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COMMUNITY FOCUS

The impact of the Contaminated Blood Scandal on the next generation: the state of the evidence

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The Contaminated (or Tainted) Blood Scandal was a worldwide event that infected many people, including people with haemophilia (PwH), with blood-borne diseases. This has had a significant psychological impact on the families involved, alongside the physical and financial toll. Although some studies have focused on those directly affected – PwH, their families, and the community – very little is known about the intergenerational impact. This narrative review explores the impact on the children of PwH affected by the contaminated blood, demonstrating a significant gap in the understanding of the families' experiences.

Keywords: *Haemophilia; Contaminated blood; Hepatitis; AIDS; Iatrogenic harms*

The Contaminated (or Tainted) Blood Scandal (henceforth referred to as the CBS) was a worldwide event that infected many people, including people with haemophilia (PwH), with blood-borne diseases in the 1970s-1980s ^[1,2].



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A survey of published literature on the impact of the Contaminated Blood Scandal on the children of those affected finds a limited focus and general paucity of information. The authors highlight a need for a broader understanding that enables intergenerational trauma to be addressed.

This not only impacted PwH with loss of health and life from liver damage secondary to hepatitis, HIV, and AIDs, but their families as well. Many adult children of those PwH experienced the CBS during their formative years as parents, siblings and other relatives became unwell or died. Some may have lost both parents during this period, as many partners of PwH also contracted the diseases. Many then had to make similar decisions about their own or their children's treatment. This experience may have left this group of PwH and their families with trauma that is being passed down the generations.

Transgenerational transmission of trauma has been a known phenomenon since 1966 ^[3], where children

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of those affected by the Holocaust experienced consequences of their parents' experiences. This and similar studies can be transposed to the families of PwH who were affected by the CBS, as many people in this community were lost within a short period of time. The shared environment influenced by that traumatic experience can cause psychological, behavioural, and social changes for those children ^[4]. In some cases, children lost one or both of their parents or lived with the shadow of their infection through their lives. The collective trauma for PwH and their families can be communicated down the family line through the ways parents or others act around the child and from the child's own reaction to the situation they are in ^[5].

This paper presents a narrative review to explore the literature to date on the personal and intergenerational trauma within the haemophilia community. The aim is to explore the current evidence in academic and other published literature that highlights the experiences of community members, identifying directions for future research.

BACKGROUND

The development of factor VIII concentrate (FVIII) was a major development in haemophilia treatment, allowing people with haemophilia A to have their needs met at home. However, it required up to 40,000 units of blood to be mixed and concentrated to create it, which allowed a single blood donation contaminated with AIDS, HIV, or hepatitis to affect the whole batch of treatment, infecting those who received it ^[6]. This risk was increased due to the use of units of blood from high-risk individuals and communities in the US, including prison residents ^[7]. The risk of blood-borne disease was known as early as 1971 ^[8] but heat treatment to prevent transmission was not introduced until 1985 ^[9].

The actions taken by officials, authorities, and suppliers of blood products to safeguard and reduce the risks to PwH and others has been described by Leveton et al. as "the least aggressive option that was justifiable" ^[1] and meant that the speed of transmission through the haemophilia population was not slowed. Leveton et al. note that, by 1976, 80% of PwH in the US were positive for the antibody for hepatitis B, with up to 26% having clinical hepatitis. In addition, choices made by individual clinicians in the UK set the infection risk for PwH accessing their service; each specialist centre received funding from their district general hospitals and went on to source the treatments they would use with PwH with some guidance from the United

Kingdom Haemophilia Centre Directors' Organisation (UKHCDO) ^[10].

In the UK, several inquiries ^[10,11], including the current Infected Blood Inquiry ^[12], have demonstrated the loss of life and the iatrogenic harm suffered by the haemophilia community. However, there remains limited published literature on the impact on both individuals and the haemophilia community in the UK.

MATERIALS AND METHOD

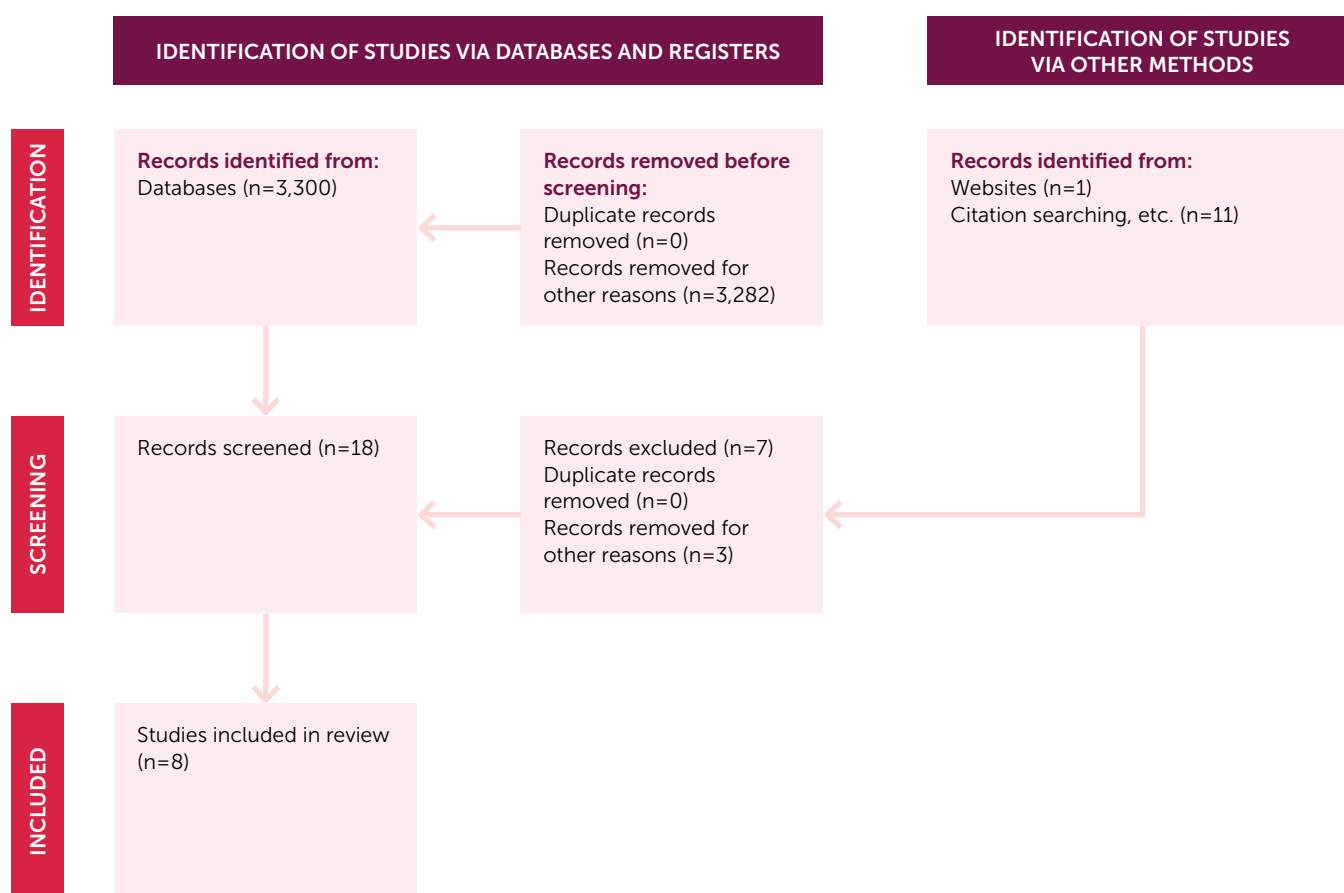
A literature search was undertaken using PsychINFO, PubMed, EBSCO, WorldCat, and MEDLINE, with the Boolean search strategy to combine the following keywords: tainted OR contaminated blood scandal AND haemophilia* OR hemophilia* (US spelling) (Figure 1). An additional search for grey literature including dissertations was completed using search engines and known sources of information on this topic.

Several articles provided insight to the history and context of some community response but were outside the scope of this paper ^[1,13,14,15]. Studies that did not speak to the experience of PwH directly were excluded; the majority of publications on the Contaminated Blood Scandal focussed on the policy and legal situation, providing context ^[16,17,18,19,20,21]. News stories, reporting on the scandal, were also excluded.

Studies were included if they included PwH whose lives were changed by the scandal and other publications if they contained narrative that explored the experiences of this group. Having reviewed article titles and abstracts, a full paper review was completed. A secondary search for other articles within previous and subsequent publications linked to the papers was added, including self-published literature written in an autobiographical style by members of the community ^[22] and a Masters dissertation ^[23]. Two books were excluded from the discussion ^[24,25] since they appear to be recently self-published and very closely resembled the self-published work by DePrince ^[22]. This similarity and the lack of information about the authors was felt to be problematic.

There is also a considerable amount of detailed data within the various inquiries, which contain witness and impact statements alongside evidence of the decisions made by governments, health care professionals (HCPs) and commercial companies which contributed to the CBS ^[10,11,26]. These testimonies are not included in this review as, although they add a large amount of factual evidence, the current published formal reports do not explore the intergenerational impact. There

Figure 1. Search strategy and findings



were also strong ethical concerns about including the personal statements made to the current Infected Blood Inquiry^[26] in the review without consent. Although they are in the public domain, some statements specifically reject use in research. The complexities of seeking consent to include the statements in research made it unfeasible but could be explored in future research with appropriate measures taken to ensure the safety and wellbeing of the people involved.

FINDINGS

Six journal articles provided literature on the impact of the CBS, either as the focus of the work or as a by-product of the primary aim (Table 1). Fillion provides evidence in the form of multiple semi-structured interviews with PwH in France, exploring shared decision-making and the impact of iatrogenic harm on clinical relationships^[27,28]. Fletcher et al. identified reasons men with haemophilia may be willing to have gene therapy, finding some wariness around being used as trial participants and the long-term impacts of the treatment^[29]. Keshavjee et al. explored the politics of healthcare and economy of representation in the

US, including the testimony of those who spoke to the Institute of Medicine during their investigation of the iatrogenic HIV infections^[30]. An ethnographic study by Hughes et al. discusses the impact of the CBS as part of their exploration of normality for the current community^[31].

Two publications were included among self-published and grey literature. The deepest and more detailed accounts of the impact can be found in self-published literature by PwH and their families (Table 2)^[22]. The MSc dissertation by Grayson^[23] was included in this section, since her work is representative of a thorough examination of the experiences of her community, alongside her analysis of the causes of the CBS.

The literature that included the children of PwH in the narrative was limited, with only Keshavjee et al.^[30] and DePrince^[22] providing detailed accounts. However, the other literature can be considered as transferable, demonstrating the situation the children were raised in.

Four themes arose from the literature: intergenerational memory, public perceptions, betrayal and justice, and relationships with HCPs. The focus has been to draw out those that might impact the children

Table 1. Published academic literature

AUTHOR	ARTICLE TITLE	ADDRESSED ISSUES	RESEARCH METHOD	FINDINGS
Cullinane (2005) ^[32] Based in Japan	Tainted blood and vengeful spirits: the legacy of Japan's yakugai eizu (AIDS) trials	Anthropological exploration of themes used by those in the infected blood trial	Narratives taken from yakugai eizu AIDS trial, including interviews, published accounts, newspapers and legal documents	Themes of lost trust, filial piety and desires for good deaths
Fillion (2003) ^[27] Based in France	How is medical decision-making shared? The case of haemophilia patients and doctors: the aftermath of the infected blood affair in France	How haemophilia patients and doctors in France rethought shared decision-making after the CBS	Qualitative survey. The interviews covered 31 clinical haemophilia doctors and 31 patients/service users: 21 adult males with severe haemophilia (21/31), infected (14/21) or not (7/21) with HIV, the infected wife of one of the latter (1/31), and nine parents of young PwH with severe haemophilia (9/31), either HIV positive (6/9) or negative (3/9).	Both groups rethought their roles and changed their practice. Individuals made different changes, but all shared more medico-scientific knowledge.
Fillion (2008) ^[28] Based in France	Clinical relationships tested by iatrogenicity: The case of haemophiliac patients faced with the epidemic of transfusional AIDS	Insight into the impact of the CBS on changes in relationships and commitment to medicine for PwH and their families	57 biographical life narrative interviews (of an average of 3 hours) of adult PwH (38) or their families (19). Included in the study were HIV-negative (15/38) and HIV-positive (23/38) PwH, parents of children who were infected (13/18) or not (5/18) – 6 of whom had lost at least one son through AIDS – and the wife of one PwH who had been infected and who had infected her through sexual contact.	Changes in attitude among PwH and their families. New moral expectations of the medical world. The importance of not being oblivious to who the victims are and what they want, which varies from person to person.
Fletcher et al. (2021) ^[29] Based in UK	An exploration of why men with severe haemophilia might not want gene therapy: The Exigency study	Attitudes of men with severe haemophilia towards gene therapy	10 adult men with severe haemophilia (8 haemophilia A; 2 haemophilia B), mean age 34.3 years, participated in a 1-hour focus group (n=9) or interview (n=1).	A variety of factors influenced this, including efficacy, safety (among older participants who had experienced the CBS), treatment burden and self-identity.
Hughes et al. (2020) ^[31] Based in Denmark, Ireland, Germany, UK and Spain	"He's a normal kid now": an ethnographic study of challenges and possibilities in a new era of haemophilia care	Views of normality in families affected by haemophilia	Grounded theory approach, with semi-structured interviews of families	The theme of normality across different generations identified that PwH from older generations were aware of the ability of younger PwH to live normal lives, and identified the trauma of the CBS as still present for them
Keshavjee et al. (2001) ^[30] Based in the UK	Medicine betrayed: hemophilia patients and HIV in the US	Exploration of the Institute of Medicine (IOM) report process	Examination of process, including testimonies provided to the IOM	That the IOM report obfuscated the moral dimensions of suffering

Table 2. Self-published and grey literature

AUTHOR	TITLE	NOTES	METHOD	FINDINGS
DePrince (1997) ^[22] Based in the US	Cry Bloody Murder: A Tale of Tainted Blood	Original self-published literature used in discussion with US Senators	Autobiographical narrative of the US CBS	A powerful narrative of the experience of a mother whose five sons had bleeding disorders, three of whom died of AIDS after receiving contaminated blood products
Grayson (2007) ^[23] Based in the UK	Blood Flows Not Just Through Our Veins but Through Our Minds. How Has the Global Politics of Blood Impacted on the UK Haemophilia Community?	Masters dissertation	Textual analysis of material and anthropological inquiry, using questionnaires.	PwH and their partners re-evaluated their identity and collective response, creating subculture

of those affected. Some themes were excluded as they were outside the scope of this work, including any relating to the response by government, the legal profession, organisations that represented PwH, or legal or financial outcome

Intergenerational Memory

Hughes et al. focused on the view of normality in children with haemophilia and found links to the CBS there, with the memory of poor quality of life for the generations that came before them ^[31]. Definitions of 'normality' were perceived to be a life lacking in the challenges previous PwH had faced, including restrictions on activities and inferior or risky treatments. They found specifically that those who had experienced that era viewed the present as an opportunity for their children and grandchildren, and this had been passed down, with one participant stating: "The really hard days are over" ^[31]. Fletcher et al. explored the reasons PwH were not taking up opportunities to have gene therapy and found that safety was an ongoing concern ^[29]. One respondent stated: "It would be the most hideous irony if, in ten years' time, there was a problem with genetic cure [...] I'd hate to be an agent in history repeating itself" ^[29]. Another noted: "Safety, that's a big issue, of course, for all of us [...] we've been through the very dark past of the haemophilia community, so that undoubtedly scars us to a large extent" ^[29]. The connection to the liver was one that triggered memories for one person: "Historically, that's bound to send shivers up the back of most haemophiliacs" ^[29]. Others found this less of a concern, placing their belief in the lessons learnt. Participants in Hughes et al.'s study were very aware of the changes in quality of life,

experiences, and treatments across the generations ^[31]. Keshavjee et al. described the testimony to the Institute of Medicine (IoM) as evidence of "deep memory", where "enduring experience of extreme suffering that cannot be assuaged or easily transformed back to ordinary life conditions" ^[30]. They compare the CBS to the Holocaust, Vietnam, refugees from war or atomic bomb survivors, calling it an "alarmed vision" which both witnesses and requires action. This personal and community impact was confounded by the public response to the CBS, which differed from that of other communities affected by the same diseases, such as the Queer community.

Public Perceptions

Kleinman explored the positioning by the community as "innocent victims of a system of negligence" when public discussions around the issues were explored ^[14]. In Japan, the CBS was less visible, a deliberate choice based in cultural roots around anonymity; AIDS, untimely deaths (particularly those with extreme suffering) and the death of children before their parents are considered "defiling" ^[32], particularly in relation to Buddhist culture, and come with taboo, with consequences for the families who spoke publicly. In the UK, Grayson found that PwH and their families felt that the media were disinterested and had a desire to sensationalise and misrepresent them, resulting in stigma for those within the community ^[23]. Similarly to the Japanese families, stigma was also a consequence in other countries, with Grayson finding that PwH and their families were living double lives, speaking openly within their community but concealing their status, sometimes from close family ^[23]. This response to the situation added to the sense of betrayal and injustice experienced by this community.

Betrayal and Justice

Hughes et al. found that their older participants still viewed themselves as needing justice, working together to achieve it ^[31]. In France, some people with haemophilia and their families opened criminal prosecutions primarily to highlight to the medical world that it must understand and correct mistakes ^[28]. This reflects the findings of Keshavjee et al. in the US, where those who testified did so to represent the victims, being both survivors and witnesses, with one mother saying: "Statistics have faces folks. You have seen them today" ^[30]. The extensive campaigning by the haemophilia community across the world is a strong theme throughout the literature, with some setting up campaign organisations and groups ^[23].

DePrince wrote her book to campaign for justice in the US, providing a detailed autobiography of her family's and the community's experience as the CBS impacted their lives ^[22]. The loss of three of her sons to AIDS is described in powerful detail, alongside the stories of others. In one case she describes the post-traumatic stress of a child watching a sibling die from AIDS, and in another she describes the experiences of a person with haemophilia whose fears are primarily for his family. The journey through the courts and legislative branches of the US is described in detail, including the emotional and financial toll on the families. Cullinane also cites those who spoke out in Japan as having the theme of "avenge" or "dispel their anger" ^[32]. This is illustrated in the statements of children of Japanese PwH who died as a result of the CBS. One, who lost both parents, stated in the yakugai AIDS trial: "Tell me, is it all right for doctors to murder people for money? Can they do whatever they want as long as nobody finds out about it? Can they use people for human experiments? Do you have the right to wreck my family?" ^[32]. Her sister expressed her anger: "Even if you were to apologize to my face, my anger would not subside. However, you don't even try to apologize and that is why I am full of hatred for you" ^[32]. Many equally heartfelt statements were made by parents in the Japanese, UK and US literature, often expressing betrayal in the losses of their family. One statement to the US Institute of Medicine (IoM) said: "My sons took the product and became infected with the AIDS virus. My sons died feeling betrayed. My son David is having a difficult time dealing with the loss of his brother and the knowledge that he was also betrayed. I feel betrayed" ^[30]. In the work by Grayson, anger and betrayal were expressed around the sharing of the HIV or hepatitis diagnosis, with one spouse being told: "I

see your husband has picked up HIV along the way" ^[23]. On pointing out that he didn't pick it up but was given HIV, she was told: "Well it's the same thing" ^[23]. Others defined their generation as people who had "been lost needlessly" ^[30]. Some of these feelings of betrayal and desire for justice extended to individual clinicians and HCPs as a whole.

Relationships with Health Care Professionals

Fillion notes that the CBS changed the way PwH and their families interacted with medical teams ^[27]. For many, the relationship became less hierarchical and one where PwH or their parents made active informed decisions around their treatment options. This frequently included self-education, reading instructions, press articles and medical literature, before contacting their doctor and discussing the prescribed treatment. One individual explained: "In some ways it's true that from the point of view we replace the doctor [...] but we mustn't get too carried away because it's not easy to treat yourself" ^[27]. Due to the nature of their condition, they must balance the need for and suspicion of specialist medical input, with almost all PwH and parents seeing delegation of the decisions and information seeking to the doctors as a risk. One person described themselves as alert for the next time, and those who described themselves as having "slipped through the net" also felt the impact of what Fillion describes as the "collective trauma" ^[27]. Each person made an assessment of their medical team before developing a partnership or exiting the relationship, and put their own boundaries around behaviour and expectations. Fillion suggests that the lack of consent for treatments and research impacted the intense relationship families affected by haemophilia had with their medical teams before the CBS, calling it into question ^[28]. Fillion cites one person who said: "He surrounds himself with specialists [...] and he doesn't say he's the one who is always right" ^[27]. Many took on tasks such as documenting reactions to treatments, patterns of bleeds and specialist articles they read. The contemporary message from some HCPs is that treatment is different, with one participant in Hughes et al. stating that she had been told to "delete everything you know from your hard drive, it is all different now" ^[31]. A few people fully rejected medical support, which seemed to be related to either the death of a child or transference to another speciality to manage a more immediate concern (for example HIV) ^[27,28]. No single model dominates the shared decision-making, with individual PwH and parents choosing their own boundaries. However, Fillion found that "metamorphosis

following the iatrogenous contamination took place at both cognitive and ethical levels” [28].

DISCUSSION

Throughout the literature, the four themes identified have dominated where PwH and their families have been asked about the CBS. It has left an inheritance of anger and a need for justice for those who survived it, bearing witness to the experiences of those who did not. It demonstrates the social cost to PwH, facing stigma in different cultural forms, such as their exclusion from society in Japan. The literature provides a stark picture of the impact on PwH, their spouses, and the haemophilia community, but with very little known about the emotional inheritance to the children of those who experienced it directly. Statements to the IoM from some children made their anger and need for justice clear [30] but no research has focused on the experiences or feelings of this cohort.

The detailed descriptions in the book by DePrince demonstrate the impact on siblings who survived, illustrating their anger and guilt [22]. This impact has created an intergenerational memory that affects relationships with HCPs and treatment choices throughout the community. Although it is unknown how much this impacts the generation that came after the CBS in the same manner, glimpses in the literature demonstrate that it is present in their choices, whether through deliberately excluding it from their thoughts or changing their behaviour entirely. One correspondent in Fletcher et al. felt that the lessons learnt would protect them from the same risks with new treatments [29]; however, it is unclear whether that person is a sibling or child.

The story of siblings and children of PwH affected by the CBS is told more fully in other media. The documentary *In Cold Blood* presents a detailed exploration of the CBS, illustrating some of the experiences and emotions of those who lived through it [33]. For some, it emerges in the songs they write, with lyrics such as Bobhowla’s “Breathing is hard enough without the demons waiting at your bed, masquerading as the light ahead” demonstrating the impact [34]. Some – those that Seward MacKay and Milbouer would refer to as “the Warriors” [35] – continue to write articles highlighting the experiences of their parents and the impact on their lives. An example of this would be one of the campaigners, Jason Evans, who wrote: “My father’s untimely death devastated our family. I spent most of my life slowly learning about the horrors he had been put through, and trying to find some justice

for him and thousands of others like him whose lives were destroyed by Factor VIII” [36].

CONCLUSION

With limited focus and understanding of the experiences and impact for all those affected, including the children of affected adults and the younger generation, full understanding of the CBS cannot be gained. The paucity of information in written, published sources demonstrates that ripples continue to spread across the generations and requires that we pay attention to this intergenerational iatrogenic harm, allowing these stories to be told. It is imperative that, with the new evidence emerging from the UK Infected Blood Inquiry, we now highlight the harms done to this community and ensure that their stories are told. It is vital that clinicians working with people affected by this issue are mindful of the need for trauma-aware care to prevent further harm. Further research that tells these stories and explores interventions that enable this cohort to process and break the chain of intergenerational trauma may be vital in understanding and supporting these generations.

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This paper does not contain any studies involving human participants or animals performed by any of the authors.

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