

Title: Why stay? Resilience in haemophilia physicians in the 1980s

Short title: Resilience during the time of uncertainty

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Abstract: The occurrence of AIDS in 1980s posed difficult problems for haemophilia clinicians world-wide. The impact of these events is substantial and the events continue to be subject to judicial proceedings and publications. The stance of Haemophilia physicians, particularly their professional resilience is of importance and remains unexamined. Deploying oral histories informed by literature review of scientific publications and past inquiry reports, this qualitative study addresses how physicians continued to work in Haemophilia during those years and attributes that contributed to their resilience. Experience and role in laboratory aspects were of value in handling and communicating uncertainty. Collegiality, peer support and scholarship were important in sustaining their roles, in clinical decision-making and re-instating confidence in the therapeutic relationship during the toughest years of their practice.

Introduction: The AIDS crisis in haemophilia was an unprecedented world-wide iatrogenic disaster with tragic and calamitous consequences. Since first reported [1] its incidence increased through the 1980s; annual death rate rose from a baseline 8/1000 to 24/1000 in 1985 peaking at 80/1000 by 1990 [2]. Unlike previous health crises it was prolonged, scientifically and medically complex and stigmatising with significant socio-political dimensions [3,4,5, 6]. Haemophilia physicians have spoken about emotions of grief, guilt, fear, ineptitude [7]. Many held complex portfolios and could have chosen to diversify. However, very few quit.

The scientific efforts and advocacy by physicians contributed to the improvements in 1970s when life expectancy improved and patients could aspire to 'normalcy' [8]. The emergence of AIDS, its containment and treatment unravelled over five years. During this period, as the iatrogenic nature of AIDS became clear, physicians struggled to make sense of events. Their position has been described as 'the stuff of nightmares' [9]. How did they sustain their roles through this period? Why did they stay? These questions can clarify attributes that enable physicians to endure and adapt during crises.

Methods: A literature review was conducted from pubmed, google scholar and Jstor using key words Haemophilia, AIDS, HIV, anthropology, sociology, epidemiology, history between 1975-2019. Primary/secondary sources of national inquiries were analysed. Between June and

November 2019 oral history interviews were conducted after informed consent with 14 respondents (11 male, 3 female) from 4 countries (Australia, Canada, Italy, Netherlands). Interviewees were identified on the basis of being consultants in Haemophilia during the 1980s and were recruited by snowballing technique. No invitations were declined. Interviews were based on a semi-structured questionnaire constructed on the basis of literature review and discussion with experts, they lasted 1.5-2 hours. They were audio-recorded, transcribed and analysed using established thematic content analysis methods [10]. Themes extracted from both literature review and interviews were grouped into broader domains cross-checked for validation by the second author. Data and analysis are presented as broad domains (sections 1-7) detailed further in Table 1. Verbatim quotes elaborate themes. Respondents are identified as R1,2 etc., demographics are not provided to protect identities; this was a consideration for ethical approval of this study. Four vignettes (section 8) are described to illustrate individual experiences.

Results and Discussion:

1. The therapeutic relationship: The prolonged collaborative relationship that physicians developed with their patients became complex through the 1980s [11,12]. Patients suing the state or institution sought the help of their own physicians to complete their legal paperwork.

'I was at a court as witness. I had to hide myself the night before. When I went to the court there was a queue of patients who started to boo at me as I approached the entrance- it was a very unpleasant situation.' (R1)

'..he gave me his number because he wanted to speak to x (his consultant) because he felt so guilty that it looked like it was against x- while it was against the producer.....because the producer and the treating institute were seen as one party and he was at the other end. But he wanted to separate those two. That is why he wanted to call, to talk to him.'(R11)

Few patients moved their care elsewhere [11] and some collaborative relationships continued.

'Our patients appreciated the fact that we were actively trying to answer questions by research. Personally my patients were sad but not angry. I don't feel guilty but very very sad at what happened'.(R1)

'It was really sad because most of these were adolescents and I had seen them growing. We had a relationship of friendship. They were relying on us'. (R2)

'the great majority of patients- their coping was really to fight, to feel to have an ally, who could take care of them...I moved only after 30 years- felt I could not abandon my patients. Also some of the seropositive patients were collaborating in the approach of washing of semen- in a way it was almost part of the family'. (R3)

'...but one could sustain it when patients accepted it as misfortune rather than blame you for the turn of events'.(R4)

For some the experience affected practice and posed dilemmas:

"My chief had done a lot for patients from early years and when this occurred, he had sort of burnt out. He was saying 'I am not able. I was thinking that I had brought the treatment of life to these patients but ...' He could not deal any longer with the patients and he left everything to me.. Anyhow my responsibility was to be there till the end and probably postpone the end."(R3)

'I tell you I don't absolve myself. I was a wimp in a way, but for me it was very difficult. He was younger, less involved originally- I relinquished dealing with patients on a day-to-day basis but I continued to advise and direct and write....And then the change with HIV treatment- I was part of that- I remember a lady at the edge of the tomb and she was saved by HAART. That was really in a space of 2-3 months that things changed'. (R1)

'....during the trial he kept having TIAs and I was terrified that he was going to be killed by this. I said to my patient (plaintiff) I really don't know that I can keep treating you and am quite confused by all this. But my hospital has advised me that I had to.'(R5)

2. Labelling and communication: Labelling a disease and ascribing aetiology generate powerful metaphors which shape illness, meanings, experience and doctor-patient relationship [14]. This evolved over time with Haemophilia-AIDS:

'Nobody could understand, nobody knew until they isolated the virus, until then we didn't even know it was a virus. Nothing. We'd talk about drugs, homosexuals and the rest of it but no talk about the virus until much later.'(R6)

'Patients assumed that I was knowledgeable because I had been in USA. But I wasn't. Because at that time in USA it was a nightmare of discussion of different hypothesis and proposals. No one knew. It was only in 83 that we started to understand and I made my mind up after a lengthy discussion with Bruce Evatt when I discussed my cases.'(R2)

Biopsy reports of lymph nodes lacked precise categorisation:

'there was hyperplasia, necrosis- they had never seen this picture before'.(R2)

3. Advocacy: Through 1980s physicians lobbied with blood services, the state sector and pharma but mostly the choices and decisions regards specific products lay outside their departments; it was difficult to ensure adequacy, self-sufficiency and safety of factor concentrates (FC). Self-sufficiency could not ensure safety as HIV affected the blood donor pool world-wide. Still, it was considered the safer option and physicians lobbied intensively for increased local production [9]. In countries where self-sufficiency was policy, there was the matter of how best to use these scarce products.

"The critical event was the letter you wrote in November 1984 after you learnt about heat treatment and I think it helped sway the group.'(R7)

'Yes, on my flight back I dictated the letter to ...(the authorities) and copied it to you as Chair.'(R8)

'The guilt I have relates to not reacting to this letter sooner- we are only talking about 15 months here- I wish we could have got the message to everybody earlier- it was difficult at that time..'(R7)

4. Clinical decision-making: It has been argued that an expert practitioner, when facing uncertainty of their knowledge-base are pragmatists rather than sceptical, detached, scientific observers. They do not set out to falsify a hypothesis. Rather, they rely on their versions of common-sense thinking that inform everyday practice dependent on the state of current knowledge and available recipes [15]. Clinical decisions had to be reviewed in real time: choice of products, changes to treatment including the question of 'Should treatment be changed?' and balancing the risks of bleeding vs AIDS. These were difficult decisions for a generation of specialists who, through the 1970s, had defined their standards for managing Haemophiia and promoted the idea of 'normalcy' in life-style. Neighbouring hospitals had different approaches to

treatment. Some physicians and patients aspired to normalcy; while others elected to accept some of the limitations of arthropathy. Regarding two institutions with different ethos:

'the conflict between our institutions was deep and open'.(R4)

'the younger pts I think the patients in their 20s and 30s , so the real young pts- they came here because they know that there was another attitude compared to them. So that attracts also a different kind of patient. (R11,R12,R13).

Two respondents, one of whom used cryoprecipitate and the other FC stated:

'Our backgrounds were different which influenced our practice between 83-85; clinical practice got more cohesive towards late 80s. I don't think we said in the beginning that we have a common standard- that came much later. '(R8)

'There were papers but no firm guideline. There has always been collegiality and some collaboration between centre directors.They recognised our expertise and we facilitated the development of haemophilia centres'.(R1)

The febrile atmosphere was further complicated by the competitive nature of assay development. Assays raised practical questions- should existing samples be screened? How should a diagnostic test be offered when no treatment was available? Many but not all physicians screened samples and communicated results through letters or at out-patient appointments.

'When they tested stored samples with HTLV3 antisera in 1984, then they realised that there was a problem. They had to get the patients in and test them properly. That was the first time they realised that they had the infection. '(R5)

'Most did not want to know the results because there was no treatment. Only I and my coordinator knew. '(R8)

In countries where HIV was reportable, some patients preferred the anonymity of testing at central research laboratories rather than the local diagnostic laboratory - adding a further dimension to the burden of making a diagnosis. Practices around consent and communication differed. Conveying uncertainty and fallibility in medicine was difficult [21]:

"At a certain point patients started to disappear. We started asking what was going on and why. So, I started calling them. But calling patients is not straightforward- I felt uneasy to ask how are you knowing that there was this big problem behind. They said 'if I already got the virus what's the difference?'"(R2).

5. Scholarship: A particular characteristic of this period was the increased scholarship at a time when demands on clinical time were high. Since the 1970s problems with hepatitis B, Non-A non-B hepatitis, factor-inhibitors and variations in quality of FC had ensured systematic documentation and monitoring: serial blood samples were frozen, clinical registries were maintained. Between 1982-1983, publications relating Haemophilia with AIDS increased 39 fold [22]. The opportunity to mine registries and samples for answers, to describe and label an evolving disease and to frame the next question were powerful incentives ('AIDS has been good to me' statement by physician cited in [23]). At every turn, new questions generated scope for further studies:

"I was collecting sera and realised that HIV- patients were seroconverting despite heat treated concentrate. I asked my people what's going on? I checked the data 3-4-5 times. It was real. I went to my boss- 'I got this data and I don't know what to do'. He immediately called the national head of.....I was invited to CDC to present the data".(R2)

'...no time to get any research. I told my registrars- you have to get the publications out. I really regret the lost opportunity- there was just no time...The hospital had me on the cheap'(R5)

'...research is the positive attitude- looking for explanations, answers. It helped me to be better organised in terms of scientific productivity. In fact my very best period was when I had funds to have a secretary who stayed for 6 years and helped me establish projects across Europe.' (R2)

6. Knowledge management: There was a time-lag between generating and publishing data: e.g. 21 months elapsed from the time of the first documented symptoms of AIDS in a Haemophilia patient in October 1980 to publication[1]. In those early years, information spread by word-of-mouth.

'A lot of it was personal contact...really word-of-mouth and lot of phone calls and reading journals that came by mail. I remember getting an urgent report by telegraph-' (R8)

In some countries (e.g. U.K.) there was a clear hierarchy of guideline development. In others, individual physicians sought out expert opinions- given the nature of events, these were largely from USA.

'It's nice that we established connections with CDC, people came over and we got a bit of privileged information from them.' Samples were important in transactions: 'my patient died while I was still at CDC. My hospital called me and asked did I want the specimens or did CDC. I ended up saying

CDC.'

Although informal discussions were critical to discuss patients and calibrate bias, these were simultaneously grounded in appraisal of available evidence. Given the publication lag-times and the complexities of dealing with an iatrogenic crisis, it was a lonesome time for clinicians, patients and carers. Conferences afforded the opportunity to share concerns and experiences. Although not formally planned till later, conferences through the early 1980s provided spaces to tap into primary data and experience and maintain international links.

7. Clinician-pathologist: Many haemophilia physicians were both patient-facing clinicians and pathologists directing coagulation laboratories. This dual role offered a structured space outside the clinic:

'I think for a haematologist it's important to have both kinds of experience- the different perspectives probably helped deal with the crisis because it's a different involvement. I liked the lab. Of-course you are more knowledgeable with data to support your decisions- although I don't know if patients understood these nuances'.(R2)

'During that time I was also in charge of lab haematology. In fact I got more involved with the local Haematology society and that gave me a lot of access to colleagues and companionship.'(R5)

8. Personal and professional reflections:

8a. In his 80s, more than 35 years after these early events, S (R9) was in tears as he reflected on his patients. S and his wife had welcomed me into their home with consternation and apologies; the electricity was off and we sat in our coats, talking in the cold sunlight. S was a leader in the development of a global haemophilia network.

'S..., it's here....'² He recalled the exact precise moment when the crisis became local: he was sitting at a local conference when the national transfusion lead rang him on his mobile to say that HIV had arrived in their country. It was no longer a foreign disease. S founded a haemophilia network and established a multidisciplinary team framework for the city. The task of this team was to prioritise patients and allocate FC based on expectation of overall outcome. Concentrates were in short supply. Sometimes there were ugly scenes arising from the

pressure of simultaneous patients requiring surgery. Surgeons were angry. Once a patient held a gun to his head in clinic. He was grateful for help from the infectious-disease fraternity who took over the care and thus, to some extent, the burden of AIDS.

8b. F (R6), a prominent haemophilia physician recounted (with hesitant laughter) how colleagues wouldn't shake hands with him for months. During litigation, as an expert witness at court, a barrister asked him, 'how does it feel to have killed so many children?' Loneliness, ostracisation, blame were important themes in his professional life. *'What kept me going was that I felt that I needed to be part of the solution.'* He attributed his resilience to his origins: *'..my very early past ...I am a holocaust survivor... So when this happened I had certain defense mechanisms that were ..sort of turning inward towards my own inner strength. In those 3-4 years I would come home pretty miserable.'* He discussed things with his wife, but did not think he burdened her or his family. His wife said as she drove us to the station, that those were very difficult years. They would go away with the children over the weekends and he would try to switch off. In 1987 at 47 years of age, she pursued her dream of becoming a nurse and F taught her anatomy and physiology. He still intensely regrets the 'double-whammy that patients had to accept- the pain and arthropathy of sub-optimal treatment but yet developing infections- they lost out on both counts'.

8c. P(R10) was appointed to his consultant role in 1985- relationships with his patients were yet to be forged. Whereas the ravages of AIDS were personal to his predecessor, P had the space to forge new basis of trust and renew the therapeutic relationship. Recently, P needed coronary surgery and found himself suspicious of his cardiac physicians and their decisions. Half sedated as the oxygen tubes were being inserted as things were going wrong, he remembered his own patients' suspicions. He dreamt about the journeys he made as a newly appointed consultant with the nurse to treat patients in the hinterland, driving miles to persuade a parent to treat their child. Hinterland hostility had combined with mistrust of the treatment and the treating team. It required all the skills of the nurse and social worker to make the breakthrough to at least have a conversation, although not to treat the bleed. There were deaths due to bleeding in his practice after years as a registrar of not having seen such deaths.

8d. You were doing this job you were comfortable with, you were seeing changes with new treatment. You were wanted by colleagues. The centre-directors who were there in 1980, none of them quit. To a man and woman they kept going. Its fascinating. For me there were 2 reasons- the group across the country was supporting each other. The other thing is that Haemophilia services had a team- at least 4 members and so the team supported each other. For a long time we saw the same old faces at the Centre Directors' meetings. We couldn't attract young people to come- not until 10 years ago.(R7)

Based on the illustrative oral histories with physicians, these were their toughest years. The emerging themes across all interviews suggest scholarship and collegiality within the haemophilia physicians' network provided a refuge during troubling times. Key professional aspects sustained the physicians- (a)these events happened 'in their watch' and they had a responsibility to see it through; (b)worthiness of being at the core of a crisis and addressing uncertainty in clinical decision-making; (c)recognition that their scholarship and advocacy mattered; (d)the competitive edge of publication, practice and maintaining trust; (e) simultaneous challenges e.g. inhibitors and NANB hepatitis and (f)advances in science/therapeutics.

In sustaining their role they were enabled by professional attributes and team structures: (a)The dual role of clinician and pathologist likely enabled them to deal intellectually with medical and scientific uncertainty; (b)centralised structures of haemophilia care enabled trans-national connections and a hierarchy of opinion leaders with opportunities to collaborate and network; (c)Where available, the roles of team members (nurse, social worker) were indispensable to providing a supportive and stable service. (d)A working relationship with blood services and policy-makers through joint responsibilities or committee representation enabled confidence in the system - physicians were able to communicate this confidence to their patients and many believe that this attenuated the level of national scandal. (e)The role of collegiality as a peer-regulatory influence (often non-critical of erring colleague) on physicians facing medical uncertainties and fallibilities has been described [21]. With the haemophilia AIDS crisis, collegiality served a different and important role in both critiquing and supporting the generation of knowledge, practice and scholarship through collaborations and competition. (f)The availability of infectious-disease physicians served to reduce the emotional burden of the

haemophilia physician; as did assuming greater responsibilities in non-clinical work. (g)Where available, a psychiatrist-led regular de-brief opportunities were valuable.

This combination of scholarship, collegiate support and a nuanced sense of managing uncertainty enabled physicians to address problems and develop solutions under difficult circumstances. This helped maintain their patients' trust to the extent that patients chose to stay on. By the early 1990s there was a recalibration of trust in the therapeutic relationship, with changing stances of patients and their expectations, differing nature of professional accountabilities and changes in policies to ensure safe future therapies.

Infections and epidemics recur through history [29]. Since the 17th century patterns of physicians' behaviour during public health crises have been determined by a combination of civic authority, economic interest, moral obligation and scientific interest [23]. During the 20th century, financial or academic incentives are likely to have served to retain physicians' services including those treating AIDS [23]. The situation with haemophilia physicians differed in that the central pillar of the therapeutic relationship bound the patient, disease, laboratory and the physician.

The events of 1980s led to increasingly safe treatments in haemophilia, due to harnessing technology, increased state investment and lobbying to enable world-wide access to high quality care. Lessons from 1980s resulted in introduction of precautionary policies in response to transfusion-transmitted vCJD [30]. These responses were notable for reviews of precautionary policies based on emergent data from commissioned research; the costly nature of responses by blood services and the emphasis on policy rather than practice to address perceived threat [31]. As normalcy (of life-style, of blood factor levels) swings back as the treatment goal, our respondents had no sense of foreboding. The systematic, costly and collective efforts of physicians and patients, state and the pharma industry have reinstated confidence in therapeutic products.

The limitations of this study are the small sample size and non-systematic sampling to address gender, ethnicity and religion of interviewees. We sought participants through snow-balling and their institutions may not be representative of the experiences of all haemophilia physicians, including those who felt professionally defeated. Nor were physicians from low-middle income

countries included where non-availability of concentrates and higher prevalence of AIDS posed different problems. The strength of our study, as the narratives demonstrate, is both the individual nature of experiences and common themes across countries answering the questions of why and how did physicians sustain their role through 1980s; and the comparative historic approach [32] which enables assessment and analysis of cross-national data.

Conclusions:

This study aimed to identify professional challenges faced by haemophilia physicians and their resilience during the AIDS crisis of 1980s. The long-standing therapeutic relationship with patients was an important dimension to physicians' experience of managing their roles. Physicians who chose to stay in their roles during the 1980s shared experience that professionally these were tough times. Trans-national networks and local team support were crucial enablers of resilience. The notion of being part of the solution to a problem that happened in their watch was equally crucial. These lessons from the haemophilia-AIDS crisis are relevant for the future. Our study generates data that contribute to future research on physicians exposed to prolonged uncertainty in practice, and their response to mass iatrogenic events.

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Column 1: DOMAIN	Column 2: EMERGING THEMES	A: FROM REVIEW OF LITERATURE	B: FROM INTERVIEWS
1. Therapeutic relationship			
	Patient autonomy, shared decision making [11]	√	√
	Aim of 'normalcy'[12]	√	√
	Reshaped hierarchies, Loss of trust [11]	√	
	Coping with sadness, anger, despair, suffering and deaths of patients, personal relationships [7]	√	√
	Patients' litigation		√
	Stigma of patients, hierarchy of stigma compared with homosexual patients, the double tragedy of haemophilia and AIDS – 'innocent victims' [13]	√	
	Relationships with patients, with peers, institution	√	√
	Conversations with patients: Advice re risk, modifications of treatment	√	√
	Awareness and acknowledgement of iatrogenic nature of events	√	√
2. Labelling and communication			
	The value of defining causative agent, of assigning a label to AIDS/HIV [14]	√	√
3. Advocacy			
	Lobbying for access, sufficiency and safety of factor concentrates	√	√
4. Clinical decision making			
	Allegations of inappropriate decisions by physicians- a moral dimension [16]	√	
	Clinical isolation, physician stigma		√

	Collegiate support from other specialities eg infectious diseases specialists for management of affected patients is of value [17]	√	√
	Psychological support and debriefing is of value to staff [17]	√	√
	Vocabulary to express fallibility, uncertainty, fears, disclosure, apology, explanations [18]	√	√
	Consent for testing		√
	Clinical decision making: challenges in choice of products, algorithms, doses [19, 20]	√	√
	Recombinant Factor products, gene therapy and optimism	√	√
5. Scholarship			
	Academic publications: increased publications, data mining from registries and samples		√
6. Knowledge management			
	Treatment algorithms and protocols: Increasing use of protocol based treatment through 1970s [24]	√	
	Algorithms for changes in treatment protocols eg allocation of specific products for specific groups of patients	√	√
	Clinical decision making- how? Mindlines [25] Guidelines	√	
	Expert (peer) view		√
	Networks of specialists: Organized professional networks across countries facilitated access to expert views and opinions, a prominent source of information		√
	Networks of specialists: Professional regional/national networks enabled better networking to seek new information, opinions on practice		√
	Attitude to blood services: voluntary donation considered safer and more laudable to paid donation	√	

	Attitude to blood services: Donor populations and exclusion criteria were variably implemented [27]	√	√
7. Professional identity: clinician-pathologist	Clinician-pathologist dual identity prevailed and were co-located in some countries and were mutually exclusive in others: scientific analytical identity and clinical therapeutic identity [28]	√	√
	- enabled research based clinical progress (narrative) -enabled understanding and communicating about uncertainty		√

Table 1: Emerging domains and themes contributing to resilience of Haemophilia physicians in 1980s.

Themes (Column 2) extracted from literature review (Column A) and interviews (Column B) were grouped into broader domains (Column 1) and cross checked for validation. '√' represents the occurrence of theme in literature-review and/or interviews.