported experiences that crossed the boundary of lack of respect for human dignity towards instances of perceived or actual contempt on the part of medical staff specifically, and the NHS and government more widely. For instance, participants commonly reported that medical staff assumed they were sex workers or injection drug users, had alcohol abuse issues, or had become infected through same-sex activity.

> *It was a very harrowing experience sitting in that room with the doctor asking me – before he told me what my symptoms were, or the conclusion of the blood tests, he actually asked me about my lifestyle. He was quite forceful with his questions in that had I had sex with other men? Had I had rough sex with other men? Did I drink to excess? And at the end of all the questioning, I can't think of any other questions – or he obviously asked the question, 'Is there any other situation you can think of that you've had other people's blood passed to you?'* [119]

In some cases, medical staff refused to test children at risk of infection and to treat people because of their infections. Medical staff were described as dismissive, particularly to mothers with young children, who reported having symptoms consistent with hepatitis C who had to ask or demand multiple times to be tested. One woman was alleged to be an alcoholic, and when she told her doctor that she did not drink alcohol, she was nonetheless told to *'cut down on the drinking'* [138]. After hearing about the contaminated blood scandal on television, she demanded a test and was finally diagnosed two days later. The doctor reportedly knew throughout this process that she had had a blood transfusion in the past.

We also heard several accounts of denial of the seriousness or impacts of medical treatments by medical staff. Having a diagnosis of hepatitis C infection was reportedly minimised as unimportant and an issue that would not need to be addressed for decades, despite evidence that was available at the time showing that it could lead to fatal outcomes.

> *I think it was five years, or four years after he had got the all-clear from this dreadful thing, that we discovered on a routine sort of scanning that he had liver cancer. And then they said, 'But of course you will'. When they told us about it, we were together with the consultant, and they said, 'Well, of course you would have known that the hepatitis within five years can cause liver cancer' and I was shocked again because I didn't know that.* [208]

Similarly, for people with haemophilia who had also been infected with HIV, hepatitis C was seen as a secondary or tertiary concern only. One woman who underwent the treatment to clear her hepatitis C infection was only told after she and her partner had trouble conceiving that infertility was a known treatment side-effect.

Discrimination by medical staff was an experience that several participants related to, describing being made to feel *'dirty'* or *'unclean'*. Such feelings could become so consuming and literal that participants described scrubbing themselves raw to try to remove the proverbial dirt of a life-threatening infection.

> *[W]hile I was in the hospital I got wheeled in to day surgery and they put a big red cross across me. 'She's contaminated, stay away from her'. [. . . .] And they put me in a different theatre, and they really made a big hoo-ha and I said 'Look I'm cured, I haven't got it now', but that upset me, and then I went back into the day ward, and everybody was looking at me like I was a leper basically. It was horrible.* [139]

As noted in the introduction to this paper, the UK government has gradually made available some financial and other support since 1988, including, from 2011, payment for psychological support and counselling (Cyhlarova et al., 2023). However, many of those we interviewed reported poor experiences when trying to access this support, which in itself was described as a unique source of harm. One person described the process of applying for help as '*. . . so traumatic. I mean, I literally felt suicidal having tried to get the help*' [105]. Although applications for support were meant to be assessed on a balance of probability, participants spoke about how they were subjected to allegations of having 'caused' infection through their own behaviours, and how they had to convince assessors and make every effort to get support.

> *Yes, but when they gave me the letter [refusal of financial support] back, their decision is because, because they can't find it, none of the proof that I had the blood transfusion, they're saying that maybe I was a junkie at the age of 13.* [121]

Others reported being made to feel that they were beggars or trying to steal money, or being told that they had misremembered key events like receiving a blood transfusion. We heard several accounts from people who were required to prove their eligibility for support by providing their medical records, but discovered that these had been destroyed, redacted, or were missing altogether, either by accident and without authorisation, or in line with NHS policy.

We also heard numerous reports of applications for support being rejected, sometimes multiple times. The government support scheme's justifications for rejection included that infections via contaminated blood provided by the NHS had occurred after September 1991 (the initial cut-off date for eligibility for compensation through the government support scheme (Infected Blood Inquiry, 2024c)) and incorrect assumptions about individual routes of infection. While some people fought until their applications were approved, others simply gave up, sometimes losing the will to fight while undergoing treatment for their infections.

Discussion

In this study we used the social harms lens to begin to systematically assess the different forms of harm experienced by people affected by the contaminated blood scandal in the UK. To the best of our knowledge, the social harms framework has not been used in the health literature more widely, or the patient safety literature specifically. We argue that traditional conceptualisations of patient safety and harm are insufficient for understanding the permeating impacts of the contaminated blood scandal. The social harms lens, in contrast, allows the multiple harmful consequences that have followed from the scandal to be captured; it acknowledges that harms have several dimensions and rarely occur in a linear fashion but are layered, cumulative and interact, and 'in combination they synergistically produce new and heightened levels of harm' (Tombs, 2019) (p. 60).

Mirroring those reported by the Infected Blood Inquiry (Infected Blood Inquiry, 2024b), our findings demonstrate that people were harmed by the medical system, by the social context that perpetuated stigma and shame against them, and by successive governments largely unwilling to act on a 'catalogue of failures' (Infected Blood Inquiry, 2024a) (p.2) and to address the many health, social and economic impacts that infection of and through contaminated blood had on thousands of families. Our analysis considered five dimensions of harm as proposed by Tombs (2019), based on Pemberton (2016) and others. Some of the identified harms are more readily apparent than others, in particular the physical harms, with study participants recounting the very many direct and indirect effects of infection and subsequent treatment, and their long-term health impacts. Our research suggests that infected and affected people have found it more difficult to reconcile harms of misrecognition than their initial experiences of infection. In addition, it is these harms of misrecognition that remain largely unacknowledged and unaddressed outside of the Inquiry. The physical harms are perhaps also the only harms that have been responded to by the NHS in some way, albeit slowly in many cases. Our data demonstrates that other harms have had devastating impacts, too, but that these had been largely ignored or only belatedly, and largely inadequately, received some form of government recognition, including through the set-up of successive schemes to provide financial and other support to people with HIV and their dependents from 1988 and people with Hepatitis C infection from 2004 (Infected Blood Inquiry, 2024a), as well as limited payments to enable beneficiaries access psychological support and counselling from 2011.

The notion of misrecognition has only recently been acknowledged as an important facet of patient safety (Wailling et al., 2022), with Mitchell et al. (2023) introducing the concept of 'dignitary harms' which are caused by 'disrespectful, humiliating, or dismissive conduct' (p. 35). There remains debate whether dignitary harms should form a core component of patient safety, given the challenges of 'proving' that dignitary harms have taken place, how to identify these and who should be held responsible.

This last point highlights the need for further debate of the nature of 'harm' and how it is conceptualised, in particular whether harm is to be considered a cause or an effect or both. In some of the literature, adverse events are described as the cause and 'harms' are considered as the resulting effects (Wailling et al., 2022) while in other conceptualisations, 'harms' cause physical, psychological, social, behavioural, and financial impacts (Ottosen et al., 2021). We found in our analysis that the physical, psychological, cultural, and economic consequences were clear, whereas the impacts categorised under 'harms of misrecognition' functioned more as negative feedback loops whereby the harm experienced is both a consequence of earlier harm (receiving contaminated blood and/or blood products) and the cause of later harm. For example, discrimination may not be a harm in itself, but it results in harm both as emotional distress and the creation of disadvantage through the unfair denial of or access to appropriate services. Tombs' conceptualisation of social harms is useful for expanding the recognised reach of the consequences of the contaminated blood scandal, but further clarification is required.

This raises a broader question about applicability of the 'social harms' perspective to patient safety. It could be argued that the scale of the contaminated blood scandal lies outside the scope of patient safety, which understands harms as 'preventable' or 'avoidable', whereas infection through contaminated blood and blood products has, for a long time, been viewed as 'unavoidable adverse effects of medical treatments', and a persistent claim that 'nothing had been done wrong' (Infected Blood Inquiry, 2024a) (p. 120). However, as the Infected Blood Inquiry concluded, the scandal 'could largely, though not entirely, have been avoided' (Infected Blood Inquiry, 2024a) (p. 5).

We argue that the social harms lens helps provide important new insights into patient safety incidents more generally as it can reveal the complexity of different dimensions of harm that individuals and their families experience, thereby informing more systemic approaches to protecting patients. At the core of any such system must be an acknowledgment of people's experiences and of the harms they suffered. Similar to what our study participants expressed, those seeking redress and reconciliation after adverse medical events stress the need to be heard, for concerns to be taken seriously, to be treated with sensitivity, for a transparent assessment and common understanding of the circumstances that have led to the adverse event and for an apology that incorporates an admission of responsibility (Shaw et al., 2023). The need of a duty of candour has been growing in the UK, particularly in response to high-profile breaches within health and policing (Gardiner et al., 2022).

What has come out most strongly from our interviews is the irrecoverableness of the harms. There is no scheme that can undo the infections or the damage to quality of life, but people we interviewed emphasised the importance of an acknowledgment of their experiences and of the harms they suffered. The Infected Blood Inquiry led by Sir Brian Langstaff was reported by participants to be 'cathartic' and provided an avenue for public recognition of the injustices and harms faced by infected and affected people (Carlisle et al., 2025). On publication of the Inquiry's final report in May 2024, the UK government finally accepted responsibility for the failings that led to the contaminated blood scandal, apologised, and accepted the moral case for compensation (Prime Minister's Office, 2024).

Strengths and limitations

We sought to recruit a wide range of infected and affected people, and we were able to interview people from a fairly broad age range and across regions in England. There was a larger number of women and people identifying as White British than are seen in the UK population (Cyhlarova et al., 2023). The latter likely reflects the demographic composition of the infected and affected communities although there is no comprehensive data on the total infected and affected population. We conducted interviews as the Infected Blood Inquiry was ongoing, which may have affected the willingness of people to participate in our study.

As noted, this study was part of a wider project that sought to understand the need for psychological support for infected and affected people. Data was thus collected for a different purpose and applying the social harms perspective retrospectively has been challenging. For example, our study frame did not explicitly explore the economic harms that infected and affected people experienced, and, although our interviews provide some insights, we were able only to touch upon much wider impacts that the contaminated blood scandal had on individuals and society as a whole (Infected Blood Inquiry, 2023a). The materials collated by the Infected Blood Inquiry, which includes evidence provided by some 4,000 infected and affected people, may allow for a fuller exploration of this issue.

Conclusions

This study has demonstrated the value of using a social harms perspective to better understand the impacts of the contaminated blood scandal in the UK. By moving beyond patient safety, which often focuses on physical harm and medical error only, our research shows the importance of recognising the layered, cumulative and interactive nature of harm. The contaminated blood scandal shows that harms extend far beyond the physical, encompassing emotional, social, cultural and economic dimensions that have long-lasting and often irrecoverable consequences.

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