

Negotiating trust during times of uncertainty: haemophilia and AIDS

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Abstract: Trust forms the core of healing relationships. Mistrust can co-exist and complement trust by enabling patients' to challenge medical decisions without fear of repercussion, thereby negotiating a more patient-centric approach. While trust can safeguard the therapeutic relationship during periods of medical uncertainty, a reappraisal of trust at such times can lead to its loss, adversely affecting this relationship. This occurred during the 1980s when haemophilia patients contracted AIDS from their treatment, a situation of iatrogenic harm at a time of evolving uncertainty. Published literature on how this impacted on doctors' response is absent. Using legal and narrative material from the UK and elsewhere, this paper will address profoundly distressing dilemmas in the stance of haemophilia physicians towards their patients during the 1980s and how this impacted on trust. The paper argues that trust and mistrust are fluid during times of uncertainty. This trust is subject to social forces that are ethically challenging and beyond individual control. Its recovery requires fresh societal debate. This understanding is of fundamental importance in the training of medical students and doctors to become better physicians.

Keywords: haemophilia, AIDS, Infected Blood Inquiry, iatrogenic, ethical, uncertainty, trust, mistrust, therapeutic relationship.

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'It has been said to me in several statements that the author has lost trust in the doctors and clinicians who have treated him and therefore finds it difficult to accept medical treatment now. I think one person described it as the single greatest loss arising out of the infected blood events.' Chair, UK Infected Blood Inquiry (IBI).¹

The period between 1982 and 1985 was a watershed in medical history. Many patients contracted AIDS via blood transfusion. Patients with haemophilia were amongst the worst affected by this iatrogenic event. Haemophilia is an inherited lack of clotting proteins, which results in poor formation of clots and, in its severe forms, can cause uncontrolled bleeding and death.² Clotting proteins or factors are usually identified by numerals. For example, in Haemophilia A, there is an inherited lack of Factor VIII. To replace the missing protein, for example, Factor VIII, haemophilia patients rely on treatments which typically involve large volumes of blood plasma transfusions to treat and prevent bleeding. HIV was transmitted via donated blood to recipients, such as haemophilia patients, in many of whom it caused AIDS. A definition of iatrogenesis is 'the unintentional causation of an unfavourable health condition during the process of providing medical care',³ and since the transmission of HIV was a consequence of medical treatment, AIDS was an iatrogenic disease in these patients.⁴ Transfusion-transmitted AIDS constituted an iatrogenic crisis with high fatality, affecting patients worldwide and had profound implications on patients and the physicians involved in the treatment.

This paper will identify changing notions of trust in the therapeutic relationship (TR) in haemophilia during the 1980s. The first section sets out the theoretical and narrative context for the iatrogenic event. The second section describes the objectives and methods. The third section presents results of key themes in the

¹ Stated by the Chair of the Infected Blood Inquiry on 24 February 2020 (page 104, line 25) as a preamble to his question to the expert panel 'Inquiry intermediaries and psychosocial experts'. All IBI related citations are available at: <https://www.infectedbloodinquiry.org.uk/>

² Haemophilia is a category of enduring affliction, one that medical anthropologist Estroff groups as an 'I am' illness. 'I am' illnesses are distinguished from 'I have' illnesses in which the notion of the self is not so intimately fused with the disease or sickness itself. Estroff suggests that 'I am' illnesses are more stigmatising than I have illnesses (Estroff 1993).

³ Gk *Iatros* = physician, *genesis* = origin, noun. The unintentional causation of an unfavourable health condition during the process of providing medical care (Merriam Webster dictionary, accessed 15 February 2023).

⁴ Biggs (1977) calculated that in 1974 there were 3500 patients with haemophilia treated across 47 centres in UK. 1250 patients were infected with HIV, of whom 75 per cent died by 1991, half of them due to AIDS, and the majority of the others due to hepatitis or bleeding. Annual morbidity, mortality, demography, and treatment data on haemophilia patients were published on behalf of the UKHDO, the United Kingdom Haemophilia Centre Doctors' Organisation, based on registries maintained by haemophilia doctors. Data from such registries served a crucial role in analysis of clinical outcomes.

disruption of trust. The fourth discusses these data. The fifth and final section summarises and concludes.

1. Theoretical and narrative context

1.1 The place of trust in uncertainty

When a doctor is the recipient of their patient's trust, it enables decisions in periods of uncertainty. Trust empowers both patient and physician to cope with the probabilistic nature of knowledge and the ambiguities in decision-making.

Uncertainty is intrinsic to medicine.⁵ However, while doctors are taught to deal with uncertainties, they are trained to seek certainties; these certainties establish the framework for consolidating trust.⁶ Prolonged uncertainty, such as when a new disease is recognised, raises important problems in medical decision-making and challenges patients' trust in physicians. As knowledge about the new disease evolves, it shapes the understanding of future outcomes, thus reducing ambiguities in decision-making. This influences trust at many levels, most importantly in the TR.

Trust as a noun first entered the medical vocabulary in Western literature in 1398. As a transitive verb in medicine, it first appeared as an ironic statement in the English language in 1973. More recently, it has been described as a 'social glue', an attribute reflecting social capital.⁷ Medical trust has been described as the optimistic acceptance of a vulnerable situation in which the truster believes the trustee to care for the truster's interests.⁸ These descriptors emphasise the symbolic and emotional components of the belief that the doctor has the best interests of the patient at heart. Patients place trust at early encounters with their doctor, usually as a default position. This fosters reliant behaviour by the patient which in turn

⁵Fox (1980, 2000) was key in describing the nature of medical uncertainty and the preparatory training of medical students to deal with these in practice. She described uncertainty arising from a lack of medical knowledge, a lack of personal knowledge of medicine, and/or a difficulty in distinguishing between the two.

⁶Atkinson (1984) and Light (1985) dispute Fox's thesis and discuss how doctors are trained to convert uncertainties to certainties to deal with clinical events at a practical level.

⁷Trust, n., entered the medical vocabulary in 1398: Bartholomaeus Anglicus wrote '*He [sc. a physician] hotip to alle men hope and trust of recoueringe and of hele.*' *Oxford English Dictionary* online (Oxford University Press), September 2023. <https://doi.org/10.1093/OED/8799644750> [accessed 30 October 2023]. Doctors asking patients to 'trust' them, first appeared in 1973. A. Linkletter used the sentence '*take this medicine; trust me, I'm a doctor, the only who really understands your inner workings*' to express that the profession is a sufficient guarantee to be trusted. *Oxford English Dictionary* online (Oxford University Press), September 2023, <https://doi.org/10.1093/OED/1016407860> [accessed 30 October 2023].

Trust is listed as '*the latest candidate for an all-purpose social glue*', *The New Fontana Dictionary of Modern Thought* (Bullock & Trombley 1999).

⁸Hall *et al.* (2001)

encourages the physician's trust in the patient.⁹ However, since the doctor–patient encounter is not a singular phenomenon, simultaneous emotions of mistrust may complement trust. This is increasingly so with team-based healthcare where the patient-facing doctor is one of many involved in the care of the patient. Questioning, scepticism, and attempts to seek clarity represent aspects of mistrust¹⁰ and, depending on the outcome of this questioning, these can serve to enhance trust, or lead to a deeper mistrust of individual, team, institution, and the state. A reappraisal of trust occurs at this point and the patient situates it either at the same or another locus; for example, the patient may choose a different doctor, institution, healthcare system, etc., or trust the physician in one situation and not another.

1.2 Uncertainty and iatrogenic harm in haemophilia

These notions of trust during medical uncertainty are exemplified by events of the 1980s, when people with haemophilia contracted AIDS from blood transfusions given to them.

The time between 1945 and 1980 has been described as the golden age of haemophilia,¹¹ when life expectancy improved from twenty to sixty years because of plasma treatment, aided from the 1970s onwards by using factor concentrates (FC).¹² FC was potent and easy to use and it became possible to establish self-treatment at home.¹³ This post-1970 period manifested active

⁹Pedersen (2015) describes the philosophical basis of the social phenomenon of trust and offers a perspective on the theoretical understanding of trust behaviour by considering two axes: the nature (prima facie or reflective trust) and the locus of trust. The paper also describes reciprocal trust by the physician: e.g., trust in compliance with treatment, that the patient is not hiding relevant information about their health.

¹⁰Armstrong *et al.* (2008), Govier (2008), and Jaiswal and Halkitis (2019) describe mistrust as more than an absence of trust; mistrust often refers to the belief that the entity that is the object of mistrust is acting against one's interests or well-being. Thus, trust and mistrust are a range of interdigitated intersecting feelings rather than a dichotomy. Griffith *et al.* (2021) distinguish a general mistrust of medicine/institution often arising from historic legacies of oppression and stigma from a specific distrust of an individual, decision, or organisation arising from suspicion of motives and competence. In this paper, 'mistrust' is used to depict both of these: the rationale being the pervasive and broad nature of the feelings and behaviour of patients who were affected.

¹¹Resnick (1999) and others have described the events that led to the impressive progress in life expectancy in haemophilia. Tansey and Christie (1999) curated the Wellcome Witness seminar on haemophilia, recording the medical narratives around developments in treatments.

¹²A bag of donated blood, when centrifuged, yields liquid plasma rich in clotting proteins. This plasma was used in treatment of deficiency of clotting factors. Refinements to this product comprised more concentrated products, cryoprecipitate, and then factor concentrates or FC. FC production was done on a small scale by blood services, but on an industrial scale by pharmaceutical companies, primarily based in the USA.

¹³FC entailed mixing gallons of donated plasma to manufacture a therapeutic dose, and this increased the risk of contracting HIV several fold, as a single infected donor's blood could potentially contaminate a whole batch of products, thus affecting many patients.

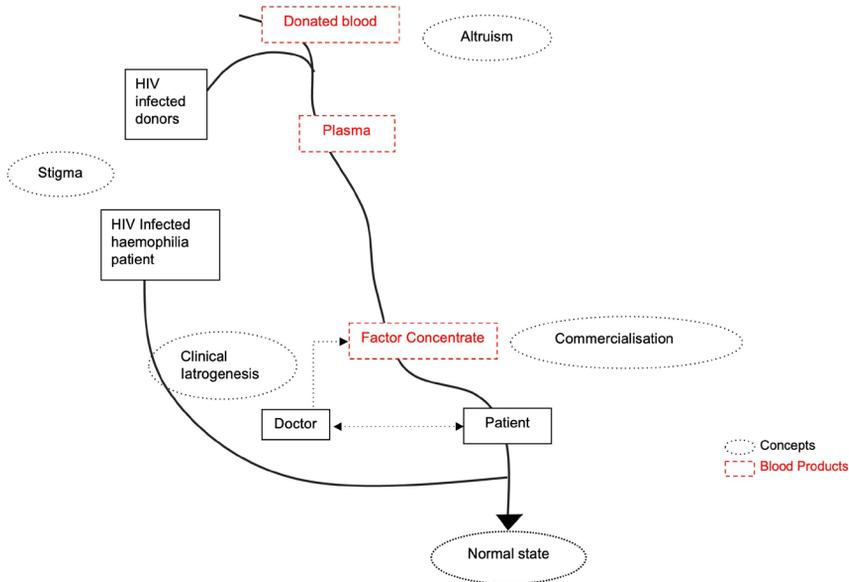


Figure 1: Illustration of connections between people and institutions in haemophilia. Institution 1 and Institution 2, depicting the connections between people and institutions in how the blood flowed through the FC production into the patient’s veins; and the key promoters (altruism and the value of normality) and disrupters (commercialisation, iatrogenesis and stigma).

physician–patient collaboration, minimal therapeutic uncertainty, and increased patient autonomy.

In the matter of iatrogenic AIDS via transfusion, the chain of connection is complex, leading from the donor of blood to the patient, a recipient of the donated blood (these relationships, depicted in Figure 1 are described further below). The iatrogenic crisis developed in the context of a highly personalised therapeutic relationship in haemophilia.

Between 1982 and 1984, research generated multiple data and different conclusions, and a causative label for AIDS was indefinable. The time lag in publishing data meant that physicians relied on formal and informal meetings to stay informed, to appraise treatment choices. This prolonged uncertainty disrupted the sense of normalcy¹⁴ that patients and their physicians had come to expect as standard. It questioned the basis of the TR, even while the relationship continued

¹⁴ Patients still felt the burden of disease and the tensions between the promise of normalcy and the need for normalcy. Pemberton (2001) writes of the complex and sometimes contested values placed around normality in the USA. He cites a physician, ‘patients wanted to be normal risk-takers rather than normal people’. Tansey and Christie’s (1999) ‘Witness’ series describes the value of normalcy as perceived by physicians. Carricaburu and Pierret (1995) cite a physician: ‘We denied haemophilia. The haemophiliac person could do anything just like everybody else.’

over years.¹⁵ Patients expressed feelings of anger and betrayal at their treatment, and scepticism about the motivations of organisations and people involved in the therapeutic chain. The altered dynamic of trust in a doctor involved the individual patient but, given the collective identity generated by haemophilia, it affected the community of that doctors' patients and haemophilia patients as a group. By the mid-1980s, ruptures of trust between patients and doctors became entrenched. In many countries, public inquiries and lawsuits found medical, institutional, and governmental decisions wanting. Reforms in medicine, policy, and law introduced after this crisis transformed professionalism¹⁶ and safety in healthcare.¹⁷ Later than other countries, the UK Infected Blood Inquiry (IBI) was tasked with investigating these matters and commenced its public process in 2019.¹⁸

1.3 Therapeutic relationship before the onset of AIDS

Three aspects of the doctor–patient or therapeutic relationship (TR) in haemophilia provide a framework to locate the rupture of trust: patient autonomy, the doctor–patient axis, and the blood donor axis.

1.3.1 Patient autonomy

The inherited nature of haemophilia meant that multiple generations attended the same haemophilia centres (HC). With increasing survival, the doctor–patient–family relationship was lengthy. As home treatment became popular, the nature of the relationship changed. Physicians trusted their patients to follow protocol and patients trusted their doctors' judgement.¹⁹ The rituals of diagnosis, dosing, injection, and record-keeping increased patients' autonomy and changed the nature

¹⁵Fillion (2003) interviewed patients and physicians to examine the evolution of the therapeutic relationship in France.

¹⁶Medical governance, accountability, and rules on consent were some of these reforms.

¹⁷Kohn *et al.* (1999) address failures in safety of healthcare and provided the basis of sweeping reforms in the USA.

¹⁸The UK Infected Blood Inquiry conducted public hearings between 26 July 2019 and 7 February 2023: <https://www.infectedbloodinquiry.org.uk/>

¹⁹Haemophilia mainly affects men due to the pattern of inheritance of chromosomes. Men and boys initiated treatment at the inception of bleeds using FC stored in their kitchen fridge, dosing themselves based on agreed protocols. Families were taught to give intravenous injections/infusions of FC, which was injected either by the patient himself or their wives or mothers. Mothers have expressed their guilt in causing pain (and, later, inadvertent harm) to their child through their injections. See Carricaburu and Pierret (1995) for this latter point.

of the relationship to one that was mutually constructed.²⁰ A growing community of people became actively involved in shaping their own treatment,²¹ and patient collectives were connected through organisations such as the Haemophilia Society (HS) in the UK and the World Haemophilia Federation (WHF). With autonomy, there was also a tacit acceptance of moral liability in the event of errors (including the guilt of injecting infected²² product) by the injector. In the majority perception, the value of FC was clear: the risks of bleeding were annulled by an effective product which promoted normality and autonomy.

1.3.2 Doctor–patient axis

This axis, referred to in this paper as Axis 1,²³ was a shared enterprise of the affected community of patients and physicians, collectively involved in structuring, lobbying, studying, and refining a transformational approach to the treatment of haemophilia. Its success relied on the availability of FC, and this axis persuaded governments to fund treatment.²⁴ The home treatment project also characterised the role of the physician. Simultaneously clinician, researcher, lobbyist, they tailored individualised care, conducted clinical trials with FC, lobbied to maximise supply and established structures for equity of access to FC. The UK professional network was seen as an exemplar, with collegiate sharing of knowledge. Professionals and patients networked worldwide and the two groups shared platforms at WHF conferences.

²⁰ For example, nurses observing self-injections; doctors discussing home treatment records; scope to discuss research; ongoing blood tests; interpreting data from results to monitor dose adjustments, etc.

²¹ Over the years, patients made treatment decisions independent of the treating centre, i.e., they would treat without making an initial telephone call to confirm the indication and dose. In some places, e.g., parts of Australia and Canada where FC was supplied by an external institution such as the Red Cross, some patients chose to not attend the HC for clinical reviews.

²² At that time, Hepatitis B and Non A Non B (later Hepatitis C) virus infections were the main concerns.

²³ Axis 1 comprises the patient, the physician, and their collectives, i.e., Haemophilia Society (HS) and UK Haemophilia Centre Doctors' Organisation (UKHCDO), as having a stake in shared values in treatment of haemophilia. These values differed in specific preferences, but were aligned in the overall vision of preserving and improving life.

²⁴ Aledort (1982, 2016) showed that comprehensive care models provided by multidisciplinary professionals showed 'overwhelming advantages' in haemophilia, with 80 per cent savings in time lost from school or work, reduced mortality, and reduced long-term complications of arthritis, and reduced healthcare costs. With increasing use of FC in home treatments, patients developed antibodies to the clotting protein in FC. Called inhibitors, they were the subject of many research studies worldwide, and patients actively participated in these studies.

1.3.3 Blood donor axis

A parallel axis, labelled Axis 2, comprised the blood services and blood donors. This axis, which this paper will not detail, was core to the needs of Axis 1. A vast body of donors²⁵ supported the blood industry to produce blood and products such as FC. The detail of the relationship between the two axes varied across nations but, in general, it was qualified by trust, or an assumption of trust since the blood donor was anonymous. This relationship was indirect, existing between blood services providing assurance of donors, and physicians using donated plasma which was quality-assured to treat their patients—a trust by proxy. Most nations imported FC from the USA,²⁶ where it was commercially manufactured using paid and incarcerated donors. FC, therefore, was a consumer product—a transaction based on contracts and paid for by governments.²⁷

Trust between patients and their physicians before the onset of HIV/AIDS did not arise because of a need caused by uncertainty or ambiguity. Rather, it arose as a *prima facie* trust, and in wealthy countries, it was consolidated over decades because of a shared journey with a shared vision. During this process, trust in the agent shifted locus to trust in the technology.

2. Objectives and methods

2.1 Objectives

Using data from oral narratives and legal testimonies of haemophilia physicians, this paper identifies changing notions of trust in the doctor–patient relationship in haemophilia during the 1980s. It focusses on the physicians’ stance in the TR and provides narratives to illustrate the lived experience during this period.

2.2 Methods

Haemophilia–AIDS was a worldwide crisis. Haemophilia physicians were networked internationally and care structures were similar across high income nations; we therefore interviewed physicians from five countries. Sixteen

²⁵ Blood donations were from voluntary donors, directed donations from family and friends, the incarcerated, and paid donors; their proportions varied worldwide.

²⁶ Jones *et al.* (1978) report on the adequacy of FC availability for home treatment in the UK and the need to import commercial FC comprising 55% of FC used in 1976.

²⁷ Despite the contractual transaction, people placed faith and confidence in FC, and competing pharmaceuticals argued why their product might be more effective and, with the onset of AIDS, more trustworthy than a competitor’s.

haemophilia physicians from Australia, Canada, France, Italy, and the Netherlands, sampled through a snowballing technique, were interviewed in 2019. These countries were selected based on personal contacts. Three physicians were female and fifteen were white north European. The physicians, aged 68–82 years, were prominent clinical academics at haemophilia centres providing complex haemophilia care to many patients. Most specialised in haemophilia; some also practiced haemato-oncology. Thirteen had been consultants for over five years by 1980 and three were newly tenured in the 1980s. Specific demographics are not provided to protect their identity in keeping with ethical approval. Interviews were based on a semi-structured questionnaire constructed based on literature review and discussion with experts (see the Appendix); they lasted 1.5–2 hours. They were audio-recorded, transcribed, and 30 hours of narrative were analysed by the first author.

In 2019, the UK IBI commenced proceedings; UK physicians were therefore not interviewed. From the proceedings²⁸ of the IBI, oral evidence by eighteen physicians, three expert panels, and seven closing submissions by representatives of the affected were analysed, comprising c.400 person-hours. One physician was a female, and seventeen were white north European. The chair of the inquiry was a male legal professional of white north European origin.

Consent for interviews was obtained by telephone and/or in person; no consent was sought for quotes from the IBI, which are open to public access. Ethical permission for the project was granted by UCL (16179/001/2019, 2021).

Interviews and testimonies were analysed using a grounded thematic approach.²⁹ An initial phase of open coding identified common topics that were categorised to refine themes and subthemes after triangulation of data. Themes were grouped into broad domains and cross-checked for validation by the second author. These analyses yielded key themes affecting trust in the therapeutic relationship during medical uncertainty. These are described below. In presenting the results, each theme is illustrated using *quotes*. Unless specified, quotes are from physicians. Testimonies are annotated with the prefix IBI; narratives annotated as country of narrator. Each quote is annotated with the gender of the speaker and the date of the quote. Although data from six countries are cited, a formal cross-national comparison is beyond the scope of this paper.

²⁸All transcripts and video recordings of oral hearings, written statements, and testimonies by the affected and infected and expert reports are available on the IBI website. Sources used for quotes in this paper include physicians' testimonies, and ethics, psychosocial, and clinical expert panels (<https://www.infected-bloodinquiry.org.uk/about/inquiry-experts>) and statements of closing submissions pertinent to this paper. The first author served as a member of three expert panels and also attended its proceedings as a lay person and in 2021 published a podcast series on this subject: <https://thebitterpillpodcasts.libsyn.com>

²⁹The grounded thematic approach described by Glaser and Strauss (1967) and the guidelines on techniques to identify themes by Ryan and Russell Bernard (2003) were used in analysis of narratives and testimonies.

Table 1: Emerging themes in the physicians' stance contributing to unstable trust in the therapeutic relationship during uncertainty.

<i>Domain</i>	<i>Emerging themes and subthemes</i>	<i>Clinical examples from narratives and testimonies</i>
Testing blood samples		
	<i>Assumptions by physicians</i>	
	<i>Assumptions regarding patients</i>	Consent for testing
	<i>Assumptions regarding science</i>	Interpretation of laboratory data from testing
	<i>Ethical shift</i>	
	<i>Beneficence</i>	Public-centred actions versus individual-centred actions
	<i>Justice</i>	Research value and clinical value
	<i>Loss of patients' autonomy</i>	Use of batched samples without consent
	<i>perception over time</i>	Clinical vs research use of samples
	<i>perception across cultures</i>	Consent not a core issue in previous legal inquiries
		Consent not a core issue in many countries
	<i>Nature of knowledge</i>	
	<i>Uncertainties</i>	Interpretation of evolving data
	<i>ambiguities</i>	Interpretation of complex data
	<i>Evolving contested certainties</i>	Disbelief
Treating haemophilia		
	<i>Assumptions by physicians</i>	
	<i>Assumptions regarding patients</i>	Paternalism, beneficence
	<i>Assumptions regarding science</i>	Decisions pertaining to treatment choices
	<i>Ethical shift</i>	
	<i>Resources</i>	Rationing of time
		Factor concentrate
	<i>Loss of patients' autonomy</i>	Paternalism in decisions
	<i>Nature of knowledge</i>	
	<i>Uncertainties</i>	Interpretation of evolving data
	<i>ambiguities</i>	Content of decisions
		Variability in decisions
	<i>Evolving contested certainties</i>	Appraisal of risks
	<i>Slow evolution</i>	Lack of therapeutic choice
	<i>Decision-making</i>	
	<i>Clinical freedom</i>	Mode of decision-making
	<i>Structures</i>	Guidelines, mindlines, care pathways
	<i>Values</i>	
	– <i>stance</i>	Stance of optimism
	– <i>body</i>	Values of normality: disability free
	– <i>identity</i>	Heteronormative

Table 1: (Cont.)

<i>Domain</i>	<i>Emerging themes and subthemes</i>	<i>Clinical examples from narratives and testimonies</i>
Treating haemophilia (Cont.)		
	<i>Physicians' emotions</i>	Stigma, fear, blame, anger, sadness, vulnerability
	<i>Engagement of patients</i>	Drop out, death of patients Continuity of therapeutic relationship through the crisis New patients whose relatives had died of AIDS
	<i>of physicians</i>	Poor recruitment into specialty, collegiate support
Communicating with patients		
	<i>Transparency</i>	Delays Limited transmission of information
	<i>Structure channels of communication language and vocabulary</i>	Batching patients Nomenclature of pathogen, breaking bad news, discussion of complex data
	<i>Reassurance, framing</i>	Optimistic stance, denial, euphemisms, using historic models
	<i>Communicating difficult emotions e.g., hopelessness, ambiguity</i>	Breaking bad news without offering treatment options Non-committal until clear evidence of causality

Column 1 defines key clinical domains. Column 2 lists key themes in bold with sub-themes in italics. Column 3 lists clinical examples illustrating the themes and subthemes. In all, eight themes and eighteen sub themes were identified across three domains. Three themes (assumptions, ethical shifts, nature of knowledge) and five subthemes were repeated in the domains of testing and treating.

3. Results

Analysis suggests that challenges to maintaining trust spanned the three key clinical domains that form the clinicians' responsibilities on a day-to-day basis, namely, testing, treating and communication. Eight themes and eighteen subthemes were identified in all; three themes and five subthemes occurred in both testing and treating domains. These, along with clinical examples are as shown in Table 1.

The eight themes comprise *physicians' assumptions, ethical shifts, the nature of knowledge, clinical decision-making, physicians' emotions, engagement in the therapeutic relationship, transparency in physicians' communication, and structures of communication*. These are discussed below under thematic headings.

3.1 Physicians' assumptions

Physicians made assumptions about their patients and about the science of HIV/AIDS. Leftover material from blood samples taken for routine monitoring of patients was used for HIV testing when tests first became available. In using stored samples for this purpose, physicians assumed their patients' consent, in keeping with the medical practice then and haemophilia patients' research ethic then.

The scientific interpretation of a new test such as that for HIV involved subjectivities.³⁰ In addition to their patient-facing role, haemophilia physicians also routinely dealt with research and diagnostic testing of their patients' blood and were therefore knowledgeable about the subjective and empirical limitations of assumptions in interpreting the results of such testing.³¹

The nature and significance of HIV positivity were initially unclear and physicians made assumptions based on their knowledge of Hepatitis B virus. As data evolved, these assumptions were proved wrong.

IBI, Chair: *You have told us about how after receiving the results of tests in October 1984, you've essentially, I think, given a description of not quite knowing where to turn; just trying to work out, come to terms with the situation. Am I right in that?*

IBI CL, male, 1/12/2020: *You are correct. I was very much taken aback.*

France, male, 2/3/2021: *At the first AIDS meeting in Atlanta in, April 1985, I had a discussion with one of the best immunologists discussing precisely what antibodies meant. And that was really a very important discussion, because it proved the significance of the data we had collected.*

Assumptions were also made about treatment of the haemophilia. Values of the FC era influenced treatment decisions and, although treatment patterns became more conservative with the onset of AIDS, these values were not formally reappraised. It was deemed negligent to not treat bleeds optimally and the therapeutic products were limited. The treatment criteria seemed self-evident given these values, and medical decision-making proceeded based on these assumptions: a stance that has been criticised for its paternalism.

³⁰ Jasanoff (2012) cites Fleck's (1979, 1935) descriptions of thought styles as a subjective phenomenon deriving from a wide array of influences and his view of scientists as people situated in a culture and history; and Latour in his rendering of science as a human, flesh and blood enterprise (Latour & Woolgar 1986).

³¹ Blackburn (1973) describes the role as crossing boundaries and across clinical, diagnostic, and research realms. Thus, a haemophilia doctor would diagnose their patient, treat, and conduct investigations on a research question: e.g., the natural history of inhibitors to clotting factor treatment.

3.2 Ethical shifts

Assumption of consent posed ethical problems. Historically, leftover material from routine blood samples was frozen and stored. These samples allowed investigation of unforeseen clinical events, such as development of antibodies to FC or infection with Hepatitis B virus (HBV). On publication of a HIV test, physicians raced to use the stored samples to interrogate HIV infection.

Italy, male, 23/4/2021: *At that time, Montagnier³² had developed a test. I went to Paris, I met him in a café and I told him, 'listen I have here a sample of these patients.'*

The stated purpose of testing at that time was to define the prevalence³³ and interrogate a causal connection to the transfusion decisions that physicians had made. It was more sense-making and less to answer clinical questions pertaining to the patient, questions which at that time were still being framed.³⁴

It was considered good stewardship to utilise a sample³⁵ to its fullest potential; in this case, to generate data to inform clinical/research questions. These data enabled qualified assumptions about sources of infection and thus public health measures to stem this.

IBI Chair: *As between³⁶ his duty to his patient and his interest in publishing research, where do you suppose the ethical position lies? Might it not lie with the duty to the patient as trumping all?*

IBI GL, male, 9/12/2020: *No, I don't, with respect. I think the first duty ... was doing a time-tested emergency procedure in public health.*

In prioritising the public health aspect of testing over the individual patient aspect, physicians harnessed their professional expertise as clinicians familiar with the patterns in haemophilia, physicians caring for their patients, pathologists competent in the critical use of laboratory tests, and epidemiologists who maintained

³²Montagnier was the lead author of the paper (Barré-Sinoussi *et al* 1983) describing the first test for the virus causing AIDS, which he named as LAV or 'lymphadenopathy associated virus'.

³³It also reveals how knowing the denominator might be relevant for a more discriminating approach in choosing blood donors.

³⁴For example, what did it mean that a particular patient, otherwise well, had so many lymph glands enlarged? The connection between enlarged lymph glands noted in 1982 and an abnormal result in 1984 made diagnostic sense only retrospectively.

³⁵Given the history of haemophilia treatment, serial blood samples stored in freezers mirrored the long relationship duration with patients. Products, trust, and science form an assemblage (from Deleuze & Guattari 1994).

³⁶This question comes after a discussion regarding the time lapse between obtaining test results and revealing these to individual patients; the Chair of IBI is questioning Dr GL on the acceptability of this time lapse.

registries of their patients' data. This complex identity afforded them scope to generate data: i.e., a stance of public beneficence.

The dual alignment of physicians—patients/samples, patients/public—meant that physicians treated stored samples as distinct entities, separate from the patient. Although using stored samples to answer new questions had historical precedent, patients' testimonies at the IBI expressed concern at this breach of their autonomy by not being explicitly consented. In some countries, e.g., Italy, this concern was absent. Instead, physicians were lauded for being part of the 'solution'.

Ethical practice was also affected by limited resources: lack of clinical time, the logistic challenge of putting support structures in place before informing patients of HIV positivity, limited FC supply, limited access to 'clean' products, and limited assurance of quality and safety of Axis 2. In particular, there was a lack of therapeutic alternatives until 1985. Australia, male, 3/8/2019: *He put a gun to my head [stated of a patient denied FC].*

3.3 Nature of knowledge

During the period when the viral etiology could not be proved, physicians held many views and debated the implications at meetings and conferences. A collective stance was one of watchful optimism. When tests became available and these showed abnormal results, the initial reaction in some countries was disbelief.

IBI, DB, male, 12/01/2021 *So those doctors were in many ways admirable doctors, far more distinguished clinical scientists than I ever was. I would feel embarrassed confronting them with it but ... I think they held the line to the point where it almost became like denial, a denial problem, into 1983. To continue to propose that there was no conclusive evidence that AIDS was caused by an infectious agent was simply, in retrospect of course, untenable.*

Australia, male 3/8/2019: *I remember the day clearly. I got a phone call; it was the director of the blood bank. It was in their blood. They'd discovered that HIV was in Australia.*

Data from testing stored samples were hard to interpret, but in the face of iatrogenic AIDS the imperative to change treatment was high. However, this was constrained by the slow evolution of the science of HIV and its elimination from FC.

IBI, BC, male, 7/10/2020: *I sit in my office with my head in my hands saying what on earth do we do next because we had reached really rock bottom in December 1984 of our understanding and our power to deal with this crisis.*

By the end of 1984, the crisis of care turned into what an Italian physician described as a nightmare.

Whilst patients consented (explicitly or otherwise) to treatment, the specifics of product and dosing were based on national guidance which varied across nations. Local data informed some of these variations, but national policies and protocols also reflected the collective bias of experts and politicians. This bias involved medical practice and political values. Some countries, e.g., Australia, had a policy of no US imports on the basis that the indigenous product was safer, a thesis that was disproved with time.

In the Netherlands, where there were open discussions with blood donors about transmission of AIDS, their policy of self-reliance in FC achieved traction as the donor axis could be protected through better management of donor behaviour.

Netherlands, female, 13/6/2019: ... we discussed how can we just be next to each other, standing next to each other. And also at that time, the Netherlands was a really free country, free of thinking, free of mindsets. And so we were not opposite the homosexuals.

Dosing strategies too varied. UK dosing was 50% of dosing in Norway. Individual physicians varied in their interpretation of data, which led to different treatment decisions based on a physicians' judgement of dose and product (and therefore, its infective risk).

3.4 Decision-making

IBI, BC, male, 7/10/2020: I mention this in terms of the decision Mark made and which I don't criticise, because as he said himself, it was the hardest decision he probably ever made. He said he was personally convinced that it was the right thing to do, but that conviction was based on zero evidence.

These convictions were shaped by guidelines produced by specialist societies, often endorsed by patient organisations. Principles of clinical freedom and peer opinions influenced how doctors evaluated uncertain evidence and made their clinical decisions. Clinical guidelines offered the reassurance of organisational endorsement, but complex science and decision-making choices meant that, presented with the same data, physicians acted differently. When these did not coincide with guidelines or when guidelines were slow to evolve, decisions were based on the opinions of peers and mentors,³⁷ and these clinical networks were usually patterned on historic relationships. Treatment decisions were usually consistent within

³⁷Gabbay and le May (2004) describe decision-making strategies and knowledge management in primary care where collectively constructed mindlines are preferred to evidence-based guidelines.

networks, and clinical trials with new ‘clean’ products were promoted within the more powerful networks. Physicians’ connections with American scientists were seen as trustworthy, as they provided reassurance of the physician being well informed and the likelihood that they may access new treatments sooner.

This period was also characterised by forging new care-pathways, to involve other specialists, such as infectious disease experts, and expand the pool of expertise to benefit the patient. Decisions were weighted toward the known risks of bleeding, with the attendant optimism of being able to treat bleeding rather than the unknown risks of HIV/AIDS and an inability to treat it: an implicit value was placed on quality of life versus the uncertain risk to it. These networks of decision-support structures helped physicians to share knowledge and navigate the burden of uncertainty of AIDS. They also provided the emotional space for haemophilia physicians at a time when AIDS-related deaths were increasing.

3.5 Emotions

Despite the passage of time, most interviewees as well as physicians providing their testimonies at the IBI were emotional, some tearful.

IBI CL, female, 21/10/2020: *It was the saddest tragedy of all, but I think to suggest culpability is wrong. I am sorry. My speech is over, but it does upset me because one of the ... said I killed somebody. It is so hurtful. And then I think, well, I'm pathetic. These patients have got far more problems than me.*

Narratives talked of fear, helplessness, professional loneliness, stigmatisation (*‘colleagues would not shake my hands’*, Australia, male, 8/7/2019), the worst period of their lives, anguish at their fallibility and witnessing their patients’ death, gallows humour, and the importance of family and institutional psychological support. None of the interviewees doubted the beneficence of their actions nor questioned the combination of ethical stances of their roles. Many physicians were glad to have been part of the solution. Clinical iatrogenesis was their main emotional burden; while all interviewees expressed sadness and enduring apology, few expressed guilt. Some expressed anger at governmental and other institutional failures, but many felt that this was a terrible misfortune, one that could not have been foreseen nor, given the facts of the time, dealt with differently.

France, male, 2/3/2021: *Moments ago, you mentioned the word ‘scandal’ about what happened in haemophilia. There is no scandal. It’s just the normal way things run when there is an issue where you don’t know the answer to.*

3.6 Engagement

Both physicians' and patients' engagement in the TR suffered. Use of FC fell between 1983 and 1986³⁸ reflecting a degree of prudence in its use, but also reflecting patient disengagement/death. Some patients stopped attending hospitals and declined home visits or telephone calls.

Italy, male, 14/8/2019: *At a certain point, patients started to disappear. I called them, but felt uneasy asking how are you, when there was this big problem.*

Australia, male, 19/6/2019: *By early 1990s, we went to find the patients. There were many people who were country, and they didn't want us to come and see [them].*

Deaths increased during the 1980s, mainly due to AIDS but also due to bleeding.³⁹

Netherlands, male, 18/1/2020: *There were quite a few who said that 'we are the canaries in the mine. We have to die first.'*

The second half of the 1980s witnessed lawsuits against physicians, yet doctors helped their patients complete litigation forms. In courts, patients analogised the iatrogenic events to the holocaust;⁴⁰ yet, simultaneously, patients apologised to the doctors they were suing. As patients' testimonies increased in intensity over time, professional cynicism increased, affecting physicians' trust in the TR and it became hard to recruit into the specialty. Many physicians stayed on in their roles⁴¹ while some moved laterally to less patient-facing roles.

Australia, female, 2/11/2019: *... when I started in early 1986, I was able to provide the support to the patients. A lot of my colleagues before me had a very difficult time, as they had not been responsible for the infection, but they had been there during the time of infection, and I think that made it much harder for them. I was lucky that they did not have to trust me before they got HIV. I was not conflicted the way like some of the others, who had been around that long.*

Engagement by patients improved over time with the appointment of new consultants who had been in training during the years of the crisis. These new cohorts of nurses, social workers, and doctors brought with them a professionalism defined on a post-AIDS ethic.

³⁸Data provided by the Scottish National Blood Transfusion service for the Penrose Inquiry (P.R. Foster, January 2011): www.penroseinquiry.org.uk/finalreport

³⁹According to Darby *et al.* (1989), data on causes of increased mortality in the UK reflects the increased deaths due to AIDS and higher risk of bleeding due to treatment choices. In low-income countries, death due to bleeding was the norm as FC/plasma etc were unaffordable. HIV/AIDS added to their burden too.

⁴⁰Starr (2000)

⁴¹Sekhar and Jadhav (2020) studied the resilience of haemophilia physicians during the 1980s by analysing oral histories of physicians.

3.7 Transparency

Physicians' communication with patients was beset with problems related to timing, manner, and content. This affected communication about results of HIV testing, (re)appraisal of treatment options, and the nature of HIV/AIDS. These problems in turn shaped patients' perception of their doctors.

IBI ethics panel: *The particularly unfortunate characteristic of the events is ... the person you trusted to tell you what was important, what you needed to know, had decided for themselves that you didn't need to know or that your knowing would be too damaging and therefore, balancing considerations, they chose not to tell you.*

Physicians deployed the notion of therapeutic privilege of not disclosing information that would cause distress/harm. Euphemisms were used, including in death certificates; in part this arose from scientific uncertainty. This was prevalent before the viral etiology of AIDS was identified, but continued until its natural history became clear. Patients' testimonies at the IBI are critical of this aspect of paternalism, as patients were used to owning their data, such as factor levels in relation to their treatment. Intended as beneficent, it was sometimes perceived as deception. Rather than the years of familiarity reducing the burden of communicating uncertainty, the struggles reveal a tension in the stance of some physicians between reassurance⁴² and openness.

3.8 Structure of communication

Many accounts describe a tone of moderate optimism rather than the usual stance of mild pessimism, criticised in IBI testimonies by younger generations of physicians as denial: denial of reality leading to an optimistic assessment of data and therefore a reassuring stance whereby physicians reassured patients about the implication of their HIV positivity, their treatment options, and the reassurance that they would not be abandoned.

IBI IF, male, 27/10/2020: *you can say reassurance is a sort of a panacea ... but I think it has other meanings. When we were getting the positive tests back, there was still a role for reassurance in trying to let people know that we will continue to look after them ... and deal with the issues.*

Since the HIV test was not used as a diagnostic tool in the early years, and because of interpretative difficulties, disclosure of results testing was patchy.

⁴²The reassurances were: reassurance of fact (based on their knowledge about Hepatitis B, the benchmark virus for blood-transmissible infection, and a flawed model, as time revealed) and reassurance of commitment to the care of their patient.

At some centres, patients were hastily invited as a batch to convey the fact of abnormal results in their cohort.

IBI CL, male, 4/12/2020: He wished to publicise this in the Yorkshire Post the following day, and I was absolutely furious with him ... because this sort of publicity is not the way that patients should be informed about the situation.

The ultimatum by a journalist led to a meeting with a group of patients convened after hasty preparations.

Some physicians thought it appropriate to relay results to patients or change treatments after there was more clarity or more consensus. This was because patient communities were closely networked, and the uncontrolled flow of information would have the potential to spread distress.

France, male, 2/3/2021: Maybe I was wrong, but I saw that it should be a collective decision. So, although I disagreed, I was a good soldier ... if I discuss my information with my patients ... they communicate a lot with each other, that would make the situation very difficult and uncontrollable.

Many physicians experienced difficulties in enunciating the scientific uncertainties surrounding tests and discussing next steps in the clinical care. ‘Breaking bad news’ posed psychological, linguistic, and epistemic challenges to haemophilia physicians, unlike their oncology counterparts where it was a familiar theme.

4. Discussion

The themes described above had a profound impact on trust in the therapeutic relationship. This was not uniform, and the same theme resulted in rupture of trust that varied across nations and was fluid over time.

4.1 Assumptions and ethical stance

The priorities of the 1980s were cancer and chronic diseases, and the age of transmissible, lethal infection was deemed long past in the Western world.⁴³ In this context, HIV/AIDS was perceived initially as another infection like HBV. The use of historic models of infections (and investigating them) enabled assumptions of patients’ consent that challenged the ethic of autonomy.

⁴³ Brandt (1988)

Historically, patients viewed participation in medical research (and by inference, use of their samples) as a way of giving back to their community: i.e., the reciprocity in the gift exchange of blood that society gave them, with its connotations of high moral value.⁴⁴

The ‘affront to patients’ autonomy’, then, was about not being asked, rather than ‘their samples should not have been used’. O’Neill and others⁴⁵ describe autonomy as an overvalued notion: the correct ethical stance before demanding a right is to acknowledge the corresponding duty. That is, if it is a patient’s right to be consented before testing,⁴⁶ it should be the duty of the doctor to consent the patient.

In contrast with home treatment, where consent was explicit, and autonomy promoted, here consent was assumed, the line between research and diagnostic use was blurred, and from a contemporary viewpoint, autonomy was breached. In this, it is reminiscent of emotions of bereaved families after the UK retained-organ scandal.⁴⁷ The grief of families was partly about the loss of parts of the deceased, but mainly about their use without consent. Both reveal aspects of suffering due to infringement of autonomy featuring the body: stored samples of a patient’s blood affected by iatrogenic harm in one, and stored body parts of a dead child in the other, and both matters led to fundamental reforms on the ownership of tissue and organs.

In a scenario of uncertainty and fear, where trust in the doctor’s treatments was already suffering, this paternalism⁴⁸ and loss of autonomy further contributed to mistrust. There is heightened expression of this at the IBI: forty years on, values of

⁴⁴Fillion (2008) provides insight into the modes of commitments of haemophilia patients pre and post AIDS. Titmuss (1971) describes the societal values shaping altruistic blood donation.

⁴⁵O’Neil (2002) in her lecture series, cites Beauchamp and Childress (2001: 272) regarding the rise of autonomy at the expense of beneficence: ‘Whether respect for autonomy of patients should have priority over professional beneficence has become a central problem in biomedical ethics. ... The physician’s primary obligation is to act for the patient’s medical benefit, not to promote autonomous decision-making.’

⁴⁶Explicit consent for testing to answer a public health or clinical question was not mandated in the 1980s.

⁴⁷Retained body parts after autopsy caused mental anguish to many families and was reviewed by the Presidents of the Royal Colleges of Paediatrics and Pathology in 2001. Stringent laws were introduced in 2004 to reinstate trust in coronial and autopsy processes. Discussions have continued across learned societies in the need for amendments in the interest of science (e.g., learning) and society (e.g., organ donation).

⁴⁸Paternalism in medical decisions was the accepted norm by the Bolam principle in law (1957) until the Montgomery principle replaced it in 2015. Legal historians cite Bolam as aiding paternalism, which became more acceptable in the eyes of the law when compared to the 19th and early 20th centuries, a blip that professional ethics and guidelines sought to address and sometimes remedy. Aspects of paternalism in the medical stance were discussed further by IBI’s Ethics panel: [https://www.infectedbloodinquiry.org.uk/sites/default/files/documents/Transcript - London - Wednesday 27 January 2021 \(Medical Ethics Experts continued\)_0.pdf](https://www.infectedbloodinquiry.org.uk/sites/default/files/documents/Transcript - London - Wednesday 27 January 2021 (Medical Ethics Experts continued)_0.pdf)

personal and cultural autonomy have sharpened..⁴⁹ These concerns were not prominent in other national inquiries,⁵⁰ most of which were completed in the 1990s.

Individual autonomy, though central to medical ethics, is a debated entity.⁵¹ For example, environmental ethics, focusing on public benefits and harms, deems it acceptable to curtail individual autonomy: e.g., mandatory HIV testing. In haemophilia, physicians wore several hats simultaneously and prioritised the public health imperative of ‘turning off the tap’ of infected blood at source. This ethical stance impacted on their priorities in communication and actions. The IBI chair refers to this as an example of an ethical failure. GL’s response (see Section 3.2) is illustrative of how physicians viewed this stance. GL expresses moral certainty with no conflict between the public and private duty of the doctor. GL’s perception of duty lay in prioritising the public health response, because, in an unfolding health crisis, clinical decision-making must be individualised, but the physician must also consider the general consequences to the broader population (of patients with haemophilia, of other recipients of blood, of society). It differs from the ethical viewpoint where ‘the clinician’s priority is their patient’.⁵² Epidemics present scenarios where utilitarian ethical principles deem that individual rights are balanced against notions of the common good, and an obligation to act on those principles. These actions contradict deontological principles, an ethical practice that underpins much of medicine, since it flouts the ethical pillar of autonomy and, thus justice to the individual.⁵³

GL’s actions heed the four ethical pillars;⁵⁴ but by acting on the blood donation chain, they benefit uninfected patients, they prioritise a notion of justice over that of autonomy. They are simultaneously utilitarian and deontological, serving the broader good but also aimed at their patients.

⁴⁹Hellin (2002) describes from a European perspective, the current phase of the therapeutic relationship as one of the most fraught, yet one of the most humane, with conflict between societal notions of autonomy, beneficence, and justice. Steinhart (2002) discusses from an American perspective the role of the doctor and patient in the notion of autonomy in the therapeutic relationship.

⁵⁰For example, Canada: <https://www.taintedblood.info/tb/krever-report/>; USA: <https://nap.nationalacademies.org/catalog/4989/hiv-and-the-blood-supply-an-analysis-of-crisis-decisionmaking> Unlike in the UK, these inquiries were held soon after the iatrogenic events developed, and the emphasis of the suffering and complaints was more on aspects of treatment and compensation.

⁵¹As discussed by O’Neil (2002)

⁵²Wulff (1981), states: ‘He must balance his duties to the patient, including fulfilment of the patient’s autonomy with his wider duties including his duties to future patients and to the national economy.’

⁵³Garbutt and Davies (2011) describe deontological ethics as patient-centred; hence consequences are not used to justify means. Utilitarian ethics, inclined to be more society-centred, values care for the greatest welfare for the greatest number of human beings: hence outcomes determine means.

⁵⁴The four ethical pillars are beneficence, non-maleficence, autonomy, and justice (Beauchamp & Childress 2001).

AIDS was a public phenomenon in its uncertainties, suffering, and activism, and the actions of the haemophilia physicians extended beyond the patient–doctor dyad. Instead of a dyad, the patient was now involved in a tetrad of healer/patient–scientist/community. This ethical shift in the stance of physicians was not mirrored by that of patients whose vulnerability had vastly increased. As with the perception of loss of autonomy, this shift caused patients in some nations to question their physicians’ priorities, further exposing the TR to increased mistrust.

4.2 Knowledge and decision-making

Since HIV science evolved slowly, medical decision-making relied on assumptions. These fostered an element of certainty that enabled physicians to take pragmatic treatment decisions, while simultaneously investigating the scientific questions from a detached stance.⁵⁵ In our study, physicians’ decision-making placed importance on accruing evidence while making assumptions that were based on their cognitive biases.⁵⁶ These biases, shared by members of a clinical network, would be replaced with evidence-based decisions once such evidence accrued. As such, the situation bears some similarities with the COVID-19 pandemic. In their analysis of narratives shaping flawed policies in the COVID-19 pandemic, Greenhalgh and others consider the pandemic an example of Mauss’s total social fact, a phenomenon affecting many domains of society and where cognitive biases were important in structuring scientific narratives.⁵⁷

Decision-making based on clinical freedom, peer opinions, and guidelines enhanced patients’ trust in the structure of care for three reasons. Patients were organised as a collective and they too networked. Shared values and considerations between their doctors provided them with reassurance about consistency of decision-making criteria. Second, the existence of structures in health care enabled trustworthiness in the process of decision-making if not the decision itself. Third, new products and clinical trials were viewed with hope because of previous successes with technology: i.e., a technological solution for a failed technology. The manner of decision-making provided some assurance. However, the assumption of values shaping decisions were viewed by patients in some nations as paternalistic, further denting patient’s trust in their physicians. Assumptive decisions were also challenged in courts as negligent and, given the networked nature of decisions, this

⁵⁵ Atkinson (1984)

⁵⁶ Evidence-based medicine was a movement that gained in importance from the early 1980s. The precautionary principle that fostered caution in decision-making became prominent in medicine after the AIDS era.

⁵⁷ Greenhalgh *et al.* (2022)

was an expression of mistrust at networks of physicians. In France, where public fallout was high, the haemophilia TR was transformed post AIDS to a more negotiated space.⁵⁸ Fillion describes this in moral terms: ‘this recovery forces actors to re-examine their conception of knowledge and their conception of what is right and wrong’.

4.3 Emotions and disengagement

Disengagement of patients was the definitive expression of loss of trust in the TR, representing a point when the emotional burden of fear, stigma, risk, and blame affected the stability of the TR. Fear of AIDS and fear of avoidance of treatment were compounded by stigma arising from connotations of homosexuality and from being perceived as HIV spreaders. These emotions led to blame and anger at physicians and organisations. Two core agents of Axis 1 previously considered trustworthy, namely FC technology and the physician, became blameworthy. Axis 1, splintered by now, continued to function out of necessity as many patients wanted treatment, no other doctors could provide this, and FC was still needed.⁵⁹

This emotional atmosphere caused patients to interrogate their trust in physicians, whether it was misplaced, whether it should be suspended in part (e.g., trust in the clinical care but not in the information) or full (continue to seek care, cynically). Some physicians assumed they were trusted, which, when reflected upon in retrospect, turned out to be misplaced: some physicians were trusted and then lost the trust; some gained trust with time. The balance of trust, mistrust, and suspicion was fluid and based on reappraisal of the clinical, personal, and social realities that changed with time. Scientific advances were rapid after 1985 and with the appointment of a new generation of haemophilia doctors, trust in the TR grew. But the intergenerational impact of this has meant that successive generations have commenced their engagement in the TR with more suspicion than trust.

As physicians grappled with culpability and blame, they too re-appraised their trust—could they trust their patients to continue to trust them? Which product, peers, science, institutions to trust? The vulnerability of doctors as second victims of medical error has been explored⁶⁰ and Bosk has addressed the experiences of the

⁵⁸ Fillion (2008)

⁵⁹ Between 1982 and 1985 some treatments were downscaled to cryoprecipitate, which used fewer donors; locally produced FC where possible was favoured. Treatment decisions were complex, varied, and personalised.

⁶⁰ Wu (2000) has discussed the notion of the doctor as the second victim in medical error; this has been contested on the basis that it disempowers the first victim: i.e., the patient.

distress and scepticism of trainee doctors on AIDS wards.⁶¹ More recently, the distress experienced by physicians because of witnessing and contributing to iatrogenesis has been studied in settings of opioid treatment⁶² among others. Kleinman⁶³ describes the real-life messiness in clinical situations: ‘The hidden conflict is between what the professional persona seems to demand and what the personhood of that professional actually feels but cannot or will not speak.’ Sabroe and co-authors highlight the need for self-compassion and self-justice as tools to cope with uncertainty and error without shame or taboo.⁶⁴ These notions of physicians’ vulnerabilities underscore the stressors of physicians’ trust and engagement in the TR.

4.4 Transparency and structures of communication

Communication with patients was shaped by two movements of different pace: the slow evolution of AIDS and its science (AIDS defined 1982, HIV test 1984, safe FC 1985), and the faster evolution of fermenting uncertainty at the recognition of the iatrogenic nature of the infection on the other. The shared history of a long TR and the reality of past iatrogenic events were insufficient to ease communication of uncertainty.

Transparency comes into question in situations where epistemic uncertainty makes it difficult to convey ideas about the future. Transparency is considered important in maintaining trust and assuring trustworthiness, but transparency in science has led to distrust.⁶⁵ In particular, verbal rather than numeric descriptors of uncertainty were perceived as untrustworthy and unreliable⁶⁶ and, in general, the communication of ambiguity or uncertainty has not increased trust. When faced with individual circumstances at times of uncertainty, it is more important to reduce

⁶¹ Bosk and Frader (1990) have described medical safety and error in clinical practice: i.e., ‘the shop floor’.

⁶² Chary and Flood (2021) and other authors have discussed iatrogenic harm in contemporary medicine; they described the situations of being inadvertent contributor to harm due to processes beyond control.

⁶³ Based on his personal experience, Kleinman (2011) describes the difficulties in expressing moral sensibility and hidden values in medical transactions.

⁶⁴ Sabroe *et al.* (2021)

⁶⁵ Jasanoff (1992) cites the example of the Environment Protection Agency’s (EPA) work in risk analysis of carcinogens in the late 1970s. Under hostile scrutiny of its data and claims, the EPA proffered increasing explanations, but increased clarity did not help decrease the conflict. Instead, it led to litigation, which led to further explanations of the assumptions and uncertainties and thereafter to the deconstructing effects the law.

⁶⁶ van den Bles *et al.* (2020) examine public perception of ambiguities in connection with COVID-19 communications where verbal descriptors were received less well than numeric assessments.

deception and lies (including euphemisms) than to increase transparency.⁶⁷ In particular, if the relationship has not suffered from prior deception, transparency does not serve to increase trust; instead, it may confuse by increasing unsorted information, and potentially spread misinformation.⁶⁸

Untruths, lies, denial, misinformation, euphemism, and deception are some words used to describe this stance of optimism.⁶⁹ Philosophy and ethics examine lies or deceit in moral terms. The anthropological examination of lies addresses their ambiguous nature, where the label of ‘lie’ depends on the social context and the act is under perpetual construction in a therapeutic relationship. The doctor–patient relationship is characterised by lies under certain circumstances: i.e., knowing one thing and saying another. Lies serve paradoxical functions and are an expression of power.

Doctors lie to patients, an action that is legitimised by the utilitarian philosophy for its useful consequences to the patient.⁷⁰ Patients lie to their doctors through fear of blame or recrimination, expressing resistance but not daring to be openly resistant, or to leverage gains. Silence and secrecy, too, have a place in the relationship, e.g., patients withholding information such as their HIV status or seeking alternative healthcare, or their haemophilia diagnosis, for fear of being stigmatised.⁷¹ Implicit in these is intentionality, or awareness of what is being said.

The testimonies and narratives above describe the shifting framework of truth, and thus communication of truth; in such a shift, several stages exist of which silence is one. This was exemplified by CL (see Section 3.8) who felt that silence was justified until evidence was clearer, but was pushed into hasty communications with patients because of a journalist’s ultimatum. The interpretation of ambiguities also reflects the social and cultural contexts of actions; illustrative of these changing contexts are the different perceptions of physicians by another group of patients: people with thalassaemia the majority of whom did not believe that their doctors were blameworthy.⁷²

⁶⁷ O’Neil (2002) examines the ethics of trust in her Reith lectures.

⁶⁸ O’Neil (2002)

⁶⁹ Van Dongen and Fanzang (2002) reflect on the role and the use of a lie, its meaning—whether as strategy or pathology, whether as denial or protection—and its social implications.

⁷⁰ Fanzang (2002) cites Bok’s argument that it also benefits the doctor.

⁷¹ Carricaburu and Pierret (1995) examines secrecy and stigma in HIV/AIDS and in haemophilia patients who contracted this. Contracting AIDS, in many settings, was taken as a marker of belonging to stigmatised groups in whom AIDS was prevalent.

⁷² Thalassaemia major is another ‘I am’ disease; it is inherited and fatal without transfusion treatment. Sufferers depend on monthly, life-long, transfusions of red blood cells. It affects people of Asian, African, and (some) Mediterranean ancestries. Unlike severe haemophilia which mainly affects men, the gender distribution in thalassaemia is equal.

The haemophilia TR has not been studied systematically.⁷³ Research has focused mainly on individual components of this relationship, such as treatment adherence/trust. Some studies⁷⁴ have examined physicians' trust in their patients and its impact on defensive practice.⁷⁵ These studies situate trust as a fluid entity across the therapeutic dyad and beyond. Wilk⁷⁶ highlighted the need to study trust during situations where the TR is stressed, especially how the TR is shaped over time as trust is gained and lost. The examples cited in our study provide evidence for a fluid level of trust that sustains the TR even while mistrust is felt and expressed. Loss of trust in the TR occurred everywhere, but the expressions of public scandal in haemophilia–AIDS differed across nations. This difference did not reflect the organisational steps taken to stop iatrogenic⁷⁷ infections; rather it reflected on the level of public protest, and the actions of the press. The shared nature and long duration enabled the resilience of haemophilia TR, but at significant cost to trust and to the individuals in the relationship.

5. Summary and conclusions

The aim of this study was to describe the changing notions of trust in the haemophilia TR through the 1980s by examining the physicians' stance in the global north during this period. The iatrogenic events and uncertainties of haemophilia–AIDS disrupted patients' trust in physicians, the clinical process, and the technology. Blood, its donation and its transfusion evoke deep emotions and hold symbolic significance across the world; the iatrogenic harm from blood transfusion disrupted

⁷³McCabe *et al.* (2018) examined publications addressing haemophilia therapeutic relationships: e.g. Tran *et al.* (2011). They identified two key gaps: connections over the physical body, which in haemophilia, is a major component; and second, the lack of consideration given to the theme of the 'personal' in the therapeutic relationship, the failure to address the deep personal and professional involvement of haemophilia physicians with their patients.

⁷⁴For example, two studies examined the therapeutic relationship in other situations: primary care by Petrocchi *et al.* (2019) and obstetrics by Diamond-Brown (2016).

⁷⁵Fritz & Holton (2019) and Parker (2019) debated the issue of trust in patients and how they influence medical practice with an increase in defensive practice, including over-investigation.

⁷⁶In their scoping review, Wilk and Platt (2016) raised crucial points that require addressing in measuring complex medical trust. Thom *et al.* (2011) validated a quantitative instrument to study medical trust.

⁷⁷For example, Spain had done far less to assure safety and there was no scandal; in contrast, physicians were imprisoned in France. Berner (2007) analysed two studies to examine why the conclusions of the studies were different and why events took a different course: *Blood Feuds: AIDS, Blood and the Politics of Medical Disaster* (Feldman & Bayer 1999) and *Success and Failure in Public Governance* (Bovens *et al.* 2001). Drawing on the same events across the same eight countries, the two drew strikingly opposite conclusions on the national responses and scandals that ensued.

trust across society. These events expose the vulnerability of the trustee and the trustor, even in longstanding relationships. Whilst these could be viewed through the prism of the failures of the medical industrial complex,⁷⁸ they also shed light on medical and societal responses to major uncertainties.

Despite prolonged periods of suspended trust, active suspicion, and mistrust, the TR survived, suggesting that, when presented with new uncertainties, a reappraisal of the substance of *what* is trusted can help physicians and patients to recalibrate a shared vision. When interpersonal trust is actualised at times of need, individuals and their social worlds shape each other. If trust is lost during this appraisal, a cohesive society enables its recovery by providing the conditions by which it can be relocated. This was evidenced by the traction gained in the Netherlands (see Section 3.3) where open discussions with the gay community addressed the risks of donating blood; this benefited all. Perceptions of mistrust live alongside trust in medicine. Despite professional failures and perceived untrustworthiness, trust is placed at *some* locus either out of necessity or because the untrustworthy person could be replaced: people find a reason to continue to trust medicine. This trust is discriminatory, and it is not exclusive, as increasing number of patients choose to seek care from other purveyors of health.⁷⁹

This study's focus is on physicians. It did not examine patients' perspectives of trust. Physicians interviewed were selected for convenience through snowballing and physicians from Asia, Africa, and America could not be included as the timeline of the project was affected by the COVID-19 pandemic. Some demographic details have been withheld in compliance with ethical permissions. Oral histories and legal testimonies have been analysed using the same criteria. Despite these limitations, the study provides a nuanced understanding of the impact of uncertainty and iatrogenesis on the doctors and the TR. This understanding is of value in unpacking mistrust related to the COVID-19 pandemic and in shaping the medical stance during future events of major uncertainty.

Health outcomes are better in societies where trust is high; but societal changes, such as those that occurred with AIDS and COVID-19,⁸⁰ led to disruption of trust in many parts of the world, raising new ethical imperatives for patients and physicians. Notably, beneficence of intent, notions of justice, and value-based decisions

⁷⁸ Illich (1974) and Varley (2021). The limits and iatrogenic harm of the medical industrial complex were extended to contemporary issues in a series of articles introduced by Varley.

⁷⁹ Narrative from Netherlands: '*... giving female hormones to boys. It was during the growing phase and they couldn't grow anymore. And the simple thinking was that women don't have haemophilia. So we give them hormones that then they won't have hemophilia, Such things never happened in an academic centre, but it happened outside.*'

⁸⁰ British Academy (2021)

made in their patient's best interest by haemophilia physicians were insufficient to sustain trust. These have important implications for the training of doctors about dealing with epistemic uncertainty and on managing trust in their clinical encounters.

Our study shows that disruption of trust, like fallibility and uncertainty, is inevitable in medicine. Mistrust coexisting with varying levels of trust is an inevitable response and is a driver of change in the therapeutic relationship. They shape societal expectations while being shaped by them. Medical students and practicing physicians could be sensitised to this notion so that they are less damaged by disruptive emotions and more thoughtful in their medical decision-making and their communication. Medical educators should consider the relevance of learning from past disruptions and how such learning and conversations could be embedded in the training curricula. Regulatory changes in the post-AIDS world have shifted the locus of trustworthiness to systems with increased accountability. Societal expectations have been protected by these acts of law, but there is still a need to explore processes of transformation in societal stance during serious uncertainties and therefore a need to enhance medicine's dialogues with society.

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APPENDIX

Interviews with Haemophilia physicians: Template for semi-structured questionnaire

Culture

Tell me about yourself. Where are you from, where did you train, what are your qualifications, where did you work?

Prompts: Ethnicity, gender, university of qualification, large vs small centre, Pathology vs clinical affiliation (i.e. Haematologist vs non Haematologists in UK); paediatric vs adult physician.

Categorising iatrogenesis

When did you realize that this was an iatrogenic event? How did you label it?

Prompts: What category of medical mishap did you map it to?

Movement of knowledge:

How did you gain knowledge about these events? How was this shared? Were there guidelines for your region?

Prompts: What were the sources? How were they disseminated in your hospital or region? Did you seek advice from your peers in your or other hospitals? Would people ring you for advice? Would your advice be different to—say a neighboring hospital's advice? Were there recommendations that you or others made during this period? How did it move in both directions: from local and tacit knowledge to cosmopolitan and abstract form? How did dialogue and debate occur?

What was the hierarchy in knowledge generation in your hospital and region?

Method of decision making:

How did the events of 80's influence your clinical decisions at the time? Specifically with treatment strategies, choice of products and dosing strategies. How did your patients' decisions affect your decisions and vice versa.

Prompt: Why did the use of imported products and dose per population increase through the 80's. How would your decisions compare with that of your peers? How much did guidelines influence your practice? How did you make decisions if there were no guidelines?

How did your patients' decisions match with your decisions on treatment preferences? How did the patients' association influence your decisions?

Language:

Disclosure. Apology. How did you communicate the events with your patients/parents? What vocabulary and metaphors did you use? How did you consent to testing and how did you manage the results of tests?

Prompt: How did your vocabulary match with that of that of your patients? Did you use metaphors such as were used in oncology? Did you feel the need to apologise, to explain?

Effect on you:

What were your emotions during this period? How did you express these to patients? What and who were your supports?

Was there any litigation? How was it conducted?

Prompts: Many physicians experienced guilt, suffering, and latterly anger: How did your feelings change in that period? What were your fears? Did you experience stigma due to association to AIDS, of being part of iatrogenic crisis?

How did your patients' emotions affect you emotionally? Was repentance and forgiveness discussed or implied? Did you attend funerals of patients?

How did your family deal with your experiences? What was the impact on your personal life?

Relationships:

How did the events affect your professional relationships?

How was your institutional support for your work?

How was the relationship with the blood services and with the government?

Prompts: Relationships with managers and health officials: How did you lobby? With the blood service, with government. How did your managers view the service? Was funding to individual departmental level suffer?

Relationships with specialist nursing and therapists: What was the role in decisions, emotions, management and matters of judgment. How was power distance between medical staff and other health care practitioners?

Symbolism:

How do you think that the ideas of local, voluntary, altruistic donation connect with the fact of transfusion transmitted infection?

Prompts: Do you think that use of local products would have been a satisfactory alternative? What do you think of the idea of safe, voluntary, altruistic donation leading to infections? How do you view the 'villainy' of USA products and yet reliance on USA imports.

The clinical relationship:

What did care mean then and now? How they have changed? How they reflect on change.

