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Exploring Medical Mistrust: From Clinic to Community

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Exploring medical mistrust: from clinic to community

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Abstract: This introduction to the special issue, *Exploring Medical Mistrust: From Clinic to Community*, provides a conceptual framing of 'medical mistrust' from a critical social science lens. This special issue explores and unpacks the complex temporal, social and scalar relationships which are intertwined with contemporary manifestations of mistrust in medicine. We ask what social science and humanities disciplines can offer in relation to wider understandings of the processes driving resistance to and refusal of medical interventions, including but also beyond vaccines. We distil insights derived from diverse spaces of medical encounter, ambivalence and resistance that serve as arenas which generate mistrust. We bring this analysis to deepen an understanding of the frictions and affective relations which exist between vertical and horizontal relations which constitute health systems.

Keywords: medical mistrust, social science, anthropology, COVID-19, trust.

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Note: MS and ES contributed equally to the writing of this introduction.

Introduction

Prior to the COVID-19 pandemic, public trust in formal medicine and public health actors and authorities was often taken for granted within health policy. Yet, highly variable public responses to COVID-19 policies across global, national and local contexts have revealed how deeply medical technologies and practices are entangled with everyday lived realities of mistrust.

This special issue explores and unpacks the complex temporal, social and scalar relationships which are intertwined with contemporary manifestations of mistrust in medicine. We ask what social science and humanities disciplines can offer in relation to wider understandings of the processes driving resistance to and refusal of medical interventions, including but also beyond vaccines. We distil insights derived from diverse spaces of medical encounter, ambivalence and resistance that serve as arenas which generate mistrust. We bring this analysis to deepen an understanding of the frictions and affective relations which exist between vertical and horizontal relations which constitute health systems.

Within health policy vernaculars, trust and mistrust are portrayed as binary states related to individual choices to accept, or refuse, a variety of healthcare interventions (Storer *et al.* 2022). ‘Medical mistrust’ has been invoked by health policy experts and scholars alike as a term which serves to encapsulate disengagement with, and exists as a barrier to, a variety of clinical interventions, from low adherence to screening services and drug regimens, to avoidant patient–doctor relationships, to engaging in ‘risky behaviour’ (Benkert *et al.* 2019, Breakwell 2020, Powell *et al.* 2019, Williamson & Bigman 2018). Benkert *et al.,* based on a systematic review of the clinical literature, summarise that medical mistrust, ‘is not the same as “no trust”; rather [medical mistrust] implies that a trustor’s negative beliefs are that the trustee will go against the person’s best interest’ (2019: 86). In other words, it is not an outright dismissal of medicine’s capabilities, but a more nuanced suspicion that medical institutions and professionals may have ill intent.

Whilst countless studies have correlated medical refusal with mistrust, left unanswered are the complex processes which generate supposed ‘negative beliefs’ that give rise to suspicions of malicious intent. Simultaneously occluded from view are trust’s ‘inner workings’ and the ‘outer’, structural and historical drivers which equally drive mistrust in the present (Richardson *et al.* 2019). This narrow research focus may be used to legitimate forms of governance under which people are blamed for their behaviour (Bear *et al.* 2020, Douglas 1992).

In approaching medical mistrust, the contributions to this special issue explore the relationships which constitute the services and structures of health systems. Entries present health systems not as abstracted constructs, but as entities which are not only pluralistic in their forms, but are sustained through human connections and bonds. This means attending not only to points of empathy and expertise, but also to an appreciation for dynamics of prejudice, dismissal and blame, which can enter into patient encounters with doctors, healers, therapists and medical scientists. In the same way, contributors call for understandings of national health services as shaped by global inequalities, which structure not only resources, but also the positioning of institutions within global flows of expertise (Crane 2013). In all, contributors call for understandings of medical mistrust which are grounded in realistic, social and humanistic understandings of health systems.

Based on situated discussions of trust processes within healing journeys, contributions to the special issue explore how trust, or mistrust, oscillates within doctor–patient power hierarchies. They foreground extensive quests on the part of doctors to get patients to trust them, and on the part of patients to get doctors to trust their own accounts of symptoms and suffering. Additionally, contributions explore possibilities to discuss trust at the level of the medical establishment; foregrounding the lingering afterlives of medical negligence, and histories of humanitarian biomedicine which have often lacked consent in the majority world. In all, the entries reveal a fraught terrain where cures are provided in contexts of changing scientific evidence, as well as place-based histories of biomedical and social exclusion.

We respond to recent calls to consider the socio-ecological lives of medical mistrust (Benkert *et al.* 2019), through offering contributions which centre patient and survivor experience. Considering how state–community relations cohere over patient bodies, we argue for understandings of trust and mistrust which ‘emerge as complex, layered, contradicting, and simultaneous social intersubjectivities permeating … healthcare provision’ (Sarafian 2023: np).

COVID-19 and the ascension of trust

During the pandemic, trust became a ubiquitous term in UK and EU government policy. Against a response backed by scientific advice predominantly drawn from epidemiology and behavioural science, trust emerged as vernacular to simplify multiple and manifest human reactions to government-mandated health measures.

At different junctures of the emergency, trust—or mistrust—was used to explain: divergent rates of compliance with lockdowns and social distancing policies, variable uptake of vaccines and, latterly, to encapsulate aspirations for, or fears around, reconstruction in the post-Covid world. Subsequently, trust has been deployed by the EU, OECD (Organisation for Economic Co-operation and

Development) and WHO (World Health Organization) as a metric to compare citizen–state, and citizen–science relations (OECD 2021, WHO 2023). Within such contexts, trust has become self-referential in character; ‘if only we had more trust, we could build more trust, then we would have more trust’ (Storer & Simpson 2022: np). As feminist scholars Leighton and Roberts (2020) note, despite lacking a precise meaning, it has come to exist as a ‘common sense’ notion.

Whilst the trust boom has grown at scale, scholars have drawn attention to the need to bring context in. Wuerth (2023) noted that, during the pandemic, politicians attempted to instrumentalise trust that existed, or was imagined to exist, within local contexts, to ensure people accepted health interventions. Yet, as the effects of the pandemic in the UK become marked by raced and classed disparities, ‘trust work’ served to distract from the effects of austerity which fed into differential rates of mortality and socio-economic suffering. Communities who were being asked to trust—often members of historically minoritised communities bluntly categorised as ‘BAME’—vehemently rejected being labelled as *mistrusting* by a state and healthcare system which had been a source of inequitable racialised provisioning prior to the pandemic.

Seeing through the performances of care which were momentarily performed by state actors towards minoritised groups, numerous forms of activism emerged to resist the erasure of inequalities. Often, efforts to bring attention to structural injustice took direct aim at histories of medical malpractice. Across many African American communities in the US, activist groups sought recognition of the historical violence rendered to communities through unethical biomedical practice; the example of the Tuskegee Syphilis trial was revived as a symbolic marker of recurrent deceptions(Manning 2020). During UK online public health briefings, Wuerth (2023) observed that community participants met calls to trust vaccines with furious chat messages about the genealogy of injustices which had distinguished communal vitality among minoritised groups, including the Windrush scandal and the Grenfell disaster. ‘Trust briefings’ presented a platform for groups to contest the denial of racism in the UK, made manifest in publications such as the 2021 Sewell Report. In Europe, Sarafian (2023) links widespread vaccine resistance amount Roma groups to a repertoire of injustice, which included taking Roma children into state care, forced sterilisation and segregating Roma women within maternity units.

In the wake of intense discrimination, mistrust related not to a simplistic enactment of non-compliance, but served as an active, communal response to intergenerational trauma (Benkert *et al.* 2019). Health providers were ill equipped to acknowledge and respond to the intensive discourse around prior injustice which resurfaced during the pandemic. Notions of ‘misinformation’ and ‘conspiracy theories' served only to inflame campaigns born from inequalities rendered through historic scientific and medical malpractice.

At the same time, complicating causal pathways between mistrust and behaviour, even in the face of these campaigns, many did not simply reject vaccines (Storer *et al.* 2022). Collective narratives of blame served to create perceptions of behaviour which disguised distinctions within groups. Yet, centring historical experiences, anthropologists and sociologists called for a centring of mistrust as the *de facto* mode through which many minoritised groups approach medicine. Throughout the pandemic, nodal figures in communities were visibly and continually invested in validating information relating to vaccine trials and their demographic inclusion criteria (Bear *et al.* 2020). The point being that historical inequalities project the need to *question* evidence; to either accept or refute the myriad dangers which could be associated with medical interventions (Storer & Anguyo 2023).

In sum, during the pandemic, activists and scholars, observing these struggles, urged for conceptions of trust which shifted the gaze away from 'transactional *trust in* institutions or supposed biomedical panacea' to relational trusts which are performed and enacted within kinship and neighbourly networks (Raschig 2022: np). Unpacking trusts' complexities was a task firmly located within an analysis which considered the ethical and social life of communities, where trust was being built in practice. In this special issue, we shift the gaze back. Building on these lessons, but considering the relationality within health systems, we ask how we can better understand the flows and functions of trusting/mistrusting relationships within the biomedical establishment.

Trust in context: history as a lens through which people view medical encounters and negotiate moral worlds

To read and frame the relationship with medical authorities, communities refer to and re-interpret history. Past experiences of discrimination, violence or racism are passed down and emerge as cultural repertoires for a subjective sense of identity bound in place and history and a reinterpretation of current relationships with health providers. These narratives of discrimination that may occur beyond the realm of medicine shape what is plausible and expected in a medical encounter in the present moment. Colonial domination was deeply intertwined with public health interventions (Vaughan 1991).

White (2005) understood 'dissent' in contemporary medical interventions as a way of assigning new meanings to specific colonial histories (2005) in the context of social and political dynamics. Thus, Fairhead and Leach (2012) warn us against linear histories of 'trust' in which 'trust' is gained or broken down. Rather they say that medical trust or mistrust is produced in particular social and political configurations (e.g. neoliberal reform, postcolonial revolt).

Violence in medical settings is commonplace in particular contexts, as bureaucratic systems have different priorities to those of patients and healthcare workers themselves, and ignore the social nature of disease and the doctor–patient relationship (Jaffré 2003). Racialised and minoritised communities systematically experience discrimination and racism in health settings (Hamed *et al*. 2020). The medical relationship is shaped by expectations based on what is 'socially conceivable' (Chigudu 2019): the apprehension that might precede it and experience of it are shaped by people's historical experience of powerful actors, including health actors. Historical cultural repertoires of state violence or medical misconduct, such as the Tuskegee trials indicated above, shape what is considered plausible, and colours the medical encounter.

Political–economic context and power in the medical encounter

Theorists of trust have written that our current 'crisis in trust' is indicative of a wider crisis society in which we live today (Corsín Jiménez 2011) marked by declining faith in modernism and liberal progress and felt fractures in our neoliberal societies. How does this political–economic context manifest in medical encounters? In places like the United States where healthcare costs are exorbitant, there is often a lived reality that medical visits and hospital stays are marked by high bills and charges for everything. Much of these expenses are passed onto patients, who if uninsured or under-insured, will end up in medical debt. This corporatisation of for-profit healthcare in some ways underpins and drives medical mistrust, with the sense amongst many that hospitals, and by default medical providers, are profiting from these visits. In the United Kingdom, austerity policies and a lack of appropriate funding for the National Health Service (NHS) have led to highly public reporting of long wait times to see a general practitioner or specialist, low pay for doctors and other healthcare providers, and generally reduced service quality. However, these issues of under-funding and concomitant poor service quality are often not fully considered in the literature on medical mistrust.

Globally, structural adjustment programmes, austerity and user fees have created similar situations in public healthcare facilities at all levels, with costly laboratory tests at primary healthcare facilities or referrals to a private pharmacy to pay for medication when there are stockouts. Anthropological research during the Ebola epidemic in the Democratic Republic of Congo and western Uganda demonstrated just that (Schmidt-Sane *et al.* 2020). There was a sense amongst many border communities in western Uganda that doctors are ‘not to be trusted’ because local clinics face stockouts and drug shortages, so the doctors ‘must be selling those to make money’.

This political economy of healthcare, and in particular, a for-profit model, may indeed be irreconcilable with medical trust, particularly for marginalised communities. Power relations within a medical encounter, between provider and patient, complicate this. Many overworked medical providers may have only 10–15 minutes to spend with a patient, and so the encounter becomes distilled and transactional. There is no time to delve deeply into medical history nor a person’s social circumstances. There is often a sense that patients must ‘comply’ with medical guidance, be it prescription or behavioural change.

Indeed, compliance is implied in much of the literature on medical mistrust. Is this the ultimate goal, to improve compliance with medical advice? Foucault’s writing on biopolitics (e.g., Foucault 2008) and Agamben’s writing on biopower (e.g., Agamben1998) come to mind here. Agamben notes how biopower is enacted during times of crisis, or states of exception, during which time crisis is used as justification to enact various policies—some may be good, but others may further exclude marginal or racialised groups. In the United States during COVID-19 and after, for example, this played out in terms of policies that negatively affected and took away from the rights of asylum seekers.

Biopower and cultural authority drive our normative assumptions that a doctor’s orders must be complied with. How, then, does subversion or non-compliance potentially serve as a type of resistance? Do patients themselves view mistrust of providers as linked to wider socio-political resistance of power? At the centre of our modern health care systems is a nexus of power, trust and risk that cannot shift if structural features of healthcare do not shift first (Grimen 2009).

Grimen (2009) tells us that physicians are socialised to see themselves as beneficial helpers, but they are also gatekeepers and controllers, and he uses an analytic category of ‘beneficial power’ which is necessary to get medical work done. The nexus of power, trust and risk comes to bear on medical encounters in Western biomedical systems, which almost rely on that beneficial power and cultural authority. Medical encounters may be different with traditional healers. Sheldon’s (2023) paper on one doctor’s traditional healing methods (through ‘nature cure’) cohere with his patient’s cultural worldview, focusing on a person’s connectedness with the world rather than individual biology, thus engendering trust in their patient–provider relationship.

Social medicine as an interdisciplinary space offers us some answers for compassionate medical care and attention to the structural factors that shape ill health. Paul Farmer's (2004) work on structural violence and the importance of providing equally excellent care to all has shifted notions in the medical field about how to be more trustworthy, rather than how to improve patient compliance. However, some of these lessons risk being lost, and they are lost in much of the dominant literature on medical mistrust. Instead, we need an understanding of medical mistrust-in-context, one which attends to those structural factors that drive ill health but also unequal relationships of power between provider and patient.

Moll's (2021) research in South Africa shows us how medical mistrust and health disparities result from interrelated problems of racism in healthcare provision. She describes how discrete historical events, such as the apartheid-era Project Coast and plans of biological warfare against the black population, are just one part of a longer story, which must include both enduring racial health disparities and a patient's experience at a clinic (Moll 2021).

This special issue includes papers from diverse contexts around the globe, and as such, explores the locally experienced and intersecting inequalities that shape medical mistrust. Relating to Farmer's and Moll's calls for improved care that attends to patients' lived experiences of structural violence and for clinicians to recognise *the biological effects of racism* and other forms of violence, the papers in this special issue explore new possibilities in clinical encounters and the consequences of *not* attending to or being aware of the wider social conditions that shape patients' everyday lives.

The special issue papers

The papers in this special issue come from a range of disciplinary backgrounds, diverse contexts, and medical issues and encounters within different spaces—from the clinic to the community. Sekhar and Jadhav's piece on 'negotiating trust' speaks about how trust and mistrust are fluid during times of uncertainty, revisiting material from the 1980s in the UK when haemophilia patients contracted HIV/AIDS from their treatment. Also taking a historical lens, Prates' work with Guarani indigenous people in Brazil show us how historical experience and conceptions of the body forged through outbreaks and trauma led Guarani people to question the COVID-19 vaccine. Based on work in Kenya, Muga and Igonya describe how the government's messaging on COVID-19 containment and prevention measures perpetuated mistrust and impeded people's ability to access sexual and reproductive health services. Grant's article conceptually situates trust in relation to pandemic preparedness in sub-Saharan Africa, arguing that medical mistrust is rooted in a population's historical experience with medicine, (in)effective health systems, social context, colonial history, and a distrust of public authority.

Perkins' research on maternal health in Bangladesh focuses on the social, how medical (mis)trust is shaped by a wider moral universe of *dhora-dhori* (translated as mutual grasping or holding), or how people participate in an uncertain world. This patients' perspective shows how women act as embedded agents within their families and appeal to various social connections to tactically access services and resources, thereby collapsing distinctions between trust in personal relationships and trust in institutions, which are intimately entangled. Sheldon's work showcases a relationship between a doctor who uses traditional healing methods and his patient, whereby the doctor has to gain a patient's trust because there is a high level of uncertainty about alternative therapies. Frisone's article explores trust in the context of people with Alzheimer's disease, when declining cognitive abilities and the loss of autonomy undermine a patient's social identity and legal status. However, when caregivers preserve an unconditional trust in the permanence of the patient's subjective identity, that trust may be transmitted to clinical teams, thereby improving relationships and a patient's quality of life.

The future of theorising and operationalising medical mistrust

Taken together, these papers contribute to wider scholarly and critical attention to notions of medical mistrust and mistrust in public institutions. Much of the extant literature focuses on medical mistrust as an attitude or behaviour, with references to context, but less clear are the ways in which medical mistrust *is* context. This special issue's social science lens is both timely and imperative. What is lost when we rely on dichotomous, bounded notions of medical mistrust? What is missed when we seek to measure and 'improve' trust in medical providers, or when we understand it as behaviour? Through this special issue, we argue that critical social science literature must come to bear on these faulty and reductionist notions of medical mistrust. We hope to see future contributions that take these arguments further. We hope that these contributions will be read and acted upon in disciplines such as public health and medicine, and that future writing on medical mistrust will bring further context, nuance and complexity. Ultimately, a better and more imperative question is how do we make *medical providers more trustworthy,* rather than how do we improve *patient trust in* medical providers. That imperative requires better articulation between social science and public health scholarship and a more nuanced understanding of context.

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Composing bodies with the COVID-19 vaccine: the cosmopolitics of health among Guarani peoples

Maria Paula Prates

Abstract: In this article, I focus on Guarani Indigenous peoples' modalities of relating to, trusting, and distrusting the Brazilian Public Health System (SUS) and its agents during the Covid-19 pandemic. I compare relational configurations as a means to understand the reasons for a low take-up of Covid-19 vaccines among Kaiowá collectives in the first moment yet a high rate of vaccination among the Mbyá. I also discuss conceptions of health and the body in light of a guiding framework that aims to reflect on epidemiological protocols that sometimes are disconnected from the Indigenous dynamics and end up clashing counterproductively with their care technologies.

Keywords: COVID-19 vaccination, Indigenous peoples, bodies, trust.

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When Indigenous peoples in the territory now known as Brazil began to fall sick with COVID-19, speculations concerning the disease—its causes, origins and potential victims—spread just as quickly as the virus. Equipped with different understandings and resources, some Indigenous collectives sought to anticipate the consequences of almost inevitable infection by isolating themselves in their villages. Others were initially unconcerned about infection as they believed it to be a disease that specifically attacked 'white people' and, since they possessed different bodies, they would not be vulnerable to the new coronavirus. But in general, for most Indigenous collectives—if not all—past epidemics and painful experiences of mass sickness are still part of living memory. Diseases like malaria and infectious ones like measles and tuberculosis, among others, continue to be health issues today. These diseases come and go with varying force as the destruction of rivers and spaces habitable to humans and other-than-humans advances and becomes consolidated through political decisions taken without Indigenous consent.[1] Until the start of 2020, COVID-19 itself was a new viral disease for everyone, Indigenous and non-Indigenous people alike, but not the experience of becoming sick collectively in the context of the power relations and distrust generated by contact with the non-Indigenous, amid a serious public health crisis.

Bodies that weaken or swell as a result of diseases and vaccines, forests that once protected from the effect of sickening winds but have been replaced by large concrete apartment blocks that open up corridors for contamination—these are among the problems discussed by Guarani-Mbyá and Kaiowá interlocutors over the critical months of the pandemic (Macedo, Huyer, Ortega & Prates, 2023). Brazil has a comprehensive public healthcare infrastructure, the Unified Health System (*Sistema Único de Saúde* or SUS). Its public health history also includes an internationally recognised vaccination programme (Camacho & Codeço 2020). When the COVID-19 vaccine programme began to be designed by SUS, including the gradual distribution of supplies of vaccines, a priority system was established to determine

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[1] The Brazilian federal government headed by former president Jair Messias Bolsonaro between 2018 and 2022 was characterised by being openly anti-Indigenous. Recognition of traditional Indigenous territories was frozen and no progress, or even consolidation, was made in the rights acquired since the 1988 Constitution. The Special Secretariat of Indigenous Health (*Secretaria Especial de Saúde Indígena* or SESAI), part of the Indigenous Health Subsystem (*Subsistema de Saúde Indígena* or SASI) was filled with military personnel in key administrative posts, while the epidemiological data, published by law, was omitted from the main health bulletins. The Ministry of Health's 'data wipe', as it became known in the Brazilian press, at critical moments of the COVID-19 pandemic also included SESAI and blocked public access to epidemiological data on mortality and vaccination rates. The Bolsonaro government was also notable for the legal actions taken by the Articulation of Indigenous Peoples in Brazil (APIB) seeking the right to vaccination of Indigenous people not residing in officially demarcated territories. For more information about Indigenous advocacy during the pandemic and the Bolsonaro government, see the article by Alfinito and Amado (2021).

who would receive the first doses and during what phase of the vaccination process. Indigenous peoples, along with other demographic sectors, were considered a priority.[2] While for some groups this prioritisation was welcome, among Guarani collectives[3] distrust prevailed.

Relations between Indigenous and non-Indigenous people, between visible and invisible worlds, and the constant oscillations between the dangers of living and the certainties of perishing are adjectivised by affective states of trust and distrust whenever risk looms. Where relations between non-Indigenous health professionals from Brazil's public health system and Guarani people are concerned, trusting-but-distrusting seems a prudent approach to take given the colonial history. Why are we a priority to receive vaccines, the Guarani ask, but not when it comes to our ancestral lands being recognised? Why should only the old be vaccinated and not children? These were some of the questions posed by Guarani interlocutors soon after the start of the vaccination campaign in Brazil.

In this article I review and analyse data collected during the PARI-c Research Project,[4] with an emphasis on modalities of relating, trusting and distrusting in the Indigenous health subsystem (SASI) and its agents. I compare relational configurations as a means to understand the reasons for a low take-up of COVID-19 vaccines among Kaiowá collectives, initially, yet a high rate of vaccination among the Mbyá. I also discuss conceptions of health and the body in light of a guiding framework that aims to reflect on epidemiological protocols that were sometimes disconnected from the Indigenous dynamics and ended up clashing counter-productively with their care technologies.

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[2] Initially, the Jair Bolsonaro government had identified as a priority Indigenous people living in officially recognised lands (*Terras Indígenas* or TIs). Only after a court ruling on the Claim for Failure to Comply with Fundamental Precept n. 709 (ADPF n. 709), an action of constitutional jurisdiction filed by the Articulation of Indigenous Peoples in Brazil (APIB), did the Brazilian state include Indigenous people not living in TIs as a priority too. It is important to note that almost the majority of Brazil's Indigenous people do not live in officially recognised territories (Census 2022).

[3] The Guarani language is one of the most commonly spoken indigenous languages in South America, along with Quechua. In Brazil, Guarani-speaking peoples include collectives known as Mbyá, Kaiowá, Nhandeva, Chiripá and Avá. They differ from each other due to linguistic and cosmological particularities and currently inhabit the Pampa, Atlantic Forest, Cerrado and Pantanal biomes.

[4] The 'Indigenous Peoples responding to Covid-19 in Brazil: social arrangements in a global health emergency' Research Project (http://www.pari-c.org) was developed over 14 months and funded by MRC/UKRI. The entire research methodology was designed on the basis of ethnographic insertions and relations created prior to the pandemic, thus permitting the interviews and data collection to be mostly conducted online. Only the Indigenous researchers who were working from their villages conducted offline dialogues. To learn more about the PARI-c methodology, a dossier is available (Marques *et al.* 2022). An article specifically published on how the data presented here was collected and discussed has also been published (Prates *et al.* 2023).

Different bodies, different socialities

Vaccines are something injected in the body, entering the bloodstream and activating the immune system. This, at least, corresponds to the biomedical perspective, in which the body is understood from a series of anatomical, physiological and molecular explanations. Vaccines correlate with this notion of the body, rooted in a material entity. Conceived from the perspective of Indigenous cosmologies, however, the body is a composite of multiple relations, both material, such as food and the use of plants, and affective, including encounters with other-than-humans and more-than-humans. Therefore, it is seen as something physical, composed of substances, yet it is not a self-enclosed entity. The body-person is made constantly over the course of life, whether through one-off rituals, such as those marking the beginning of the adult cycle and death, or through everyday actions (Lima 2002, Vilaça 2005). The incorporation of others in the making of bodies-persons is a way of relating to other vitalities by absorbing their effects and then making alterity exists. For example, when snail shell necklaces are visibly draped round the necks of Mbyá children, as well as aesthetics—where the beautiful is also good (*porã*) in Guarani—the vitality of other-than-human forces is also at work. The Mbyá say that a small kind of snail, found on the shores of the rivers of the Prata drainage basin, does not urinate. It is this capacity not to urinate that is incorporated into children's bodies; just one of the many examples involving the making of Mbyá bodies-persons, and Indigenous persons in general, through other-than-human vitalities.

There are also incorporations deriving from divine, more-than-human, vitalities. The umbilical cord of new-borns in the villages is usually cut closer to the placenta and not close to the navel, as generally occurs when births take place in hospitals. To connect the world of the living with the plane of the divinities, the umbilical cord is carefully stored in a little cotton bag, among the Mbyá, and hung on a necklace. It will stay there, next to the child's body, until its properties are completely absorbed and it disintegrates by itself. This practice ensures that these more-than-human and other-than-human vitalities compose the body-person (Prates 2021, Signori 2022).

Everything aims to preserve Indigenous (in this example Mbyá) humanity, or to make it, amid so many other humanities or existing agencies. Humanity as a biological species, *Homo sapiens sapiens*, which Western taxonomy differentiates from animals, plants, rivers and mountains, is not exactly the same entity conceived by Indigenous collectives of the South American Lowlands. Here humanity is a constituted alterity, not a population regenerated through a biological process of conception involving the encounter of two gametes. It is an existential condition invested daily and considered collectively. The risk of losing humanity is the risk of ceasing to belong to a specific collective and becoming part of the tapir collective, or the collective of the dead, or the jaguar collective and so on. Maintaining difference from these other collectives, whether by eating among kin and sharing food or by entering into reclusion during the menstrual period, is key to establishing relations, nurturing alterities and ensuring the humanity condition (Viveiros de Castro, 1996).

The qualities and modes of establishing social relations, including here what it means to be related, has been at the core of anthropological interest from its outset as a social science, including the contributions made by Radcliffe-Brown (1940) in British anthropology. Viveiros de Castro (2002), in a more contemporary contribution, thinking about the production of knowledge in the relations between anthropologists and natives, asserts that every relation is social. Adjectivising a relation as social would therefore be redundant. This can be explained by the fact that, for decades, within and beyond anthropology, the term ‘social relations’ has conventionally been limited to relations between humans (those *Homo sapiens sapiens*). In dialogue with Latour (1991) and Strathern (1988), Viveiros de Castro argues that what is in question here is the exclusion of an entire universe of beings and entities from what is deemed ‘social’ and from what, ultimately, composes ‘society’. If Indigenous socialities encompass relations with other-than-humans and even more-than-human agencies, including in their own understanding, then the ‘social’ would not be restricted solely to the world of humans but extended to all forms and variations of relations.

Along these lines, by putting together bodies and relations, we can imagine why the injection of a liquid substance into the veins may signify more than just a technology of care. The procedure can occasion a transformation, an alteration in the state of the body-person and in the humanity condition. What we should recognise here is that this alteration takes place in terms of both biomedical understandings and those of Guarani Indigenous peoples. Indeed, this is the reason for inserting a vaccine in the body: to cause an alteration in state through the incorporation of an other. For biomedicine we know that the premise of vaccination is precisely to incorporate the ‘inactive virus’ or, in the case of the most of the vaccines developed to combat COVID-19, a ‘viral vector’. But, for Guarani people, what is really being injected into their bodies when they receive a COVID-19 vaccine? What alterities are implied and applied in this action?

The place that substances, especially blood, occupy in Indigenous cosmologies is seminal when it comes to thinking about assemblages between men, women and other-than-humans, as well as consequences in terms of becoming sick or enhancing what is conceived as being healthy (Belaunde 2005, Prates 2019). Inserting something in the body, via the blood, involves activating the agency of other-than-human beings; it is to alter the Indigenous body-person in a broader sense than simply affecting the immune system. What are conceived as immunity and vulnerability also differ from the biomedical conceptions, since what signifies risk is not necessarily death as the failure of a biological organism but death as a loss of humanity. And this happens when one loses the human perspective, not necessarily when the biological body dies (Prates *et al*. 2021, Taylor, 1996).

Distrust and temporalities

In several of our conversations, Mbo'ju Jejua, a Kaiowá leader, questioned why the Brazilian government had prioritised vaccination of Indigenous people.[5] For her, this was a sign that something wrong was happening. How could she trust the Brazilian state to want the best for Indigenous people if they prioritise vaccination of her people but simultaneously deny them the right to their land? In her words: '*I always wonder why we are priority for vaccination and not for our right to territory? Why would I take a vaccine if I don't know what my future will be tomorrow?'* The future that Mbo'ju talks about is the future of being able to live as a Kaiowá Indigenous woman, in her own territory, among her kin. Vaccination aims to secure a physical, biological, future. Injecting the vaccine provides an increased chance of prolonging life or protecting oneself from premature death from COVID-19. But what about dying as a people, as a Kaiowá collective? For Mbo'ju, the biggest threat is the lack of the right to live in their ancestral territories, forced to inhabit the roadsides and living in constant danger of attacks by hired gunmen. '*What is the point of being vaccinated if tomorrow I or a relative of mine can die from a gunshot?*'

During the first year of vaccination against COVID-19, the Kaiowá people presented lower rates of vaccination, with less than 50% of people vaccinated with two doses.[6] It was also the Kaiowá who experienced one of the highest mortality rates from the disease.[7] Adding to Mbo'ju Jejua's disquiet was the influence of some evangelical churches opposed to vaccination and the countless fake news

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[5] Conversations conducted over 2021.

[6] Dias-Scopel, Scopel and Langdon (2023) have addressed in depth the health issues that were made visible - and that also emerged - during the pandemic among Indigenous collectives living in the state of Mato Grosso do Sul, Brazil. Among them is the Kaiowá.

[7] All the data on vaccination presented here comes from the site of the Ministry of Health, Brasil: Indigenous Vaccination |COVID-19
https://infoms.saude.gov.br/extensions/imunizacao_indigena/imunizacao_indigena.html

stories circulating daily via online messages. A complex array of factors thus influenced the low vaccination take-up. However, we can conclude that the distrust caused by the prioritisation of Indigenous peoples in the government vaccination programme arose both from the violent modes of relations established with them by the *karaí*[8] and the divergent Indigenous conceptions of what it means to live well and compose with others. One of the suspicions that circulated among the Kaiowá was that the vaccine could weaken people even further, making them sicken and die more quickly. If so, the Kaiowá would no longer be able to fight for their right to land. The vaccine would be an *arapuca*: a trap. It might contain an agent that weakened the body, which would thus immobilise the Kaiowá struggle for their territories either not yet officially recognised by the Brazilian state or demarcated in insufficient spaces.

Healthcare and assistance inevitably involve trust relations. In a context where distrust of any government action prevails and where Indigenous peoples are facing one of the worst scenarios of violence against them in contemporary times, with prayer houses being burned down, leaders murdered and territorial rights denied, the possibility of an effective and ample vaccination campaign runs up against widespread fear.[9] State actions to regularise and recognise the territories of Indigenous collectives are not progressing at the same pace as health initiatives—at least concerning the COVID-19 vaccines. Although guaranteeing the right to territory and the right to health are both duties of the Brazilian state, the compartmentalisation of functions into ministries and public policies, along with the slow response or absence of compliance with legal rulings, suffocate expectations of effective solutions. Until recently, indigenist policy was split between the Ministry of Justice, to which the National Indian Foundation (FUNAI)[10] was linked for the purposes of the identification, recognition and homologation of territories, and the Ministry of Health, to which the Unified Health System (SUS) and consequently the Indigenous Health Subsystem (SASI) were linked. The Special Secretariat of Indigenous Health (SESAI), part of the institutional structure of SASI, is responsible for providing healthcare and assistance to Indigenous peoples, including vaccination campaigns. In January 2023, on assuming the presidency of the republic, Luiz Inácio Lula da Silva, after a campaign marked by Indigenous support, created the Ministry of Indigenous Peoples to which FUNAI was transferred. The current heads of this ministry, as well as those of FUNAI and SESAI,

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[8] *Karaí* is the term used by the Kaiowá to refer to 'white people', the non-Indigenous population. Among the Mbyá, for their part, the term used is *Juruá*.

[9] See the following news reports: *CIMI* (2021), Câmara & Barros (2022), Scofield & Anholete (2022).

[10] The name of the institution was changed to the National Indigenous Peoples Foundation in January 2023.

are Indigenous persons. There is an expectation on the part of Indigenous people and allies that this state organisational structure and the initiatives coordinated among the different portfolios will lead to improved situations for all Indigenous collectives.

Strong, weak and hesitant body-persons

Among the Guarani-speaking peoples such as the Mbyá and the Kaiowá, the blood of white people is believed to be 'stronger' than the blood of the Guarani. Although fears concerning vaccination resonated widely among both collectives, the main factor understood as problematic among the Mbyá was the recommendation that the vaccine be taken by everyone immediately. They agreed when they heard Kaiowá relatives question the priority given to Indigenous peoples to receive the COVID-19 vaccine in detriment to the prioritising state recognition of their territories—indeed Kuaray, an Mbyá man, was emphatic in asserting that territory is health and that this is what would guarantee that the Mbyá people could take care of themselves and be strong when diseases arrive. But there was also a fear that, if a person received the vaccine while they were weak, it could cause their death. According to Mbyá conceptions, vaccines weaken the blood because it is made for the bodies of the *juruá*. Ara, a Mbyá interlocutor, told me that an elder had refused to be vaccinated because he was worried that his 'blood would swell' and weaken his body even further, provoking other diseases in addition to COVID-19. The relationship between strong/weak and hot/cold modulates understandings of the action of the vaccine in the Mbyá body-person. It is important to receive the vaccine at the right moment and it is best avoided if the person is not strong and warm enough, since the vaccine weakens and cools the Mbyá body-person. It can be noted that whereas for the Mbyá and for some Kaiowá vaccines cool the blood, for the Tupinambá they strengthen and warm the body.

In none of the cases recounted to me by Mbyá interlocutors was there any reference to an absolute refusal of the vaccine. Instead, there was a reflection on what would be the best moment to incorporate the vaccine's substances into their bodies. Kuaray says that everyone who decided not to take the vaccine in their *teko'a*,[11] when they had the first opportunity to do so, had their choices respected. The elders took the longest time to take the vaccine, not out of suspicion that there existed a secret plan of the Brazilian government, but because they believed that the best time to be vaccinated had not yet arrived. Bodily and affective states need

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[11] *Teko'a* are existential spaces that encompass the conditions for living well as Guarani.

to be ascertained as optimal for the vaccine to be injected in the bloodstream. Before taking it, their bodies need to be prepared to receive it. Today the large majority of Guarani-Mbyá people in the far south of Brazil are fully vaccinated.

As may be imagined, reflecting the diversity of Indigenous cosmologies in Brazil, responses to COVID-19 and the vaccination programmes were and still are far from uniform. Placing Indigenous epistemologies of care and healing in perspective means comprehending their distinct notions of the body-person, as well as their diverse histories and modes of relationship with the *brancos* (white people). There is a subtle difference between distrusting the action of the vaccine and distrusting the motives for the prioritisation of Indigenous vaccination. The Kaiowá interlocutors proved to be far more questioning about the latter than expressing any serious doubts or fears about the vaccine itself. The vaccine could perhaps be accepted in their bodies as a means to contain a new virus, but, in this case, distrust concerned the possibility of an ulterior motive, the orchestration of a trap: the plan would be to weaken their bodies to make them unable to continue the fight for recognition of their territories. For the Mbyá interlocutors, on the other hand, the main question was *when* to take the vaccine, not whether they should. All the Indigenous collectives in contact with the Brazilian state are familiar to some extent with the annual childhood vaccination campaigns. The Guarani distrust in general, and Kaiowá in particular, is entangled between the substance and its action in Indigenous bodies and the ultimate motive for the government's prioritisation.

It is among the older generations of both the Mbyá and the Kaiowá that a more exacerbated fear appears of both the vaccine and the vaccination programme itself. This stems from the still painful memories of the death and violence caused by past epidemics, and also for shamanic motives. Younger people, however, either mobilised to take the vaccine, without ceasing to listen to the advice of elders to better understand what was happening, or engaged in questioning the prioritisation of the Indigenous collective's vaccination in a context of their land rights being neglected. A generational marker operated symptomatically in the negotiations and speculations about the vaccine and the prioritisation of Indigenous peoples in receiving it. There are two points of convergence, then, along the same lines of reflection concerning what 'comes from outside': the vaccine as an agent that transforms the body-person and the vaccination campaign as a motor of reflection and agency in the relational politics between Indigenous and non-Indigenous people.

Beyond the Guarani, beyond social determinants

Because of the fear and distrust shown by elders in some communities, younger people assumed an active and important role in the vaccination campaign. Many of these young people are currently linked to associations and organisations and have led communication and information campaigns on COVID-19 and the vaccine. To widen the analysis beyond Guarani peoples, for example, one of the most striking examples of such initiatives occurred in the Rio Negro region of Amazonia. As part of the campaign 'Rio Negro, We Care!', led by the Rio Negro Department of Indigenous Women of the Rio Negro Federation of Indigenous Organizations (DMIRN/FOIRN), cars with loudspeakers visited the main villages to report on the numbers of local people infected, where to get vaccinated and the consequences of COVID-19. Through radio communication, more distant communities were also informed about what was happening in other locations and advised when it would be possible to be vaccinated, in addition to reinforcing preventive measures. Indigenous women from the younger generations played a key role in these actions (Olivar *et al.* 2021). Currently, the region assisted by the DSEI Rio Negro, where this campaign took place, has 91% of the population vaccinated with both doses.

Elizangela Baré, one of the leaders of the 'Rio Negro, We Care!' programme, says that whenever she had the chance, she emphasised the importance of the vaccine, which should be taken at the first opportunity, along with other precautions such as washing hands, keeping 'social' distance and using masks correctly, as well as observing the traditional Indigenous practice of reclusion and using plants in baths and healing rites. Women leaders were also prominent in Pataxó and Tupinambá communities in the northeast region of Brazil. As Elizangela Baré pointed out, Vanessa Pataxó and Jéssica Tupinambá emphasised that the prayers and rituals of their communities were of paramount importance to confronting the arrival of the pandemic, and also that the vaccine helped in everyone's 'survival'. Both women referred to 'our own health protocols' as an accompaniment to the vaccine, identified as one of the health tools of white people, their conjunction guaranteeing 'our health'. Jessica Tupinambá even mentions the vaccine as a body-fortifying agent. She says that some people in her community were infected by COVID-19, but none showed serious symptoms because they were very well prepared through ritual baths with herbs and well guided by the *encantados* (spiritual beings).[12] A composite set of actions aims to prevent or mitigate the effects of

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[12] *Encantados* are supernatural entities present in Brazilian culture in general that originate from Indigenous cosmologies.

COVID-19, which includes both Indigenous care technologies and those identified as biomedical interventions, such as the vaccine.

The relational modalities and variations within the non-Indigenous population, especially those involving the state and its agents, lead to the circulation of meanings relating to risk and vulnerability. Within a national epidemiological spectrum, Indigenous peoples in Brazil are considered a ‘population vulnerable to respiratory diseases’ (Cardoso, 2010). These categories of vulnerability and risk are presented as inherent to the Indigenous condition, frequently dissociated from socio-economic configurations that effectively contribute to their bodies becoming sick. When ‘social determinants’ are evoked to frame this vulnerability, what is conceived as social is very distant from Indigenous understandings of socialities. What would be the ‘social’ of social determinants? Based on an anthropological perspective, it is important to pay attention to how these epidemiological categories alien to emic understandings are mobilised when they become part of a vocabulary and modality of relationship with the state and its agents. On the other hand, it is also worth considering how global health actions, and epidemiological actions in particular, are based on conceptions of social that exclude other-than-humans and more-than-humans.

Among the Guarani-Mbyá, as among the majority of Indigenous collectives of Lowland South America, living is a risk in itself and assuaging these risks is a constant part of making oneself a person, as discussed earlier. What I learnt during the pandemic is that, in the view of my Mbyá friends, those at risk were the *juruá*, not themselves. COVID-19 was a much greater problem for the *juruá* because they live in places made of concrete with few or no trees. Vulnerability to the new virus was greater for white people than for the Mbyá because the latter were able to protect themselves from contact with contaminated people and to do so they did not need to cease living among kin. For the Mbyá, the idea of associating them with a ‘risk and vulnerability’, promoted by the epidemiologists and specialists in infectious diseases, was profoundly mistaken.[13]

However, this was not the understanding of other Indigenous collectives like the Hupda, inhabitants of the Amazon rainforest. In a personal communication, the anthropologist Bruno Marques remarked that for his Hupda friends, the idea of vulnerability and risk was frequently mobilised as a form of leveraging of resources and assistance from the Brazilian state to meet their demands. Being perceived as vulnerable and at risk did not seem a negative if this meant being prioritised or receiving some kind of compensation for the conditions in which they were being placed, even if unaware. The same conclusion was reached, we can conjecture, by

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[13] Cardoso’ PhD thesis (Cardoso 2010) approaches the problem from a public health perspective.

some Baré, Baniwa, Tupinambá and Pataxó collectives when it came to vaccination.

In these other non-Guarani examples, even though the priority for vaccination was explained by the 'vulnerability and risk' to which they were subject without any problematisation of the reasons behind this situation, and despite the need also to prepare the body to receive the vaccine, the government's prioritisation of the COVID-19 vaccination of Indigenous peoples was not questioned. On the contrary, it was claimed and celebrated when officially announced.

The diversity of Indigenous modes of existence is one of the factors generally eclipsed in public programmes and policies. The very category 'Indigenous peoples' is an abstraction that, though politically expedient in terms of demanding collective rights, ends up sanitising and simplifying the wealth of alterities and differences. Recently in a talk given at University College London,[14] Dário Kopenawa said '*I'm not indigenous, I'm Yanomami.*' The Mbyá say the same, as do the Kaiowá.[15] How can emergency vaccination plans and initiatives be conceived and designed in severe public health contexts without incurring the need to totalise the Indigenous population—an epidemiological and problematic term (Murphy, 2018)—and use a category that, although politically effective in some contexts, exacerbates distrust when it comes to healthcare practices?

Poets of care and the trust they weave: final remarks

Indigenous health agents are professionals recruited by the Special Secretariat of Indigenous Health (SESAI). Much of the time they work in their own communities, performing a key role in mediating between Indigenous and biomedical knowledge and in coordinating the combined use of both in the care provided for sick people. Important anthropological work has been produced over recent decades[16] on the differentiated healthcare offered to Indigenous peoples in Brazil and the public health design imbricated within it. This line of anthropologists has contributed much to the implementation and improvement of a health policy that takes Indigenous processes of health and sickness into account in the exercise of

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[14] The seminar was given as part of the Embodied Inequalities of the Anthropocene Seminar Series, University College London (UCL), on 24 February 2023.

[15] According to a linguistic classification, Kaiowá collectives are considered Guarani. Unlike the Mbyá, however, who identify themselves as Guarani-Mbyá or Mbyá-Guarani, the Kaiowá do not usually adjectivise their self-identification as being Guarani too.

[16] Such as the contributions of Jean Langdon, Luiza Garnelo, Laura Pérez Gil, Ricardo Ventura Santos, Raquel Paiva Dias-Scopel, Diana Diehl, Luciana Ouriques Ferreira, among others.

biomedical care. Indigenous health agents are frequently described as mediators between worlds, although due to the colonial pressure exerted by biomedical thought, they end up acting more as messengers and communicators of Western precepts than in the inverse way.

The article by Martín (2022), however, points in another direction in claiming that Indigenous health agents are poets of care. In providing health assistance, even if it means injecting needles into the veins of Yanomami bodies, as described in an example provided by the anthropologist, they are not copying or simply performing a practice based on biomedical knowledge. The expression *poiesis of care*, coined by Martín and Reig, editors of the special Issue of *Tipití*, 'Mediating care: Amerindian health agents across worlds, bodies and meanings' (Martín & Reig 2022), refers both to what Indigenous health agents develop as created and creative capacities based on biomedical models and to what is known by them founded on Indigenous knowledge and practices. The relations and connections mobilised by Indigenous health agents when providing care make use of their positions and creative and poetic forms to compose worlds. They thus engender skills that reformulate and provide new contours to the cosmopolitical networks in which they are situated, which extend beyond what is conceived solely as health in biomedical terms.

When Mbyá elders and some youths were wary of taking the COVID-19 vaccine because they believed it was not the best moment to do so, the Indigenous health agents working in the villages had an important role. The same applied to the Guarani nurse working for the biomedical health team. The role they performed was not to persuade the Mbyá to take the vaccine, but to make sure the non-Indigenous biomedical professionals respected the Mbyá who initially declined and waited for them to ask to be vaccinated. Yva Mirim and Kuaray, Mbyá persons living in different villages located far from each other, recounted that in their *teko'a* the Indigenous health agents consulted the shamans, listening to their advice. In each of these villages, open meetings were held to discuss all the doubts related to the biomedical functioning of the vaccine. The agents answered all the uncertainties raised by their relatives and took any questions they too shared to the non-Indigenous biomedical professionals. One of the doubts was the information that had been circulating that people who took the vaccine would turn into caimans. This arose from one of the many unfortunate declarations of the former president Jair Bolsonaro, infamous for rejecting scientific knowledge, who later said that he knew nothing about the risks concerning the recently created vaccine, insinuating in an irresponsible joke that vaccinated people might turn into the reptile. The possibility of transforming into another, losing the human perspective, is something possible in Indigenous cosmologies. This insinuation, combined with the many fears and suspicions existing at the time in relation to the vaccine and the prioritisation of Indigenous people in the vaccination campaign, reverberated in the circulation of online messages and in mouth-to-mouth communication among the Guarani. Although the majority had not really taken the former president's words seriously, the rumours circulated, and the topic was discussed in the meetings. After the Indigenous health agents had replied to all the questions and gave their assurance that nobody would be vaccinated if they did not want to be, what happened is that gradually the Mbyá themselves sought to be vaccinated, in their own time and in harmony with the affective and bodily states judged to be adequate from the shamanic point of view.

In the territory where Mbo'y Jejua's Kaiowá collective lives, there is no SESAI health service and consequently no Indigenous health agent. And its shamans and leaders have been murdered over the last decades. There was no opportunity for the suspicions and fears to be allayed or assuaged by someone they trusted. Without Indigenous health agents and without SESAI assistance, as well as shamanic relationships eroded by colonial actions against their territories and political organisations, all the rumours and misgivings lasted for months. Compared to the vaccination plan among the Mbyá, adherence to the vaccine by the Kaiowá occurred later. Only in the last months of 2021 did the number of vaccinated Kaiowá Indigenous people grow. Mbo'y Jejua and her relatives, who were initially scared of the vaccine or avoided it for the reasons discussed above, have all been vaccinated with three doses. What made them change their minds? Judging by the comments of Mbo'y Jejua herself and some anthropologist colleagues, the fact that many Indigenous people have been vaccinated and are well helped a lot in making the decision. The encouragements of Indigenous associations like APIB for all Indigenous people to be vaccinated, including demands that the Brazilian government make vaccines available for everyone, also contributed fundamentally to the COVID-19 vaccination becoming something not to be feared. On the other hand, the state vaccination campaign, focused broadly on 'Indigenous peoples', did not actually contribute to vaccine uptake among the Guarani peoples. On the contrary, without an approach that privileged the establishment or strengthening of relations of trust, these efforts ended up worsening the suspicions relative to the Brazilian state and its agents. And would the term 'trust' be the most appropriate one to use to think about vaccination adherence?

As I finish writing this article, I have just received news that Mbo'y Jejua has been imprisoned along with two other Kaiowá persons. After another attempt to retake their ancestral territories, they were arrested by the Mato Grosso state military police, even without court authorisation to do so, illegal in Brazil. The vaccine ensures life itself, in the sense given by Nikolas Rose (2007), but not Kaiowá life.

The kind of life that interconnects health, bodies and territories. In one of the last messages I received from Mbo'y Jejua, she told me that '*here we pray not become sick'*. They have no access to their ancestral territories, in the large majority of which the forests have been destroyed for soybean monocrops and beef cattle ranching, nor healthcare assistance from SESAI. The water they drink is contaminated by pesticides. In the village where Kuaray lives, thousands of kilometres from Mbo'y Jejua, the soybean monocrops also surround the Indigenous territory. What health is being talked about when speaking of care protocols and vaccines to protect against COVID-19?

An openness to interacting with others is part of Indigenous health cosmopolitics. As addressed previously, a body is not an enclosed entity in physio-biological dynamics. The body-person exists as a human because it is precisely made with and from others. And it differs from other-than-humans due to its ability to agency transformations and establish kinship, considering the point of view in the relations it gives rise to. Injecting a substance that activates or deactivates some vitalities may converge Indigenous and biomedical understandings. What does not converge is the prioritisation of life in itself and not that lived collectively, including here other-than-humans and more-than-humans.

The experience of not having suffered or witnessed body-person transformations that provoked the loss of humanity, such as turning into a caiman, added to the arguments of influential Indigenous associations that supported vaccination, and is part of a framework that explains vaccination adherence among the Kaiowá. Among the Mbyá, ensuring their right time to take the vaccine and to prepare the body to receive it contributed to adherence to the vaccination campaign. Hesitating is part of getting along with others. It is never known exactly what the other really is. It would be no different with the COVID-19 vaccine and the vitality and relationships it engenders. Trust seems to have occurred more in the process of opening and composing with others, as well as in the relationship with those who are 'parentes'[17]—and defended the vaccination—than in the health policies of Bolsonaro's government and beyond.

In an article published with colleagues (Montesi, Prates, Gibbon & Berrio 2023), we argued that COVID-19 is a disease of and with Anthropocene Health, and that the policies developed to combat it, especially where Indigenous peoples are concerned, are rooted in an epistemic coloniality that both exacerbates existing embodied inequalities and creates new modes of usurping the autonomy as an outcome of the limited possibilities for circulation and the mobilisation of care technologies that fail to do justice to Guarani modes of existence. The poets of

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[17] *Parentes* is the term employed to refer to other Indigenous people as relatives.

care are many among the Mbyá and the Kaiowá, but the possibilities available to them to potentialise their creative abilities to exist and care encounter barriers that do not always help in the composition of worlds that they induce.

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'You have to do some *dhora-dhori*': achieving medical maternal health expectations through trust as social practice in Bangladesh

Janet E Perkins

Abstract: In contrast to prevailing conceptualisations of 'trust' as an object in popular and political discourses, this article takes the concept of trust as future-oriented practice as a launching pad for understanding relationships between people and medical systems in Bangladesh. Based on ethnographic fieldwork in Bangladeshi peri-urban and rural spaces, it focuses on expectations related to advanced maternal biomedical technologies delivered through medical institutions. These technologies have recently come to dominate practices and expectations around pregnancy and childbirth care and women's navigations of health systems to realise these expectations. Within this context, trust in institutions in the public or private health sectors remains peripheral to women's experiences of accessing desired maternal health resources. Rather, women leverage social connectedness through the patronage-related practice of *dhora-dhori*, translated as mutual grasping or holding. *Dhora-dhori* is based on social rootedness, trust in that rootedness, and reciprocity. Women act as embedded agents within their families to appeal to various social connections through *dhora-dhori* to tactically access desired services and resources, with the expectation that this will result in better care at a lower cost, whether in public or private health sectors. It is through such practice that women and families work to realise their expectations of care through institutions, collapsing distinctions between 'trust' in personal relationships and 'trust' in institutions, as it is through intimate relationships that relationships with medical institutions are engaged.

Keywords: trust, health systems, maternal health, childbirth, ethnography, Bangladesh.

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Introduction

Evocations of ‘trust’, long appearing in discourses related to medical systems, have multiplied in recent years, gaining momentum in moments of epidemic and pandemic response. Within this context, trust has been reified as an incontestable ‘good thing’ (Cornwall 2010) that societies simply need more of in relation to medical systems and institutions, an object that can be measured and built. Anthropologists have rightly critiqued the uses of ‘trust’ in these popular and political discourses, noting its lack of conceptual clarity equal to its prevalence in discourse (Carey 2017: 3, Storer & Simpson 2022), how it is evoked as a tool to be leveraged toward political interests, and its potential to be used as an ‘anti-politics machine’ (MacGregor & Leach 2022), stigmatising those who are ‘deficient’ in trust and exacerbating pre-existing marginalisation (Raschig 2022). Moreover, they note the ethnocentrism within these discourses, rooted in individualism and particular notions of the self (Coates 2019).

Building on anthropological scholars and in a call for more meaningful conceptualisations of trust in public spaces, Storer and Simpson propose a conceptualisation of trust as a verb, perpetually in the making and remaking (Storer& Simpson 2022). Trust as a verb is oriented towards expectations of particular futures. As Pedersen and Liisberg write, ‘trusting is a mode of existence that shapes our outlook on the near future; a future that will probably develop according to implicitly or explicitly expressed expectations’ (Pedersen & Liisberg 2015: 1). Within the social sciences, trust as a future-oriented mode of existence has been theorised in relation to personal relationships wherein the person is known, as well as in relation to systems in which the other is ‘unknown’ (Carey 2017: 5). When applied to medical systems, trust as a verb can be thought of as anchored around what forms of care one might expect within medical institutions of care, and the practices, both taken and imagined, to realise these expectations.

This article takes the concept of trust as future-oriented practice as a launching pad for understanding relationships between people and medical systems in Bangladesh. It focuses on expectations of advanced biomedical technologies delivered through medical institutions comprising much of the medical system, which have only recently come to dominate practices and expectations around pregnancy and birth care. I use the term medical institution broadly conceived as a space recognised as enacting biomedical knowledge. In the Bangladeshi context, these include an array of hospitals, clinics, and diagnostic centres operating in the public and private sectors under more or less formal legitimisation. While institutional pregnancy and birth care until quite recently remained uncommon in Bangladesh, seeking care through formal biomedical facilities for birth has increased exponentially over the past fifteen years (NIPORT *et al.* 2019). These transitions are directed heavily toward the use of biomedical technologies in the form of foetal ultrasound and caesarean procedures (NIPORT & ICF 2019). While such technologies are only unreliably available in public health facilities (Billah *et al.* 2019), women find them widely available in private healthcare institutions, largely under-regulated, built up around the scaffolding of public institutions (Rahman *et al.* 2013, Sattar 2021).

This article examines the future-oriented navigations of women and families for pregnancy and birth in this complex therapeutic landscape. It first sets out the backdrop for the discussion, examining shifts in maternal health service delivery and expectations in Bangladesh towards institutionalised biomedical care. It then turns to the future-oriented practices of women and families to access institutionalised forms of care in both public and private health sectors, tracing the stories of two women, Tasrin and Shilpi. These examinations elucidate the local construct of *dhora-dhori*, literally translated as mutual grasping or holding, as foundational to how women and families orient practice to achieve health ambitions vis-à-vis medical institutions. *Dhora-dhori* relies on the nurturing and give-and-take of intimate social relationships, and is drawn on by people to navigate different social fields and access resources and opportunities through these navigations. These can range from accessing institutional resources, including those officially delivered through state services, and job opportunities. It is through such practices that women and families realise their expectations of care through institutions, collapsing distinctions between trust in personal relationships and trust in institutions, as it is through intimate relationships that relationships with medical institutions are engaged.

Methods

This article is based on data generated during 18 months of ethnographic fieldwork in Bangladesh between September 2019 and March 2021 for my doctoral research. During fieldwork, I engaged in participant observation and conducted interviews in various maternal health settings, including maternal health policymaking and programming circles in Dhaka and government and private facilities in Kushtia district, located in the west of the country, alongside the Indian border. In Kushtia, I spent time with women and health service providers in antenatal care service points, labour and delivery rooms and operating theatres. In addition to informal discussions, I formally interviewed 65 women in health facilities and their homes. These interviews explored the participants' experiences of pregnancy and childbirth and their navigation of the maternal health service terrain. I obtained ethical approval for this project prior to initiating data collection through the University of Edinburgh School of Social and Political Science and in-country through the ethical review committee of the International Center for Diarrhoeal Disease Research, Bangladesh (icddr,b).

Biomedical ensembles and desires

Since British colonial rule, pregnancy and childbirth in South Asia have operated as sites of biomedical interest, with efforts by the colonisers and missionaries to shift birth toward institutional spaces (Mukherjee 2017, Sehrawat 2013), an unfinished project taken up by state and development interests after decolonisation. However, despite these efforts, by the end of the 20th century, scholars noted that childbirth in Bangladesh remained remarkably similar to what it had been during the centuries prior, typically occurring in homes, with the assistance of female family members or non-professional*dais*, traditional birth attendants (Afsana & Rashid 2009, Rozario 1998).

As late as 2004, demographic data suggested that fewer than 10 per cent of women gave birth in institutional settings (NIPORT *et al.* 2005). Until this time, biomedical birth services were primarily offered through public health institutions. Indeed, the Constitution of 1972 committed the state to ensure medical services to people living in rural areas (People’s Republic of Bangladesh 1972), which, in subsequent decades, materialised in the scaffolding of a public health system with a network of district, *upazila* (subdistrict), and union-level health facilities, managed through two directorates under the Ministry of Health and Family Welfare: the Directorate General of Health Services (DGHS) and the Directorate General of Family Planning (DGFP). While health facilities under both directorates provide services for uncomplicated birth, Emergency Obstetric Care (EmOC) was primarily introduced through DGHS facilities as part of an EmOC project initiated in the early 1990s (Gill & Ahmed 2004). This project aimed to integrate EmOC, including emergency caesarean procedures, into health facilities down to the *upazila* level, a project which today remains far from complete (Alam *et al.* 2015, Sikder *et al.* 2015).

Still, by 2016, institutional birth skyrocketed to nearly half of all births (NIPORT *et al.* 2005. NIPORT *et al.* 2019). This trend was largely driven by the movement of birth toward private health institutions, while births in public institutions rose only slightly (NIPORT & ICF 2019). In recent years, unregulated and minimally-regulated private health facilities have mushroomed throughout the country in various froms, from large corporate hospitals and their satellites located in urban and peri-urban centres, to small start-up facilities, spread into the most remote corners, providing opportunities to compensate for the fragmentation and unreliability in the public sector for people of all social classes. This has emerged particularly starkly for maternal health services. These trends not only expanded relationships between people and health institutions during moments of pregnancy and childbirth, but also resulted in enormous implications for the very mode of birth—in just over a decade, caesarean birth increased ten-fold, from just 3% to over 30% (NIPORT *et al.* 2019). While these transitions are consistent with trends toward medicalised childbirth across South Asia and globally (Jullien & Jeffery 2021, *Lancet* 2018), they have been particularly rapid in Bangladesh.

In Kushtia, none of the public subdistrict hospitals offers caesareans—the only public facility to reliably do so is the district hospital. However, the maternal therapeutic landscape is replete with private health facilities promising the delivery of advanced biomedical technologies—specifically foetal ultrasound and caesarean. Many of these are built up around the scaffolding of public health facilities. These facilities vary enormously, from a few (expensive) corporate hospitals located in the administrative hub of Kushtia, to many entrepreneurial starts-up, often comprised of an austere operating theatre, a couple of recovery rooms, and staffed by informally trained providers and a clinician who rotates among such clinics to perform basic operations, such as caesareans. Many of these facilities operate without formal licenses, and those with licenses are accorded these credentials based on a regulatory framework which dates back to 1982 (Government of Bangladesh 1982). Such facilities exist tenuously—it is common to hear stories of the ghosts of clinics past; those without the social, economic, or political resources to persist.

Women in Kushtia, irrespective of social class, express the desire to access biomedical technologies in the form of ultrasound and caesareans, contained in institutional spaces. Even my poorest interlocuters articulated ultrasound, whether or not it was paired with other forms of formal antenatal care, as a basic requirement and responsibility and had at least one, and often multiple, ultrasounds during pregnancy. Ultrasound technology, for them, is imagined as an oracle, letting them know if the baby will be okay, and foretelling whether the birth will need to be through caesarean. While most of my interlocutors said that they would like to try for a vaginal birth, there was often a general resignation that a caesarean may be necessary for any type of problem, and they desired the possibility to access this service if required. The promises of caesarean are perhaps oversold, particularly in the peripheries where ensuring clinical standards is elusive; nonetheless, the procedure is generally narrated by my interlocutors as the ultimate solution for averting potential harm, especially for the baby, and therefore inspires aspirations towards birth futures previously unthinkable.

The biomedical maternal therapeutic landscape is a tenuous space to navigate indeed. Women and families tend to use a mix-and-match approach, moving between public and private sectors to realise their expectations of care. In either sector, however, what one might expect to access is characterised by unreliability. In theorising ‘mistrust’, Matthew Carey pushes past mistrust as simply the absence of trust, proposing rather that mistrust captures a ‘general sense of unreliability of a person or thing’ (Carey 2017: 8). While my interlocutors did not articulate their relationships with the medical systems in terms of trust or mistrust, they did articulate their experiences with the these systems in terms of unreliability, and a reticence to place their expectations of possible futures in the metaphorical hands of these systems. Given this general sense of unreliability of health systems, what practices do people engage in to maximise the probability of realising a future in line with their expectations of pregnancy and birth care, now incorporating advanced biomedical technologies? The next sections turn to this question, centring the practice of *dhora-dhori*, the mutual grasping or holding embedded in intimate relationships, in the everyday navigation of women and families seeking to fulfil their health expectations to maximise their health and that of their babies during pregnancy and childbirth.

Dhora-dhori and navigating public maternal medical systems

Discourses related to trust in medical institutions tend to presume particular configurations in the nature of relationships between people and institutions. When taking public health institutions as a concern, these discourses often presuppose relationships between people and medical services based on citizenship, or the legitimate claims people can make on a state delivering entitlements. An alternative, competing, and increasingly prevalent type of relationship is imagined between people and private health service delivery, delivering services to people as clients, based on their willingness to purchase health commodities and health services through capitalistic forms of exchange.

While these typologies are a vast over-simplification, and are severely limited in their ability to represent the complex and blurred boundaries between and within biomedical health delivering entities in and beyond Bangladesh, they highlight the presumptions of forms of trust as a forward-looking concept in how one might aspire to access desired health-promoting resources. How do these typologies compare to trust practices in achieving health aspirations in rural Bangladesh? To examine this, I turn to the stories of two women, Tasrin and Shilpi, to illustrate the navigation of social relations to achieve maternal health ambitions. Tasrin and

Shilpi share similarities: both live in villages in Kushtia, both consider themselves poor, residing in the in-law's household, with livelihoods sustained through farming. Both had two young children, and sought to optimise their health and that of their babies during their pregnancies and births. Both imagined access to advanced biomedical technologies, ultrasound, and caesarean birth services if necessary, as central to these ambitions. Where they differed, however, was in the types of spaces in which they sought to fulfil these ambitions—Tasrin sought to achieve these through the public health sector, while Shilpi bypassed public services altogether, staying either at home or seeking care through the prolific private health sector.

Tasrin was a young teen when she became pregnant for the first time. The Demand-Side Financing (DSF) project was in full swing in Daulotpur upazila, where Tasrin lives in the outskirts, by the time of her first pregnancy. Championed by the Department for International Development (DFID) of the United Kingdom, the DSF project aimed to lure disadvantaged women to institutionalised health services during pregnancy and birth through financial incentives (Ahmed & Khan 2011, Khan & Khan 2016). The DSF project in Bangladesh is but one configuration of conditional cash transfer schemes, a popular fixture in the development apparatus since the late 1990s (Bradshaw 2008). Such schemes remain popular among maternal health policymakers and programmers (Glassman *et al.* 2013). While these schemes vary in form, they share a foundation of market-oriented principles which leverage individual responsibility and market motivations.

The Ministry of Health and Family Welfare, supported by international development partners, introduced the DSF project through the public health system in 2006. Daulotpur upazila, identified by the programme as a 'disadvantaged' and border area, was one of twenty-one upazilas selected for the pilot. The scheme initially provided vouchers for qualifying women based on economic criteria to use institutional health services. In the model, the voucher covered costs for women to attend three antenatal care visits and one postnatal care visit, including transportation. On top of that, women received a cash incentive of 3,000 taka (~£25) to give birth in a government facility, a handsome sum where a monthly household income of the same amount was the initial cut-off for qualifying for the voucher.

When pregnant with her first child, Tasrin secured a DSF voucher, which women refer to as the 'card', seven or eight months into the pregnancy. While, officially, pregnant women obtained vouchers for a first or second child free of charge, they tend not to describe it this way. Instead, they share stories of exercising their social networks to avoid financial exchanges to obtain the 'card'. 'You have to do some *dhora-dhori*', Tasrin explains when we ask her how she secured a card, evoking her leverage of social networks to access opportunities or resources. 'I have one of my relatives … she arranged this for me. The daughter of my elder brother-in-law works [with a member of local government]. I got it through her, even though I was not directly a relative [of the member].'

Despite possessing the 'card', Tasrin anticipated giving birth at home with the assistance of her grandmother-in-law (*dadi shashuri*), experienced as a *dai*. But as her due date passed and the days ticked by with no signs of labour, these aspirations evaporated. 'My mother, grandmother, everyone over there, I asked them. They said if [the labour pain] did not come, I would need to go. It was almost just like that. "If you do not have the poison pain [*biSh byaetha*], you must go to the doctor's house", they said.' A week past her due date, her family took her to Al-Arafa Hospital in Kushtia for what would be her third and final ultrasonogram of that pregnancy. Al-Arafa, which straddles the space between a charitable non-profit and for-profit private hospital, is one of the most well-reputed hospitals in Kushtia. She consulted with Dr Sabina Khatun, a highly esteemed obstetrician in Kushtia.

'I did the *sono* [English cognate for ultrasonogram]', she recounted, 'and the doctor told me that the water inside was drying. She noticed that there was not enough water... Therefore, a caesarean was necessary.' With this news, the family returned home, determined to go to Daulotpur upazila health complex, the government subdistrict hospital, the following day. It would be her first visit to the government facility during her pregnancy. Previously, her family took her to Al-Arafa as they were not confident in the quality of the services provided at the government complex, particularly the quality of the ultrasonogram, her primary motivation for visiting any biomedical institution during pregnancy. However, the upazila health complex was an obvious choice for a caesarean. With the voucher, the services would be free of charge, and they would also receive the incentive. In contrast, a caesarean at Al-Arafa would cost at least 20,000–25,000 taka (~£170–215). That her grandmother and her *chachi* (paternal aunt) lived near the upazila health complex and could care for her and bring food during her recovery stay was no less important.

Daulotpur upazila health complex admitted her the following morning, a Friday, at 10 am. However, she was in for a long wait. 'There was no doctor there', Tasrin explains. 'It was Friday that day. As Friday is a holiday, my *mama* [maternal uncle] went to fetch a doctor that he knows'. Once the doctor arrived, thanks to her *mama*'s *dhora-dhori*, around 10 pm, he quickly performed the caesarean, and her son was born without any problem.

When she became pregnant again after seven years, Tasrin discovered the DSF project was no longer what it was during her first pregnancy, though she did not understand why. Daulotpur upazila health complex had discontinued caesarean services in the interim between her pregnancies; therefore, the vouchers no longer covered the procedure. Moreover, she could not secure a voucher, though she was well within the requirements and enjoyed the same social connections. 'We know that member gives [the cards]', she explains. 'But if he does not give it after saying so he will, what can we do? He took everything, the ultrasonogram papers, the photos, how many months pregnant I was, everything was written.' She did not provide any financial transaction, thanks once again to her connections with the local government member through the relative, but neither was she able to secure the card as expected.

Tasrin travelled to the district hospital after the labour pain struck her in the night. However, as it was night, no doctors were available to perform the surgery. Sabina Khatun finally came to her rescue at 6 am. Tasrin credits her maternal aunt's (*khala*) *dhora-dhori* for the arrangement. 'I have a *khala* that stays in Kushtia. Sabina Khatun knows us through her, so she did that [caesarean] in her free time. "I will do the operation", she said. "It will not be any problem." So, she did it.' She was grateful to Sabina Khatun for coming to the government hospital outside of regular hours to perform the surgery rather than requiring her to come to her private practice. She spent only 2,500–3,000 taka (~£21–25) for the procedure in the public hospital.

Tasrin's account highlights the challenges in pursuing birth aspirations through public medical institutions. While government health facilities promise to deliver services to women as entitlements, from the perspective of women, this provision is characterised by volatility, as a gift that may be offered one moment and withheld at another. Development actors often use government institutions to test development intervention, such as the DSF project. This practice often translates into resources and services, such as the vouchers, appearing at one moment, then disappearing or reappearing in altogether different forms at another, following the tides of development interests and agendas. These development-shaped volatilities map onto broader unpredictabilities in public health facilities, which promise services but often fail to deliver, manifesting in the vacillating presence of health staff, logistics, pharmaceuticals, and technologies.

While discourses around public health systems suggest health resources and services delivered based on the state's responsibilities to people based on citizenship, Tasrin's story illustrates that accessing opportunities and resources, even through the public health system, is often achieved through leveraging social networks. *Dhora-dhori* indicates the moral leveraging of social networks to access opportunities or resources as pervasive in Kushtia as in Dhaka. Its enactments lie on the spectrum of patronage, integral to social relations and accessing opportunities and resources in the region (Gardner 2012, Guhathakurta & van Schendel 2013, van Schendel 2021).

Much of the scholarly work on patronage in South Asia focuses on politics, viewing the rampant patronage in the region as an adulterated rendering of democratic ideals and stunting governance and development (Bardhan & Mookherjee 2012, Chandra 2007, Kochanek 2000). Others take a more generous position. Anastasia Piliavsky, for example, argues that patronage in South Asian politics is part of a moral universe rooted in mutuality and constitutive of social bonds (Piliavsky 2014). *Dhora-dhori* reflects such a moral universe composed of and generating social bonds. Tasrin's account exemplifies the centrality of *dhora-dhori* in navigating maternal health resources. Tasrin achieved her access to doctors through the public health system not as a matter of entitlement but through her social networks. Leveraging social relations was critical in enabling her to access development resources, i.e., the 'card' or voucher, through kin connected to the local member of government and access services at public health institutions, both in the upazila health complex and the district hospital. Social networks and the opportunities they open up for *dhora-dhori* are central to navigating the volatile maternal health service terrain and accessing desired maternal health services and resources at critical moments within the public health system.

'If there are any problems, tell this person': realising expectations in the private health sector

As mentioned previously, trends towards increased institutionalisation of birth care in Bangladesh occurred alongside a mushrooming of the for-profit private health sector, expanding delivery of maternal health services. Indeed, quantitative data suggests that the increase in facility births occurred chiefly within the private health sector (NIPORT *et al.* 2019). Many such facilities deliver services at prices affordable to poor families, and many such women bypass the public sector altogether and depend solely on private health services during pregnancy and birth.

The regulatory framework for such facilities dates back to 1982—outdated and mismatched to the contemporary landscape of private health service delivery. Many private health facilities remain unlicensed or operate under expired licenses, and even those with licenses tend to compromise on the minimal requirements in practice, for example in employing fewer professionalised health staff than required, as the standards are deemed too difficult to maintain, particularly in a rural context. Without institutional measures to ensure that promised health services adhering to a minimal level of quality will be maintained, women and families rely on other mechanisms to decide where and how to achieve their expectations for care.

Like Tasrin, Shilpi lives in a village, where her family relies on farming to maintain their livelihood. Also like Tasrin, she considers herself poor, and is among the exceptionally few women I met who never attended any schooling—her father passed away when she was young and her family could not afford to send her to school. Due to economic necessity, her paternal uncles arranged her marriage when she was 12 years old. Shilpi did not become pregnant until eight years after her marriage, though not for lack of trying. Once she did, and in contrast to Tasrin, who attempted to access services and resources through the public health system, and only successfully so through leveraging intimate relationships, Shilpi circumvented public health service delivery entirely.

Her labour pain started after she reached full term. She intended to give birth *normale* at home, as many women like her try. After some time, her waters broke. Still, her labour did not progress, so her uncle-in-law brought a woman to the house to assist her. Shilpi remembers the woman as someone who sees pregnant women and helps women give birth at home; she thinks she also worked in a government health facility. 'After she came', Shilpi recounts, 'She put her hand on me and examined me. She checked the position [of the baby]. When she saw that it was in a bad position, she took me [to the private clinic].' The woman took Shilpi to Meyirhashi, a small private clinic where she had an established relationship.

They reached Meyirhashi in the nearby town at around 11 pm. The health service providers there examined her. 'The doctor said that the baby was having some problems; like, the baby is going up [in my belly]', Shilpi tells us. 'Because of this, I needed to have the *shejar* [the English cognate women use to refer to caesarean birth]. There was extra water going out. If I did not do a *shejar,* the baby would have problems. I really wanted this baby because I had been trying for eight years.' Shilpi did not resist the advice. The doctor arrived mid-morning on the following day to operate. 'I was terrified', Shilpi tells us of the moments leading up to the operation. 'I was crying. My brothers-in-law were crying—because the baby was coming now after trying for so long. My father-in-law and mother-in-law were crying.'

The clinic staff took her inside the operating theatre. 'After taking me inside, they laid me on top of the bed. I was so scared because that is how you lie a person out when they are dead. It is like death is coming to see you.' The doctor sensed Shilpi's terror. '*Ma'*, he addressed her affectionately, using the Bangla word for mother, 'Why are you getting scared?' 'Sir, I am very scared', Shilpi responded. The doctor urged her to invite a family member to stand by her side during the procedure. Shilpi declined the offer, not wanting to subject her family to witnessing the procedure and thereby inflict fear upon them. However, one female clinic staff member stood next to her and comforted her, telling her not to be scared. The team spoke to her 'beautifully' through her anxiety, saying, '*Ma*, you are going to have your baby.' Soon after, the doctor lifted the baby from her incision. The clinical team wiped and bathed him before presenting him to Shilpi. 'Seeing the baby, I felt a cool breeze wash over my inner soul. Allah made this happen. It was extraordinarily beautiful', she recalls.

In the days that followed the procedure, however, the family struggled to cover the charges. 'I tell you the truth', Shilpi confided. 'For the poor, when they have a *shejar*, it is so difficult how much money is required.' Meyirhashi demanded 19,000 taka (~£165) for the caesarean, an astronomical price tag for the family. She had one family friend with connections to the clinic whom they contacted to enact *dhora-dhori*. He pleaded to the clinic owners on the family's behalf. Finally, the clinic agreed to accept 12,000 taka (~£100). She remembers the health staff visiting her on rotation three or four times a day. The 'big doctor' would come and talk to her and measure her blood pressure. The clinic staff removed her 'beautiful' stitches on the seventh day, and she and the baby returned home in good health .

Shilpi fell pregnant unexpectedly only nine months later, both a blessing and a curse. She recounted that Allah gave her this baby immediately, saving her from suffering through more years of fertility struggles, but her body was not yet fully recovered from her first surgical birth. Shilpi's labour pain hit with force late one evening, and amniotic fluid trickled from her body. As her husband was away working in another part of the country, her brothers-in-law wasted no time taking her to a private clinic. Rather than returning to Meyirhashi without the social connection they enjoyed the last time, they took her to the well-known Amin Clinic in Kushtia, a presumed upgrade from the smaller Meyirhashi clinic set in the subdistrict. However, the clinic staff refused to admit her when they reached it, saying they could not admit her in the night. 'Why won't you admit her?', her younger brother-in-law charged. 'Because we are poor? We are not people with money [*takawalla*]; there are no influential people among us. That is why you will not admit.' After saying that, another person from the clinic entered the dispute. 'What is happening?', he demanded. Her elder brother-in-law explained. 'Sir, look, my brother's wife's pain has come. Since she had a *shejar* before, we cannot keep her at home. This is why we bought her. Why will you not take her?' The staff relented and admitted her.

The trickle of amniotic fluid had escalated to a deluge by then, and she could not walk. The staff transported her to the second floor. 'After they took me', Shilpi recalls, 'they checked my pulse. They did not do anything [else].' Since it was night, they would need to call for the surgeon to come, but they would only do this at an additional cost—5,000 to 7,000 taka (~£42–60). 'Before everything started, the question was about money. Before they start, you must pay money', Shilpi said.

They demanded a down-payment of 5,000 taka before calling the doctor. The family had not brought money with them. Back in the village, her uncle pooled some money from other family members and brought it to the clinic so they would call the surgeon.

After the payment, the clinic staff transported Shilpi, petrified, to the operation theatre. Once there, one of the clinic staff told her, 'You know, usually we do two or three *shejars* at a time. In the daytime, that is how we do it.' Since Shilpi's procedure was the sole to be done at this time, and because they called the doctor to come specifically for her, it would cost more money. 5,000 taka to bring the doctor, 5,000 taka for being alone. A 10,000 taka (~£85) surcharge for the misfortune of going into labour at the wrong time.

The next moments were some of the most excruciating Shilpi, no stranger to tragedy, faced in her life. The doctor came after the evening prayer and immediately operated. 'When they did the operation', Shilpi tells us, 'I had so much suffering … . The pain that I went through, I have never been through so much pain in my life.' She remembers watching the doctor sloppily stitch her belly back together.

Shilpi's suffering extended into the days that followed. In contrast to her stay in Meyirhashi, she felt neglected. She watched the hospital staff make rounds, dressing women's wounds. 'For the wealthy people [*bhodrolok*], they dressed [the wound] beautifully. Sometimes they did it two or three times.' The doctors never passed by to see her as they had in Meyirhashi. 'It was just some woman who came to see me', she recounts. 'When the woman came, my mother would loosen the cloth from the site of the cut. Meaning, the woman said to loosen the cloth. She would look a bit, but she would not put her hands on me. She would only look.' These visible manifestations of difference in treatment irritated Shilpi's family. 'My mother-in-law's sister had to call them to come to do the dressing. "Why won't you come to do the dressing? Why won't you come and give the pad?" She would say many things like this.'

Shilpi's family arranged a stop-gap solution by leveraging the family's social network and enacting *dhora-dhori*. Her father-in-law's sister brought an acquaintance with connections to Amin Clinic. 'If there are any problems, tell this person', she instructed. This acquaintance advocated for Shilpi. When the clinic staff made rounds, she accused them, saying, 'You are doing this because she is a poor patient', and demanded that they provide better treatment. For Shilpi, this intervention made the remaining stay tolerable.

The payment still dangled in the balance, however. The family did not know how they would manage to acquire the remaining balance for the clinic bill, a further 10,000 to 12,000 taka (~£85–10) in addition to the 10,000 already dispensed. Finally, they took out a loan to cover the charges, although such a loan can be financially crippling to such a family. Shilpi left five days later with her baby. However, she still suffers pain from the incision site, which she attributes to the 'so-so' stitches.

The commodification of maternal health technologies has made even the most medicalised forms of birth widespread, placing caesareans within reach of the least advantaged women, such as Shilpi. Her story is emblematic of the volatile spectra of experiences with services delivered in the private sector. Women share stories along these spectra: spectra in the quality of delivery of care from their perspective —sometimes women share that the care that they received was good, occasionally, such as in Shilpi's case, they share that it was deplorable; spectra in the dignity of care—sometimes clinic staff treat them well, other times poorly; spectra in cost: some recount caesareans costing as little as 4,500 taka (~£40), others in the order of 50,000–100,000 taka (~£425–850). Often, the difference between these hinges not on the particularities of the clinics, but rather on the social relations one is able to leverage to mediate the relationship with the clinic.

Shilpi's story elucidates the centrality of social connectedness in the form of *dhora-dhori* in accessing desired maternal health services through the private health sector. Although Shilpi bypassed government and development entities in her birthing experiences, her narrative illustrates the variability of services one might enjoy based on social connections. In the first instance, the birth attendant assisting her at home brought her to a clinic that she had a personal attachment to, and thereby this personal attachment likely extended to compassionate care delivered to Shilpi and a reduced price of the services. In the second instance, her brother-in-law took her to a clinic where they had no personal attachment, and she recalled a much less compassionate experience. It was only by bringing in an acquaintance with a personal attachment to the clinic that the staff improved their service delivery toward Shilpi. *Dhora-dhori* was essential to accessing better resources and opportunities delivered through the market, maximising immediate benefits and reducing costs.

While some facilities enjoy name recognition, engendering confidence in the services one might receive, these are primarily larger corporate hospitals located in the administrative hub that remain difficult to reach and even more difficult to afford for most women residing in villages. Moreover, as Shilpi's story illustrates, reputation does not necessarily translate into the type of care one receives within its boundaries. This care is primarily determined by social relationships one can leverage through knowing someone and being able to appeal to that relationship. *Dhora-dhori* entails the work of building and maintaining relationships which extend before and after the moment in which these built relationships are leveraged.

Conclusion

The idea of 'trust' in medical systems has become reified in global health discourses as a 'thing', a noun, with the tendency toward instrumental use, appearing, for example, in training guides (see e.g., WHO 2015). Building on scholarship approaching trust as future-oriented practice (Pedersen & Liisberg 2015, Storer & Simpson 2022), rather than as a 'thing', this article has explored trust as practice through *dhora-dhori* in Bangladeshi women's and their families' navigations of a complex maternal health therapeutic landscape. Indeed, in Kushtia, my interlocutors did not employ a lexicon of 'trust' in institutions to articulate decisions or desires for care-seeking or the outcomes of this. As in many post-colonial contexts, institutions are not imagined as entities to be 'trusted'; they are spaces within which one may need to negotiate to potentially access goods and services which are experienced as unreliably delivered, harking back to the unreliability characteristic of mistrust which Carey describes (Carey 2017: 8).

In Kushtia, women leverage social connectedness through the patronage-related-practice of *dhora-dhori* to access expectations and desired forms of care. *Dhora-dhori* maps onto patronage-related practices which are common throughout South Asia for accessing opportunities and resources in the region (Gardner 2012, Guhathakurta & van Schendel 2013, van Schendel 2021). It is based on social connections, mutual leveraging of those connections, and reciprocity. As the English translation suggests, i.e., mutual grasping or holding, *dhora-dhori* is built in practice, in the forging of social connections through reciprocity. It is future-oriented—the practice involved in forging these connections may not be leveraged today, but perhaps next month, next year, or for the next birth. Women act as embedded agents within their families to appeal to various social connections through *dhora-dhori* to tactically access desired services and resources, with the expectation that this will result in better care at a lower cost, whether in public or private health sectors.

In both popular and scholarly discourses, a bifurcation is often made between trust embedded in social relationships of the 'known other' and trust in systems or institutions composed of the 'unknown other' (Carey 2017). In the maternal health landscape of Kushtia, these distinctions are collapsed. Indeed, it is directly through intimate relationships, the result of the ongoing practice of investing in personal connections, that one might expect to access the care they expect and desire. Trust forged in intimate relationships and trust in institutions are collapsed, as the latter depends on the former, manifest in *dhora-dhori*.

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‘What are you doing here?’: (mis)trust, COVID-19 pandemic, and sexual reproductive health rights

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Abstract: We explore how the government’s messaging on COVID-19 pandemic response perpetuated mistrust and impeded people’s ability to access and utilise sexual and reproductive health (SRH) services. While the need for SRH information increased, public health messages fostered mistrust in sexual and reproductive health services. We draw on in-depth interviews and focus group discussions conducted among women, girls, and healthcare providers in five African countries (Burkina Faso, Ethiopia, Kenya, Malawi, and Uganda) between May and October 2021. We show how trust was largely eroded through preventive measures, such as stay-at-home directives, social distancing, curfews, and lockdowns. We argue that, on one hand, while state-led epidemic preparedness and response were geared towards the common good, i.e., controlling the virus, on the other hand, de-prioritisation of much-needed services for sexual and reproductive health and rights (SRHR), as well as a lack of transparency among some of the service providers, bred mistrust in healthcare. We conclude that ambiguity in communication and implementation of COVID-19 prevention measures further compromised access to and utilisation of sexual and reproductive health services.

Keywords: COVID-19, pandemic response, (mis)trust, access, healthcare, sexual and reproductive health and rights, Africa.

Note on the authors: See end of article.

Introduction

In March 2020, the World Health Organization (WHO) declared COVID-19 to be a pandemic, that is, an international public health emergency (Mahase 2020, Wang *et al*. 2020)anxiety, depression, and stress during the initial stage of the COVID-19 outbreak. By early 2020, joint international guidelines and plans on safeguarding SRH services and information had been released by WHO, the United Nations International Children's Emergency Fund (UNICEF), and the United Nations Population Fund (UNFPA). The guidelines stipulated measures that countries should consider for the maintenance of good quality and equitable sexual, reproductive, maternal, and newborn, child, and adolescent health (SRMNCAH) services during the COVID-19 pandemic. Some of the principles in the guidelines included prioritisation and funding for continuity of SRMNCAH services and strengthening of the healthcare system (Endler *et al*. 2021, Haidara *et al*. 2022, Nanda *et al.* 2020, Schaaf *et al*. 2020).

The provision of services for sexual and reproductive health and rights (SRHR) was seriously affected due to social containment measures that disrupted and restricted access to and utilisation of these services (Caruana-Finkel 2020, Hyrink *et al.* 2022, Wood *et al*. 2021). While the effects of the pandemic on sexual and reproductive health (SRH) are not immediately known, early analyses showed a decline in modern contraceptive use (Dasgupta *et al.* 2020). The prioritisation of COVID-19 containment may have strained or drawn attention away from SRHR, resulting in inadequate provision of SRH services and information (Bukuluki *et al*. 2022, MacKinnon & Bremshey 2020, Okeke *et al.* 2022). Studies on previous pandemics have shown negative effects on SRHR, such as increases in unwanted pregnancies and reduced access to contraceptives (Bietsch *et al.* 2020, Sochas *et al.* 2017)

The public healthcare systems were the principal intervention points for managing COVID-19 disease. Responses by various governments to the pandemic were induced by fear of the anticipated devastating health impacts and the related social and economic repercussions (Essler *et al*. 2021). Social control measures, such as lockdowns, curfews, travel bans, social distancing, wearing masks, and sanitising, were prioritised. In addition, the healthcare system was tasked with biomedical interventions, including testing, treatment, and vaccination for containment of the pandemic. In this context, the need to control the pandemic overshadowed and may have impaired access to other health-related issues, including SRHR, that were not directly impacted by COVID-19 (Essler *et al*. 2021).

Compliance with the government-imposed COVID-19 mitigation measures was critical. Crucially, compliance is based on trust. Studies on COVID-19 show that the public's trust in the government was central to containment of the pandemic (Apeti 2022). Trust is associated with the public's willingness to collaborate, support, and adopt recommended policies and guidelines (Beshi & Kaur 2020, Chan 2021, Hall *et al.* 2001). An analysis of data encompassing 84 countries showed countries with a positive correlation between higher levels of economic inequality and lower levels of some aspects of social capital, such as civic participation and trust in state institutions, had higher COVID-19 mortality rates (Lindström 2020)group affiliations, civic engagement, confidence in state institutions. Another comparative analysis (Reiersen *et al.* 2022) conducted a separate study of 127 nations revealed a negative correlation between the level of trust in health authorities and the incidence of COVID-19-related fatalities. Conversely, the study found a positive association between the level of trusting fellow citizens and a lower number of deaths caused by the virus. Suppose individuals have confidence in health authorities to enact impartial and knowledgeable interventions, and anticipate their fellow citizens to adhere to them. In that case, this could result in a substantial level of overall compliance, hence reducing the number of individuals who contract infections (Reiersen *et al.* 2022). Elements of trust include, but are not limited to, safety, quality, provider knowledge, credibility, satisfaction, acceptance transparency, and communication (Robinson 2016). Several studies on COVID-19 linked high public trust to compliance with social measures (Freeman *et al.* 2022, Lim *et al.* 2021, Schmelz 2020).

This study examines (mis)trust in the healthcare system, specifically in SRHR, an area which has been characterised by mistrust in numerous African countries. Effective public health initiatives need to understand pandemic behaviour variables. Institutional, generalised, and interpersonal trust influence individual behaviour; therefore, public health efforts should consider these elements. Building trust in public health actors and organisations can raise the possibility that people will protect themselves and others during a pandemic (Skirbekk *et al.* 2011, 2023). Research has demonstrated that trust has a significant role in influencing crucial behaviours and attitudes, such as patients' inclination to seek healthcare, disclose sensitive information, and comply with treatment among other things (Rhodes and Strain 2000). In this study, trust can broadly be defined as public or client confidence in availability, access, utilisation, and satisfaction in the service and healthcare system in line with human rights principles, such as respect, confidentiality, privacy, autonomy, informed choice and decision-making, equity and non-discrimination. Trust is strengthened through democratic principles, such as accountability, transparency, and participation (Kerrissey & Edmondson 2020).

Mistrust or a lack of trust in institutions is brought about by inconsistencies, lack of transparency, and misinformation (Gilson 2003, Tarrant *et al.* 2003). The majority of online information about COVID-19 is inaccurate and misleading. Misinformation and mistrust can cause people to disregard public health regulations (Mechanic 2001, Nazir 2021). Mistrust is associated with fear, resistance, hesitancy, and non-compliance with policies or initiatives, as well as the adoption of alternative initiatives. It is anchored in power imbalances between patient and provider, political beliefs, inconsistencies, misinformation, indecisiveness, and poor quality of services. Practices that communicate dominance, fear, doubt, suspicion, and non-adherence to human rights principles are likely to induce mistrust. The paper is a modest attempt to analyse the intersection between COVID-19 mitigation measures, health providers' practices and clients' SRHR access, utilisation, and practices in five African countries.

Methods

We conducted the study in five African countries, viz. Burkina Faso, Ethiopia, Kenya, Malawi, and Uganda. Initial cases of COVID-19 were reported in these countries between February and March 2020. Data was collected in both urban and rural areas. We targeted public and private health facilities, including those run by non-governmental organisations (NGOs), to determine how the COVID-19 pandemic affected the availability, access, and use of SRH services.

In each country, a list of health providers that were fully operational as of December 2020 was obtained by research consortium partners, and from the list stratified random was used to select the facilities that were included in the study in the five counties. We also considered healthcare facilities that were owned by, supported by, or working in conjunction with the various organisations in June 2020, and were currently offering a variety of SRH services (such as contraception and family planning (FP), safe abortion, postpartum care, newborn care, post-abortion care, delivery services, HIV services, and services for sexual and gender-based violence). We focused only on healthcare professionals offering SRH services at the selected facilities. One healthcare professional per facility was chosen, and they were questioned regarding the health centre's status in terms of SRH services, as well as their own experiences in SRH service provision during the COVID-19 pandemic.

In all of the health centres chosen for the study, we focused on women and girls aged 18 to 49 years seeking SRH services at the time of the study. We informed these potential participants about the study, allowed them to consent, and interviewed those who provided their consent. The data was collected as part of a larger project on the impact of COVID-19 on SRHR across the five countries in February and April 2021. We draw on qualitative data collected through in-depth interviews (IDIs), focus group discussions (FGDs), and key informant interviews (KIIs). As shown in Table 1, we conducted in-depth interviews with 176 healthcare providers across the five countries, and 211 women and girls in all countries except Ethiopia. We conducted key informant interviews with 13 policymakers, including Ministry of Health officials, and 64 representatives from civil society organisations (CSOs) and non-governmental organisations. In Ethiopia, we conducted eight focus group discussions among women and girls.

Table 1: Respondents per country.

	Girls/women	Providers	Policymakers	CSO	FGDs
Burkina Faso	32	15		7	
Kenya	111	42	6	19	
Uganda	41	85	3	16	
Malawi	6	13		13	
Ethiopia	21	21	4	9	6

All interviews were audio-recorded and recordings uploaded to the researcher's computer. A professional transcribed the recordings verbatim and translated them into English (where necessary). We inductively and deductively developed a coding framework and coded data using qualitative data analysis software—Nvivo 10 (QSR International). We used a thematic analysis approach to summarise key findings. National ethics and scientific review committees in Burkina Faso, Ethiopia, Kenya, Malawi, and Uganda reviewed and approved the study protocol. Additional permits and approvals were obtained from national research commissions and from each participating health facility. Individual written consent was obtained from each study participant.

Findings

The COVID-19 crisis provides a window to explore citizen's trust in governments; in particular, regarding health and healthcare. We show how encounters as well as non-encounters with COVID-19 can tell how people view and approach trust in healthcare. We analyse governments' COVID-19 containment measures, and how they shaped trust issues, including doubt, suspicion, anxiety, skepticism, insecurity, resistance, hesitancy, and fear.

Government mitigation measures

After the identification of the first COVID-19 cases in the countries, governments led efforts to contain the virus. Governments adopted universal precautions, including prioritisation of COVID-19 prevention and treatment. Key informants report that containment and treatment of the COVID-19 pandemic were a priority over provision of other healthcare services. Governments' healthcare focus shifted to COVID-19 response and health emergencies only. Other health services, including immunisation, maternal care, outreaches and enrichment, were suspended:

> *COVID interfered with the government offering services to the people in the health sector where actually service delivery was changed from essential services to emergency services. For example the immunisation coverage went down because the government priorities were altered and the response by the government affected the utilisation of the services by the public.* (key informant, Uganda)

As a threat to human life and healthcare systems, public health measures were instituted. Measures comprised lockdowns, curfews, travel bans, social distancing, wearing of masks, treatment, and vaccination. In addition, communication was critical. In all sites, multiple communication channels were used by governments to provide information or directives to the public:

> *A number of communication channels were created by the government to the public especially on the televisions and radios on how to access health services by the public.* (key informant, Uganda)

Other issues communicated included positive cases and deaths, and the policing of social mobility, including stay-at-home directives, curfews, and lockdowns.

While the government took the lead, citizens were resposible to protect themselves and others by accepting and applying prevention measures. However, the containment measures were likely to be more acceptable in urban areas. Participants intimated that people in urban areas were more knowledgeable about COVID-19 compared to those in rural areas. Feelings about the government micro-managing lives in addition to low numbers of COVID-19 cases resulted in controversies and mistrust. Suspicions were noted around government reports, especially where the messages or information and prevention measures did not correspond with the low number of COVID-19 cases. There is a belief that COVID-19 does not exist because of the low or no account of COVID-19 cases. Some study clients in rural areas were skeptical that COVID-19 was a hoax in rural areas where day-to-day lives had not altered in relation to positive and death cases and government measures.

> *... there are some people who don't believe. They don't believe it. You tell them, 'I was sick.' And she tells me, 'no, you played the government, I don't believe you.' So, they don't observe those measures.* (client, Kenya)

For instance, in Burkina Faso, a country with low numbers of COVID-19 cases, government messaging on the existence of COVID-19 failed to gain acceptance. Both urban and rural study participants narrated how women found it challenging to understand the virus and distrusted government and doctors' messaging because they had not encountered COVID-19 cases, but doctors at health facilities told clients about it:

> *No, well frankly I heard that there was coronavirus* [from] *our doctors here. They told us ... so we did not even see the disease, we didn't even see anyone here with this disease. ... Some participants did not trust even the testimony of other people who claimed to be COVID-19 positive. Instead, they believed that these individuals had other reasons for claiming that they were afflicted with the virus.*

Agreeing to governments' containment measures for collaborative control of COVID-19 was problematic. The participants' curiosity was directed toward the encounter with the implementation of government measures by law enforcement officers. In urban areas, however, mistrust in government COVID-19 containment measures was embedded in the implementation of government measures. Containment measures were more punitive than preventive. They lamented police brutality on those caught violating these measures. In Nairobi, Kenya, participants discussed police brutality at the height of the COVID-19 pandemic. Pregnant women were compelled to give birth at home because they feared the brutality that would be meted out to them by the police:

> *People used to give birth at home. At night, you look for someone to take you, maybe you don't have [transport] means, and he tells you, 'With this curfew, where will we go?' Though they ... you could go to hospital but there was that challenge, like, I will meet with the police and they beat me ... People used to say the police don't understand. They [police] beat you before you explain to him what you want to do. So, you will meet with the policeman and he tells you, 'where are you going at night?' He has already hit you, and you tell him you are taking a patient to the hospital. Yeah, and again you know it was at night so people were afraid, there are not many people who are walking, so you are also scared. ...*

Such policing questioned the government measures and dented trust in government measures. SRH study participants questioned why they were punished with restrictive social measures. While masks were responsible for prevention, SRH study participants reported masks put on to escape being beaten by the police officers on patrol, but not as a responsibility to protect against transmission of

COVID-19:

> *Yes, there are some who wouldn't wear them because you see someone saying, 'I am wearing a mask so that I don't get arrested.' ... There are some who don't believe. There are those who don't sanitize.* (client, Kenya)

SRHR services and COVID-19

In all countries, key informants stated that SRH services were greatly affected. Guidelines for the continuity of sexual, reproductive, maternal, newborn, child, and adolescent health (SRMNCAH) services were developed by WHO, UNICEF and United Nations Family Planning Assistance (UNFPA) by April 2020, for adoption by countries. Despite the threat of COVID-19 to SRHR, adoption of the guidelines varied. Key informants, mainly policymakers and healthcare providers in study countries, indicated that governments formulated new guidelines and policies in relation to SRH to guide service provision during the COVID-19 pandemic.

Key informants, including policymakers, health providers, and civil society organisations' representatives spoke about how the shift in government priority focus on COVID-19 adversely affected SRHR services.. A health provider in Kenya noted: 'This area [SRH] was greatly affected and not much was done by the government…'. In Ethiopia, for example, a policymaker reported the SHR services were closed in the first three months.

When SRH services became available, policymakers, health providers and CSO representatives reported the lowest uptake of SRH services, which they attributed to trust issues. Healthcare providers in the study explained how government directives created fear and mistrust in health facilities:

> *... people got scared of coming for services because they felt that health facilities were the center of where COVID clients can easily get infected ..... So many patients started running away from our services because they were scared of the Corona issue and they felt that anybody closer to a hospital would be bringing a COVID-19 issue and they ran away.* (health provider, Kenya)

Another health provider discussed how such fears were informed by the information circulating in communities:

> *Same to family planning clients, they had fear because of the information going round that nurses and doctors are having COVID-19 and some of them have even died [...] and because of that most of our clients didn't come back for their return visits.* (health provider, Kenya)

SRHR clients, on the other hand, attributed low uptake to fear of contracting COVID-19, fear of being tested for COVID-19 and quarantined, and challenges in accessing health facilities, including being turned away or rejected by health facilities. In Uganda, participants stated that most people were afraid to go to health facilities, drastically affecting utilization of SRH. The situation was, of course, not unique to SRH but to all health services except emergency cases:

> *... access to the SRH access, especially the family planning utilization, drastically went down, and antenatal service utilization also went down; there was a reduction in the health facility deliveries, prompting increased cases of home deliveries.*

In addition, several social prevention measures, including stay-at-home, curfews, and related lack of transport, were cited to have contributed to the decline in access to services:

> *Okay. We have… COVID-19 Reproductive Maternal New Born & Child Health guidelines on how to offer services to a mother who is COVID-19 positive ... that is also what is in Child health Covid-19 guidelines for children. These were, in fact, disseminated on 5th May. On 5th February we disseminated the pediatric Covid-19 guidelines, which are already in place and they are guiding even the health care workers to offer services. So, we have RMNCH COVID-19 guidelines and pediatric COVID-19 guidelines guiding our services of RMNCH, including family planning; they guide us on to manage COVID-19 during deliveries and during postnatal.*

The 'no mask, no service' mandatory in all health facilities countries resulted in denial of services to those who did not wear masks; they were sent away.

Meanwhile, policymakers reported governments concern with the decline in access of SRH, and attempts to reclaim patient's/client's trust in health facilities. A policy maker explained:

> *There were Zoom meetings organized by the government to talk to the health managers and the assistant DHOs (maternal and child health) to guide the public to maintain and improve the service access to the public.*

Fear of health facilities being COVID-19 hotspots

The COVID-19 containment measures were to make health facilities safe for healthcare providers and patients or clients. Governments and related stakeholders were to ensure that facilities have containment measures such as sanitisers, water, and PPE (personal protective equipment). In addition, health facilities were to enforce social distancing. Despite these efforts, however, health facilities turned out to be sites for COVID-19 infection in all study sites. Healthcare providers acknowledged a reduction in the number of health seekers in health facilities, attributed to trust issues around their safety. Health facilities were considered COVID-19 high-risk places. A healthcare provider in Kenya alluded to clients not trusting the health facilities:

> they had fear because of the information going round that nurses and doctors are having COVID-19 and some of them have even died ... and because of that most of our clients didn't come back for their return visits.

This, combined with the fear of being tested and quarantined against their will if found positive, meant trusting in healthcare was dangerous:

> *Most women do not come to health facilities due to fear of COVID-19. People have fear of quarantine—isolation, fear of stigmatisation from their families due to COVID infection. Even for me, I did not come into health facility during its first phase of COVID pandemic. Some antenatal mothers missed their scheduled visits for Tetanus injection. The number of skilled deliveries in both public and private facilities also declined, all because of the fear of contracting COVID-19 in health facilities.* (healthcare provider, Ethiopia)

A health provider in Kenya noted:

> So people stayed home for some time. … They come on condition that maybe somebody is very sick. … Because they had heard the doctors are also dying, nurses are also dying, these people are dying. And you are going to intermingle with them … you are also going to affect the … family members.

Healthcare providers explained how, at the height of the pandemic, clients or patients avoided health facilities for fear of contracting COVID-19 and being tested for it, especially if they had symptoms such as high fever or chest problems, they likely would have had to be isolated or placed in quarantine. By not trusting the health facilities with their health, some of them turned to self-care with over-the-counter medication or herbal medicines.

Healthcare providers too feared contracting COVID-19 from clients and patients. In Kenya, health providers reported that 15 of their staff members and more than 30 in the entire sub-county had tested positive for COVID-19:

> There is a time, especially in March, most of our staff tested positive. So, in fact healthcare workers feared clients as much as clients feared them.

In Ethiopia, according to the Ethiopian Medical Association, about 1,500 healthcare providers were infected and more than 50 health workers died due to COVID-19. Some hospitals were closed because several providers became infected. Health providers saw clients as potential carriers of COVID-19.

As such, healthcare providers, due to the fear of contracting COVID 19, were very vigilant about the implementation and enforcement of government prevention measures among clients to protect themselves from being infected by clients.

SRH Clients' feelings of rejection and loss of autonomy

> *There they don't care about people. ... Yeah even if you sit there you are in pain no one will ask you anything, no one. You go there the whole day it reached* [unclear] *I got very sick at that place even now I am unwell. I really hate that hospital.* (SRH client, Ethiopia)

Participants provided accounts of being turned away for various reasons, including lack of masks, social distancing, lack of services, not being sick, stay-at-home policy, and being suspected to be COVID-19 positive. An SRH client seeking abortion services in Ethiopia explained how she came for family planning and found the clinic closed, and ended up with an unplanned pregnancy. At the time of the interview, she had come for abortion care. While the health facilities provided free sanitizers and water points for washing hands and took temperatures, patients and clients who did not have masks were turned away. They reiterated:

> *I could not get FP [family planning] without face a mask.* (client, Uganda).

While health providers and policymakers report a decline in the number of clients seeking services and attributing this to fear of contracting COVID-19, SRH clients raised concerns about provider attitudes. A provider in Kenya stated how health providers reinforced COVID -19 containment measures.

> *... the health providers were asking those who visiting health facilities, 'what are you coming to do here if you know that you are not that sick? Why can't you stay at home? What are you searching for?' You see such—such a comment.*

Such statements discouraged clients from seeking services from health facilities created mistrust in healthcare.

Also affected were mothers who arrived for deliveries. Clients shared how they were not treated well when they presented for delivery:

> *I was not coming here because there, Mtopanga, is a government hospital but they are not working. I went there and I was turned away. Yes I went there with my husband and I was told we will not be attended to. I pleaded they did not listen. So, even the last time that I came here for clinic, they told me in advance—to go back to Mtopanga, or to look for a hospital where you will deliver ... I already feel bad. Because they did not. I tell you I have been helped by God. ... maybe I could even have hurt the baby, maybe I would have killed the baby ... even the senior doctor was not there. Because the senior doctor is someone I know. So it's like I was talking to ghosts or I don't know what because if the senior doctor was not there, so when I arrived, I was turned back*

Another client on ART (antiretroviral therapy) explained:

> *I use ARTs so I was coming to the hospital but there were many challenges that I was going through because of this COVID-19. I go to the hospital we were told that we were not supposed to be so many in one place. So you have to go back home and the day you are supposed to go for the drugs has come and what you had is over. So you have to move forward the dates you don't take any because you have been told that you should not be at the hospital as a crowd, your dates have arrived so getting the drugs was a problem. ... It is like is like you are forcing the doctors, the doctor sees you as if you are going to infect him or what, he just takes you lightly. In July, August I decide to come to go to these small organisations.*

Experiences of rejection in health facilities were typical. In some private health facilities, clients suspected of having COVID-19 were mishandled by hurriedly being referred to other facilities. In Kenya private health facilities dissociated with COVID-19 cases for fear of being closed downhurriedly referred clients with symptoms such as high fever and coughing to other facilities. Those who did not comply with containment measures, such as wearing masks, were turned away.

According to clients, healthcare providers violated clients' autonomy to reinforce, encourage, or implement COVID-19 mitigation measures,even though autonomous decision-making is a key SRHR principle. Clients seeking family planning and abortion services explained how healthcare providers made decisions on their behalf. Healthcare providers asked clients to switch to COVID-19-compatible contraception methods. In some cases, this was based on COVID-19 prevention measures articulated in government policies and guidelines, such as Uganda's 'no touch' policy. Clients were discouraged from using intra-uterine contraceptive device (IUCDs) and implants, which require close contact and invasive procedures during insertion and removal. Instead, against their wishes, they were encouraged to use short-term methods, such as pills and injections that do not require physical contact between provider and client, or they were advised not to remove the IUCDs or implants if they already had these. Some clients seeking IUCDs and implants were dissatisfied with healthcare providers' recommendations to switch to short-term methods, particularly where family planning use was secret, as described below:

> *... somebody had a long-term family planning method. Now her time had come for removal. ... So this client was told that 'no, those procedures of removing we are not doing them now' ... until COVID-19 cases reduce. ... Because you also want to protect against unwanted pregnancy ... clients will be advised to take another method, maybe pills, we can give them that ... . They feel like they are not handled well when they are not given the correct thing.* (healthcare provider, Kenya*)*

In Ethiopia, greater attention was given to use of long-acting FP services and self-care with medical abortion drugs. Similarly, in Kenya, the manual vacuum aspiration (MVA), a medical procedure was not done for those seeking abortion services. This was in line with the country's COVID-19 protocols, which discouraged the procedure and recommended the use of medical abortion drugs. While comprehensive abortion care provides for a range of services or procedures, healthcare providers reported that the presence of the pandemic potentially limited choices. Clients were stripped of decision-making autonomy and were left with the choices made for them by healthcare providers. A healthcare provider explained:

> *... you give medication rather than do a procedure because you [fear being] infected ... that reduces that comprehensiveness. So you are limiting this patient to just a certain service, especially if a client was suspected to be COVID-19 positive. So, you give medicine to complete the abortion at home, rather than do an MVA ...*

Some clients reported not trusting or wanting to use the medicine to complete an abortion at home due to fear of excessive bleeding. Others who wanted to be discrete about their abortion feared being found out by family members.

Increased charges for services

In all countries, government SRH services remained free but evasive. Stock-outs were reported in government facilities, which was blamed government prioritisation of COVID-19 at the expense of SRHR and other health needs. Clients complained about the acute shortage of injectable contraceptives (Depo-Provera) in public health facilities. A civil society representative in Kenya speaking about the affected SRH services said:

> *... of course, the prioritising of COVID-19 over other health services affected the delivery of the commodities to our institutions. ... KEMSA was seen to be focusing on COVID-19 commodities more than reproductive health commodities, and that meant that women and girls lacked access to those services. ... We had no stock, and pharmacies were closed.* (CSO representative, Kenya)

A section of clients reported some facilities refused to provide services to clients. In Kenya, some healthcare providers evaded duty while some turned away clients, and other facilities preferred to refer clients to other facilities. However, in Burkina Faso and Uganda, key informant and healthcare providers reported that free services were available:

> *There was repeated calls to the people that services were still available at the health facilities in spite of the pandemic. There was also close supervision on the health workers not to abandon the health facilities.* (policymaker, Uganda)

The CSOs that usually provided free services closed. Some of them had repurposed funding to support governments' COVID-19 efforts. In Kenya, CSOs' clients whom they referred to public health facilities and those who sought services in public health facilities were forced to seek services from private (for-profit) SRH providers, who depend on out-of-pocket payments from clients. Overall, in all countries, participants seeking services from the private for-profit entities decried the increased cost of services,

> *Yes, the health facility is quite expensive compare to when the pandemic is not yet in place.* (SRH client Uganda)

Participants in Uganda, Kenya, and Ethiopia hinted at their suspicion about healthcare providers' integrity. While private for-profit health entities reported the high cost of commodities and providing healthcare services and passing on increased costs to clients, a section of the SRH clients alluded to the fact that they were taking advantage of COVID-19 to increase prices of services under the watch of governments. Some SRH clients in Ethiopia and Kenya stated that they could not afford the cost of healthcare services yet the governments were less concerned. A participant in Ethiopia elaborated:

> *... People lost employment ... the majority and then the country's economy at that particular point, everything was bad. ... People did not have money ... they did not have money. So actually, I think I met someone who once told me that instead of getting treatment, I only have money to buy food. I am sick, yes. I cannot be treated simply because I do not have money. The few coins that I have...* [are] *to buy food for my family and I continue being sick, yeah.*

Discussion and conclusions

The non-transparent nature of government decision-making processes may have been the main obstacle to maintaining client trust in SRH services. Mistrust in SRH healthcare is intertwined with the complexities of pandemic management and implementation of COVID-19 prevention measures. Although governments and their agencies have been able to contain the pandemic, their failure to recognise SRHR as an essential service is profound.

SRH clients are among the health seekers who have observed and experienced significant changes in the healthcare system brought about by the COVID-19 pandemic. These changes include the number of clients allowed inside facilities, clinic operations, autonomy in decision-making, and unpredictable SRH services. Institutions need public trust to implement changes. Trust acts as a stand-in for knowledge and adaptive response in the face of uncertain futures and indeterminate threats. Social prevention measures were supposed to enhance safety in health facilities, which in turn would motivate trust in health services and promote the continuity of service promotion and uptake. However, the study shows that, to the contrary, health facilities were perceived as unsafe spaces. At the time, SRH was regarded as not being an illness and its provision a non-essential service. Healthcare providers in public health facilities were keen on implementing preventive measures instituted by governments, such as stay-at-home directives, social distancing, mask wearing and controlling the number of clients in facilities,and denying SRH service provision to clients. Moreover, the government's neglect of private SRH service providers who are legitimate partners, may have contributed to clients' mistrust of healthcare services. Passing on the cost of necessary investments (e.g., in PPE) to clients, increased the cost of services in healthcare facilities.

Other measures that contributed to mistrust in health systems and COVID-19 management included the imposition of punitive measures by law enforcement agents. The institution of government measures increased pressure on law enforcement officers. While COVID-19 containment measures were necessary, travel restrictions to health facilities interfered with access to services, contributing to mistrust in the healthcare system.

The lack of information on COVID-19 posed a significant challenge to containment of the coronavirus. This insufficient information caused public confusion and frustration, and many people felt uninformed and uncertain about the virus and the actions needed to protect themselves and their families. Instead, people looked for information from various media sources, including social media, where they encountered misinformation, rumours, and conspiracy theories, resulting in further confusion and mistrust. Fake cures and treatments for COVID-19 were proposed and shared on social media platforms, while others used social media to target vulnerable people or to spread hatred and fear. Social media has also been used to spread misinformation about the pandemic, leading to public panic and hesitancy in taking needed precautions.

SRHR remains uncertain, as much in crisis as ever, and clients have nowhere to turn. Misinformation and weaknesses in implementing COVID-19 government measures no doubt combined to create fear and reduce trust in SRHR health care. The present situation of COVID-19, and future crises and pandemics needs to sharpen the continuity of SRHR by placing trust at the centre of healthcare.

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Negotiating trust during times of uncertainty: haemophilia and AIDS

Mallika Sekhar and Sushrut Jadhav

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

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[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

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[5] Fox (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.

[6] Atkinson (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.

[7] Trust, n., entered the medical vocabulary in 1398: Bartholomaeus Anglicus wrote *'He [sc. a phisician] hotiþ 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).

[8] Hall *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 mistrust[10] 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

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[9] Pedersen (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.

[10] Armstrong *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.

[11] Resnick (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.

[12] A 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.

[13] FC 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.

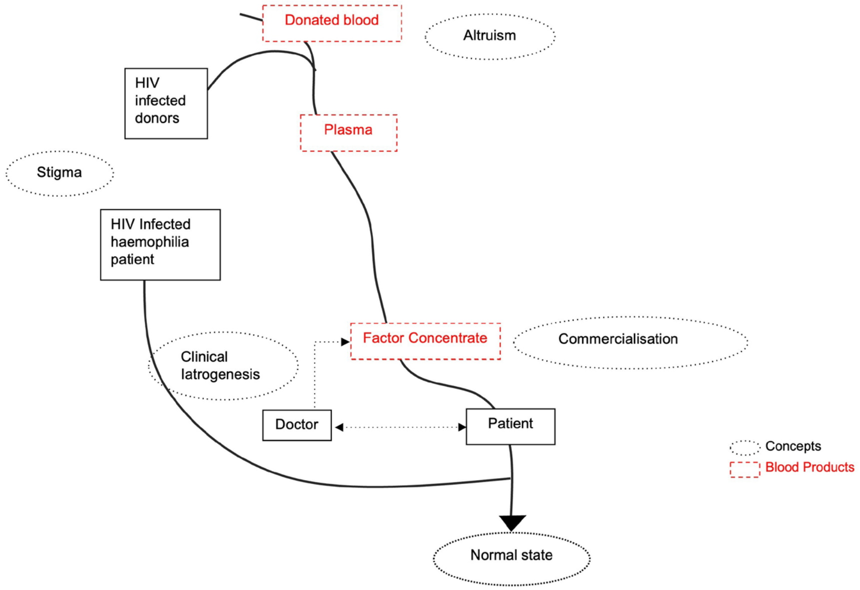

Figure 1: Illustration of connections between people and institutions in haemophilia. Institution 1 and Institution 2, depicting the connections between people and institutions in how the blood flowed through the FC production into the patient's veins; and the key promoters (altruism and the value of 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 normalcy[14] that patients and their physicians had come to expect as standard. It questioned the basis of the TR, even while the relationship continued

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[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 professionalism[16] 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

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

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

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

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

[19] Haemophilia 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 infected[22] 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.

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[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 donors[25] 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

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[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 proceedings[28] 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.

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[28] All 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

[29] The 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.

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

Table 1: (*Cont.*)

Domain	*Emerging themes and subthemes*	*Clinical examples from narratives and testimonies*
Treating haemophilia (*Cont.*)		
	Physicians' emotions	Stigma, fear, blame, anger, sadness, vulnerability
	Engagement	
	of patients	Drop out, death of patients Continuity of therapeutic relationship through the crisis New patients whose relatives had died of AIDS
	of physicians	Poor recruitment into specialty, collegiate support
Communicating with patients		
	Transparency	Delays Limited transmission of information
	Structure	
	channels of communication	Batching patients
	language and vocabulary	Nomenclature of pathogen, breaking bad news, discussion of complex data
	Reassurance, framing	Optimistic stance, denial, euphemisms, using historic models
	Communicating difficult emotions e.g., hopelessness, ambiguity	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.

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[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, Montagnier*[32] *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 prevalence[33] 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 sample[35] 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 between*[36] *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

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[32] Montagnier 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'.

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

[34] For 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.

[35] Given 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).

[36] This 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

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[37] Gabbay 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 1986[38] 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 roles[41] 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.

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

[39] According 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.

[40] Starr (2000)

[41] Sekhar 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 reassurance[42] 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.

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[42] The 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.

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[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 others[45] 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 paternalism[48] and loss of autonomy further contributed to mistrust. There is heightened expression of this at the IBI: forty years on, values of

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[44] Fillion (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.

[45] O'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.'

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

[47] Retained 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).

[48] Paternalism 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

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.

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[49] Hellin (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.

[50] For 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.

[51] As discussed by O'Neil (2002)

[52] Wulff (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.'

[53] Garbutt 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.

[54] The 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

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[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 explored[60] and Bosk has addressed the experiences of the

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[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 treatment[62] among others. Kleinman[63] 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 unreliable[66] 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

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[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]

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[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 studies[74] 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. Wilk[76] 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 iatrogenic[77] 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

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[73] McCabe *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.

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

[75] Fritz & 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.

[76] In 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.

[77] For 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

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[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 iatrogeneic 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 goverment?
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.

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Trusting the permanence of self for people with Alzheimer's disease

Gloria Frisone

Abstract: Although informed consent is rooted in the growing affirmation of the subject's autonomy, medical anthropology has highlighted the inherent limits of this procedural notion. My ethnographic research in neurological and geriatric clinics between France and Italy showed the triangular (dis)trust relationship—between older people with Alzheimer's disease (AD), their doctor, and their caregiver. Following their cognitive decline and loss of autonomy, people with Alzheimer's disease (AD) could be victims of epistemic injustice in two specific moments of the illness: the diagnostic disclosure and the institution of legal protection. If the diagnostic information diminishes the patient's credibility, the institution of legal protection undermines the patient's social identity and legal status. However, when caregivers preserve an unconditional trust in the permanence of the patient's subjective identity, this trust may be conveyed to clinical teams, significantly improving the therapeutic relationship, the course of the disease, and the quality of life for all the actors involved.

Keywords: informed consent, Alzheimer's Disease (AD), cognitive decline, loss of autonomy, diagnostic disclosure, legal protection, (dis)trust relationship, epistemic injustice, social identity, subjective identity.

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Introduction

Informed consent has become an integral part of contemporary medical practice, reflecting an ethical and political commitment that defines the doctor–patient relationship and upholds the growing recognition of individual autonomy. Article 5 of the Convention on Human Rights and Biomedicine (Oviedo, 4 April 1997) asserts the necessity for medical treatments to be administered based on patients' voluntary and informed consent. Simultaneously, Article 35 of the Code of Medical Ethics (2005) emphasises the responsibility of clinicians to ensure patient comprehension. The patient's entitlement to understand the therapeutic process is safeguarded by legal systems in numerous European countries, including laws like the Italian Law of 22 December 2017, and the French Kouchner Law of 4 March 2002 (art. L. 1111-2). Generally, informed consent stands as a fundamental principle in safeguarding patients' well-being. Its unshakable foundation must rest upon the voluntary and conscious decision of the individual undergoing the treatment (Derouesné 2005, Quagliariello & Finn 2016).

Nevertheless, medical anthropologist Sylvie Fainzang (2010) has underscored the inherent limitations of this procedural concept. Drawing from my ethnographic research conducted in neurological and geriatric clinics across France (Frisone 2022) and Italy (Frisone 2017), this article delves into the intricate and ambiguous nature of informed consent for older adults grappling with neurodegenerative conditions, including Alzheimer's disease (AD). According to the Alzheimer's Disease Association (2001), the involvement of family members in the consent process carries significant ethical weight, even when devoid of legal validation (Petrini 2008: 27). Immediate family members are often seen as the most attuned interpreters of the patient's best interests. Nonetheless, in numerous European nations, the consent of family members cannot supplant that of the individual patients (Canavacci 2006).

Background

Interpersonal trust serves as a cognitive framework that exerts influence over human social interactions and economic conduct. Contemporary trust theories draw from behavioural economics and social psychology (McGeer & Pettit 2017). In opposition to neoclassical economic theory (Von Neumann & Morgenstern 1944), which deems trust as irrational due to its non-selfish nature (Camerer 2003), psychological viewpoints examine trust as a product of reciprocal interaction between individual attitudes and societal contexts (Krueger 2009, Lewin 1936).

Consequently, personal credibility becomes pivotal for the acknowledgment of an individual as an autonomous human entity.

My ethnographic study spanning neurological and geriatric clinics in France and Italy elucidated the adverse impact of AD on patients' credibility. In essence, medical practitioners and caregivers encounter difficulty in confiding in AD patients. When cognitive decline challenges the patient's social identity and legal standing, the absence of trustful interactions erodes the fundamental perception of the patient's humanity (Hirsch 2012).

This situation could embody an instance of epistemic injustice. Broadly defined, epistemic injustice occurs whenever an individual's trustworthiness is undermined solely due to their specific identity or social attributes (Fricker 2007). Epistemic injustice involving individuals with dementia and Alzheimer's disease becomes conspicuously evident during two stages of the therapeutic process: the diagnostic disclosure and the establishment of legal guardianship.

In terms of the diagnostic disclosure, the doctor–patient relationship becomes imperilled, jeopardising the patient's credibility. Even in the absence of clinical evidence, AD patients are implicitly perceived as incapable of comprehending medical information (Lechevalier-Hurard 2016). Consequently, medical professionals tend to convey all medical information to the caregiver instead (Weber 2012).

Regarding legal protection, designating the primary caregiver as the legal guardian of the afflicted individual establishes a dependency dynamic (Blum *et al.* 2015, Capuano & Weber 2015). While chronic illnesses already impede legal status, AD notably erodes cognitive capacities and independence in daily activities (Lechowski *et al.* 2005), undermining self-concept and relational abilities (Davis 2004).

During both stages, medical practitioners exhibit minimal trust, if not outright distrust, in the patient's account, which often necessitates validation or supplementation by the caregiver's narrative. Consequently, it is more fitting to characterise the narrative of AD as a collaborative endeavour (Frisone 2022).

In advanced stages, AD can induce cognitive confusion, including episodic memory loss (Ballard *et al.* 2011, Lyketsos *et al.* 2011), alteration of autobiographical memories (El Haj *et al.* 2017), and at times, significant spatiotemporal disorientation, hallucinations, and paranoid delusions that can lead to personality shifts and severe behavioural disruption (Kim *et al.* 2021). This situation initiates a cascade of issues within families, affecting psycho-social equilibrium (Bercot 2003).

Nevertheless, ethnographic research (Frisone 2017) also underscores that, when caregivers maintain unwavering trust in the enduring essence of the patient's identity, this confidence can be conveyed to clinical teams, substantially enhancing the therapeutic relationship and the overall quality of life for all parties involved.

Method

In this article, my aim is to explore the impact of AD on the dynamics of trust and mistrust among the doctor, patient, and caregiver. The arguments presented herein stem from two distinct medical anthropology research projects.

The first ethnographic study encompassed patients, family members, and healthcare personnel across five geriatric clinics situated in Paris and its suburbs. Employing a multi-sited ethnographic approach (Hannerz 2003, Marcus 1986, 1995)[1] I conducted research within a diverse array of healthcare settings, including: 1) the neurology department of an outlying academic hospital; 2) a smaller-scale geriatric hospital within one of the more economically challenged and densely populated northern suburbs of Paris; 3) a geriatric facility located within a privileged district of the city centre; 4) an internationally renowned institute specialising in neurodegenerative disease diagnosis; and 5) an association comprised of neurologists, neuropsychologists, and nurses delivering private diagnoses and treatments across urban and peri-urban domains.[2] This investigation encompassed varying socio-economic and ethnic backgrounds. On one hand, it involved the working-class, heavily industrialised, and culturally diverse neighbourhoods of the Parisian outskirts. Conversely, it concentrated on the affluent urban populace with elevated socio-economic status and French heritage. By integrating with diverse hospital teams, I observed the activities of physicians, geriatricians, neurologists, neuropsychologists, nurses, and other professionals dedicated to neurodegenerative disease care. Through in-depth, semi-structured interviews, I elicited their experiences and reflections. Moreover, occasional interactions with patients and their families transpired amidst clinical sessions. This ethnography explores the

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[1] Muti-sited ethnographies marked the transition from a traditional anthropology based on intensive 'single-site' studies, to a contemporary ethnography, settled in cross-cultural and cross-national contexts to highlight the complex relationships and interconnections between the local and the global (Marcus 1995). According to Ulf Hannertz (2003), the univocal but still hierarchical relations between local and global can locate both along transnational routes and within narrower national and local contexts. In the present case, the socio-cultural, economic, and ethnic characteristics of each of the sites considered delineate radically diverse clinical settings in terms of the demographic composition of staff and users, health services, diagnostic devices, local prevention and care policies, treatment practices, and power relations between patients and therapists.

[2] The description of the locations is deliberately imprecise to respect the privacy and ensure the anonymity of health professionals and their patients.

historical, cultural, and political underpinnings of discourses that frame AD within the context of de-subjectification and self-loss (Kontos 2006).

The second ethnographic study was conducted within a nursing home in northern Italy. This investigation centred on the interplay among a woman exhibiting a logopaedic variant of AD (referred to as 'Manuela'), her psychotherapist ('Lorella'), and her daughter ('Elena'). Despite its relatively brief duration of six months, this fieldwork exhibited a high level of immersion, focusing on the construction of subjectivities, personal perceptions of illness, and an extensive collection of life narratives. To achieve this, I engaged with the three women twice a week, opting for unstructured and extended interviews that were intentionally not recorded to foster a natural, spontaneous dialogue with my interlocutors. Lorella shared the challenges she encountered in working with this patient due to her language deficits; Elena openly discussed her personal experiences and relationship with her mother; ultimately, interactions with Manuela occurred predominantly through non-verbal communication. Additionally, I conducted participatory observations of clinical interactions and periodic sessions involving an innovative cognitive stimulation technique known as 'window therapy'.

Findings and discussion

Diagnostic disclosure

The initiation of any therapeutic relationship is invariably marked by the disclosure of a diagnosis. During my participant observation within clinical settings, I had the opportunity to delve into diagnostic meetings among the multidisciplinary team members of the hospital, encompassing neurologists, geriatricians, psychologists, nurses, and social workers. My research unveiled that each professional employs specific approaches to collect clinical data, which are then synthesised to formulate a multidisciplinary diagnosis. Neuropsychologists administer memory tests to differentiate between normal and pathological cognitive aging, neurologists scrutinise brain imaging scans to detect the presence of lesions like amyloid plaques and neurofibrillary tangles around the hippocampus—the organ responsible for memory storage—and geriatricians evaluate whether the patient's physical and psychological vulnerabilities can be attributed to physiological aging or neurodegenerative disease. This concise overview demonstrates how memory-related issues enable clinicians to differentiate between physiological aging and conditions such as AD and other neurodegenerative disorders (Jahn 2013, McKhann *et al*. 2011).

According to medical anthropology research (Lock 2013), diagnosing AD is a multifaceted process involving an array of clinical data. Nevertheless, conveying such a diagnosis can be an even more intricate endeavour. Research from the United States has indicated that AD is communicated to patients in only around 40% of cases (Johnson *et al*. 2000, Pinner 2000). Studies in the United Kingdom have previously revealed that the diagnosis of AD is communicated less transparently compared to other grave illnesses like cancer (Vassilas & Donaldson 1998) or schizophrenia (Clafferty *et al*. 1998). Generally, it is easier to inform family members than the patients themselves. In line with a British study conducted among general practitioners, only 55% of patients are informed concurrently with their families (Downs *et al*. 2002), while the figure stands at 53% on a European scale. How can we explain doctors' reluctance to disclose AD diagnoses to patients? On one hand, this hesitance might stem from the chronic and irreversible nature of the disease. On the other hand, there is a distinct peculiarity in the context of AD.

All individuals grappling with chronic conditions inevitably undergo a transformation from their previous social roles to the perpetual status of the ill[3] (Weisz 2003). However, this phenomenon is particularly pronounced in AD cases (Weber 2012). Indeed, the diagnosis of AD accentuates intellectual capabilities and relational competencies, which have long been viewed as fundamental components of human identity since the days of John Locke (Douglas 1992, Hacking 1995). Cognitive deficits can severely impede the faculties upon which this notion of personhood is founded. These faculties constitute the bedrock of a concept of humanity anchored in autonomy, self-awareness, and liberty (Derouesné 2005: 119). Therefore, family members often become the primary interpreters of the patient's condition. As a neurologist at a suburban academic hospital aptly put it: '*The family frequently interprets and conveys the complaints as the patient may struggle to articulate or describe their difficulties'* (ethnographic interview, 8 August 2017).

According to professionals, patients are often incapable of recognising their own disorders and may even reject the diagnostic disclosure. Neurologists categorise this attitude as one of the symptoms of AD, a phenomenon referred to as 'anosognosia'. A geriatric neurologist, discussing most of her patients, explained, '*It's often others who notice memory problems*' (ethnographic interview, 2 June

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[3] The American sociologist Talcott Parsons (1951) was the first to define the 'role of the sick' in modern society. The role of the sick allows the individual not to be delegitimised in society and not to be considered deviant or antisocial. From the social point of view, sickness is perceived as an alteration of the person's social status: it marks a suspicion of the patient's social life, functions, and obligations. The diagnosis removes responsibility from the sick person, who is called upon to be a passive subject into a society of active individuals (Friedson 1970).

2017). Simultaneously, patients are often prone to paranoia: '*They sometimes believe that others are plotting against them*', shared a neuropsychologist from a reputable Paris hospital (ethnographic interview, 5 December 2017).

The erosion of trustworthiness envelops patients due to their cognitive and memory impairments, which in turn fosters scepticism among medical professionals regarding their accounts of illness. Consequently, patients' voices are marginalised, and caregivers are given more weight in discussions. This is despite legislative and ethical frameworks urging healthcare practitioners to communicate patients' health conditions to the patients themselves. For certain practitioners, the 'right to know' is deemed as crucial as the right 'not to know' (Derouesné 2005: 121). The task of disclosing 'the truth' about the disease often makes doctors uncomfortable. When faced with this legal and ethical obligation, a geriatrician acknowledged that early in his career, he found this responsibility particularly challenging: '*I found it difficult to convey things because it led to many conflicts*' (ethnographic interview, 1 August 2017).

The physician tasked with conveying the progressive decline of these cognitive faculties finds themselves in a paradoxical position: they must respect the patient's dignity even as they deliver a diagnosis that will inevitably disrupt that very dignity. Unfortunately, legislative guidance seldom resolves these ethical quandaries. Consequently, announcing the diagnosis of AD remains an especially complex and delicate undertaking.

The institute of legal protection

As seen, the AD patient embodies the quintessential depiction of a chronic patient (Attias-Donfut 1997). Diagnosed with a condition that debilitates cognitive functions, language, reasoning, and memory, those with AD find themselves relegated to the passive role of dependent individuals (Capuano & Weber 2015).

Typically, a dependent person loses the capacity to make decisions and assess potential hazards for themselves and others (Trabut & Weber 2009). When older individuals are deemed non-autonomous due to their deteriorating health, legal protective measures are enacted. These measures often involve assigning a legal guardian, commonly a family member. French legislation equates the legal status of older adults with dementia to that of individuals with disabilities (Capuano & Weber 2015).[4] In both scenarios, the establishment of a formal dependency

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[4] Law 11 February 2005: 'For the purposes of the present law, a disability is any limitation of activity or restriction of participation in society experienced by a person in his or her environment due to a substantial, lasting or definitive impairment of one or more physical, sensory, mental, cognitive or psychological functions, a multiple disability or a disabling health disorder' (author's translation).

relationship between the person unable to cater to their own needs and their legal guardian becomes necessary (Capuano 2014).[5] On the other hand, Italian legislation maintains a clear distinction between these two situations while extending legal protection to all those incapables of self-sufficiency, including those with AD.[6]

Although families frequently receive assistance from a variety of medical, social, and legal professionals (Blum *et al.* 2015), transitioning from autonomy to dependence is challenging for both patients and their relatives. For the younger population, lack of autonomy is a constant state, while for older individuals, entering a state of dependence is marked by the gradual loss of the capacity to act (Le Borgne-Uguen & Pennec 2004: 70). Consequently, dependent older adults forfeit their legal status as citizens.

The judiciary typically relies on a medical certificate to institute legal guardianship for AD patients. From this point forward, the individual with the illness forms two care relationships: an official one with the doctor and an informal one with the caregiver. This division between formal and informal care relationships aligns with Joan Tronto's (1993) conceptualisation. The care relationship involves the caregiver taking on responsibility for the person in their care while also exerting influence over them. This dynamic establishes a dichotomy between an active and a passive subject.

This relationship of dependence and care between patients and caregivers is a significant consideration for medical professionals. My research unveiled that doctors are only occasionally willing to place trust in AD patients. The erosion of AD patients' credibility, often due to memory loss, prompts doctors to supplement their illness narratives with information from the caregiver. Consequently, accounts of AD rarely reflect the patient's subjective viewpoint. Instead, they emerge as co-interpretations of symptoms, engaging in the negotiation of meanings (Frisone 2002). The perspective of illness in this context does not solely emerge as a personal account; rather, it embodies multiple viewpoints that converge in an intersubjective co-narration. Furthermore, the caregiver subtly morphs into a co-narrator of the patient's story. This co-narration underscores how illness narratives evolve into a collective narrative of intersubjective illness that shapes and is shaped by familial caregiving.

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[5] Law 5 March 5 2007: persons requiring legal protection are 'unable to look after their own interests due to a medically diagnosed impairment of either their mental faculties or their physical faculties such as to prevent them from expressing their wishes' (author's translation).

[6] Law 9 January 2004 'aims to protect, with the least possible limitation of the capacity to act, people deprived in whole or in part of autonomy in the performance of the functions of daily life, through temporary or permanent support interventions' (author's translation).

Take the case of Mr Leroy[7] an 85-year-old man admitted to a geriatric psychiatry department following a two-year history of AD prompted by a stroke. He consistently references his wife's opinions. This infusion of the caregiver's perspective aligns with the behaviour of most patients and reflects their mistrust of their own viewpoint. The recent memory loss distresses the patient, leading him to contemplate a future where his autonomy fades and he becomes a burden to his family. This sensation of being burdensome can either translate into guilt toward others or invoke a rejection of the dependence, often manifested as aggressive reactions.

The possibility of memory loss deeply concerns both patients and caregivers. Patients convey that their memory problems extend beyond recent memory to encompass older memories. Simultaneously, family caregivers dread memory lapses affecting daily life that might jeopardise the patient's safety or their own. Consequently, mutual trust in their love becomes precarious for both the caregiver and the patient.

This co-narration of illness brings to light the 'moral economy' of AD, or more specifically, the interplay between contemporary moral norms and the societal concept of AD. As described by Didier Fassin (2009), 'moral economy' refers to the exchange of values, emotions, and affections within the realm of daily relationships. The nexus between memory and value is implicit in the moral economy of familial caregiving relationships. Elements of crucial value and profound meaning need to be retained and remembered. From this perspective, the most distressing prospect for caregivers is the loss of memories that constitute shared histories with their afflicted family members.

However, the power of the diagnostic pronouncement ostensibly absolves the AD patient of responsibility for forgetting. In exchange, their credibility is undermined, and they become innocent victims of their ailment. Conversely, caregivers are cast in the role of sacrificial victims who dedicate themselves to caregiving duties. Thus, within this localised 'moral world' (Kleinman & Van Der Geest 2009), patients grapple with the sense of losing their autonomy and becoming burdens, while caregivers embrace the role of dedicated caretakers.

Simultaneously, this perspective leads caregivers to perceive the afflicted person as someone who is no longer their former self—a person who has vanished. A sense of pre-emptive mourning pervades caregivers. Nonetheless, as the subsequent paragraph will delve into, caregivers may continue to recognise the patient's subjectivity and maintain trust in the continuity of self.

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[7] The last name of the patient is fictive to guarantee his anonymity.

The permanence of subjective identity

In another ethnographic study conducted (Frisone 2017), the focus shifted to a private residence in northern Italy catering to older adults with AD or other neurodegenerative conditions. This research specifically examined the triadic relationship between a patient named Manuela, her daughter Elena, and the psychotherapist (Lorella).[8] The facility operated with a dual clinical and supportive approach, offering medical and psychological care for chronic aging-related disorders.

Emphasis was placed on non-pharmacological treatments, with a focus on cognitive and mnemonic stimulation techniques that extensively utilised autobiographical prompts. This context highlighted the unique mother–daughter relationship where mutual recognition bolstered the memory of their shared history. Furthermore, the growing emphasis on patient-centred care prompted an exploration of the patient's relational and social dimensions. Lorella, the clinical psychologist at the residence, exemplified this approach through her professional practice.

Lorella's initial interaction with Manuela was somewhat superficial. Initially tasked with administering neuro-cognitive tests, Lorella struggled to establish rapport with Manuela, who had a compromised ability for verbal expression due to her logopedic variant of AD. This deficiency in verbal language hindered the early therapeutic relationship. However, upon the intervention of Manuela's daughter Elena, Lorella's perspective gradually evolved. Elena accompanied her mother to group sessions and engaged with her, assisting in answering questions and solving basic exercises. Although significant improvements in correct answers were not achieved, Elena maintained a steadfast belief in her mother's ability to comprehend her surroundings. With time, Lorella recommended an individualised therapy for Manuela, integrating autobiographical psychotherapies and motor–cognitive stimulation. This marked the turning point where Lorella became a central figure for both Manuela and Elena, ultimately leading to the formation of a 'therapeutic triad'.

Elena's unwavering presence and commitment to her mother's care were notable. Despite her mother's verbal limitations, Elena continued to visit regularly, driven not by guilt or duty but by an innate need. Elena refused to perceive her mother as completely changed, recognising that while their relationship had evolved due to the illness, it remained profound and essential. '*I stay her daughter, she stays my mother, and this really cannot change*' (ethnographic interview, 4 May 2018), she said. This acceptance allowed Elena to adapt to their new dynamic, finding significance in her role as both a daughter and a caregiver. This shift in perspective nurtured a unique and meaningful bond between them.

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[8] Once again, fictitious names are chosen to guarantee people's anonymity.

From an anthropological point of view, believing does not necessarily concern objective reality (Needham 1972: 69). This steadfast trust in the continuity of Manuela's sense of self by Elena mirrored a type of 'faith'. This isn't an irrational belief but rather a 'truth of reason', which doesn't require empirical validation. Instead, it is reinforced daily through repeated behaviours that confirm its validity (Frisone 2017: 108). Elena's trust in her mother's constancy did not arise from empirical observations but presupposed those observations, reaffirming her trust over time.

Conclusion

As highlighted in this article, the contrast between the politics of informed consent and clinical practice becomes apparent when dealing with Alzheimer's disease (AD). Healthcare professionals, including neurologists, geriatricians, and neuropsychologists, often choose to communicate and interact with the family members of AD patients rather than the patients themselves. This tendency stems from the erosion of credibility that AD patients experience due to cognitive deficits and memory loss, leading to a strained therapeutic relationship built on trust. This situation gives rise to an epistemic injustice, where doctors implicitly distrust AD patients due to presumed mental deficits, thereby focusing their attention primarily on caregivers.

This epistemic injustice manifests prominently during two critical moments: the diagnostic disclosure and the legal protection process for AD patients under the guardianship of caregivers. The former moment involves the medical diagnosis, which relegates the patient's complaints to pathological symptoms, such as anosognosia, thereby diminishing the patient's autonomy. The latter involves the legal transfer of the patient's illness narrative to a family member, resulting in an illness co-narration. Both instances signify a transformation of roles—the patient from a free and autonomous citizen to a dependent individual, and the caregiver into a dedicated caretaker.

This transition disrupts mutual recognition and the moral economy surrounding AD, absolving both patients and caregivers from guilt. The new moral economy often revolves around the familial relationship between patients and caregivers, accentuating their roles as victims, one innocent and dependent, the other sacrificial and devoted.

However, the story of Manuela and Elena presents an alternative representation of the AD patient. Their narrative unveils a unique moral economy. Elena's approach to caregiving defies the traditional roles—she cares for her mother without seeing her as solely passive and dependent. She embraces her new role as a 'daughter–mother' without exploiting her mother's vulnerability. Elena's refusal to be cast as a sacrificial victim prevents the mother's characterisation as an innocent victim. Despite AD's challenges, Manuela's subjectivity remains intact, and all perceive her presence in its fullness.

In conclusion, Elena's unwavering trust in Manuela's subjective identity is intricately woven into their relationship. This trust forms a circular and narrative loop where Manuela's recognition of herself relies on her daughter's recognition and vice versa. As a shared experience, memory reinforces their bond, making the mother–daughter relationship resilient to the effects of AD. Their mutual story remains open-ended and continually evolving.

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Living with illness uncertainty: nature cure caregiving in Kerala, South India

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Abstract: First promoted in India as part of M.K. Gandhi's anti-colonial project, nature cure (*prakr̥ti jīvanaṁ*) draws on the metaphor of vitality to frame the body as having a natural wisdom—a vital force—that works to restore health and balance. In Kerala, South India, patients forge mentorships with nature cure healers to repair their ill bodies, revive the toxic environment, and respond to moral collapse. Based on long-term ethnographic fieldwork, this paper offers a person-centred analysis of one practitioner, Dr Vinod, as he instils trust in two chronically ill patients facing uncertain futures. First, I demonstrate the limits of public categorisations of alternative medicines in India for representing the multiplicity of healers and their care strategies. Despite nature cure being outwardly centred as a mode of self-healing, Dr Vinod does not engage liberal conceptions of autonomy and independence, nor does he solely critique biomedicine. Rather, Dr Vinod attends to patients' histories and the specific arrangements of kinship, caste, class, and gender shaping their vulnerabilities, to transform feelings of doubt into those of trust amid illness uncertainty. In this way, alternative healers hold the capacity to reconfigure socially embedded lives. Second, to illuminate how naturopathic care tactics reveal the relational dimensions of illness experience, I draw on and expand the work of philosopher Havi Carel. Carel argues that bodily doubt shapes the experience of chronic illness in three ways: loss of faith in one's body, loss of transparency, and loss of continuity. Engaging with Cheryl Mattingly's approach to narrative phenomenology, I demonstrate how Dr Vinod moves a step further, asking how articulations of illness and loss are inherently intersubjective. Empathetic to his patients' social worlds, Dr Vinod gently intervenes in their lives, forging therapeutic ties to support them—all the while outwardly claiming that the locus of healing lies in the self.

Keywords: care, nature cure, naturopathy, alternative medicine, illness experience, illness narratives, Kerala, South India

Note on the author: Victoria Sheldon holds a PhD in Anthropology with a Collaborative Specialization in South Asian Studies from the University of Toronto. Her thesis, "Vital Bodies, Natural Cures: Moral Quests for Care in Kerala, South India," examines how nature cure healers and users engage a collectivized vision of wellness and self-care, ethnographically bringing into relief the ways that biomedicine does not in itself equate to effective rehabilitation. She currently works as an Educational Developer & Learning Strategist at the University of Toronto.

“Iṟakkaṁ uṇṭeṅkil, ēṟṟavuṁ uṇṭ”
[*If things come down, they will also definitely go up.*]

Malayalam proverb[1]

Rakesh became unwell two years back. From body pain and dizziness to exhaustion and the inability to digest food, he could never, even for a minute, forget his condition. Soon, he was so sick that he had to drop his music studies in Bangalore and return to his family in Kozhikode, Kerala. One biomedical doctor declared pancreatic cancer. Another said chronic pancreatitis. From one expensive private hospital to another, Rakesh’s mother Lakshmi struggled to generate certainty.

Lakshmi had three choices: admit Rakesh into an affordable public hospital that lacks amenities, spend money at yet another private hospital, or experiment with an affordable alternative. When she saw a TV advertisement for Dr Vinod’s family-run nature cure (*prakr̥ti jīvanam*)[2] hospital-home, Swasam, she knew that it was the right choice; his warm insistence that all diseases are caused by the same issue—reduced vital force—won her over.

While this hospital-home is sparse in all technologies, it brims with medicinal plants, lush walking paths, hydrotherapy baths, and warm conversation. Meaning ‘breath’ in Malayalam, Swasam is a respite from city life. Rakesh has been living here for a month, and with that in mind, Dr Vinod has planned a special trip. It wasn’t easy, but he got him a face-to-face consultation with Mohanan Vaidyar:[3] the famous herbal *nāṭan cikista*[4] healer; a man as charismatic as he is controversial. He has made a name for himself through Facebook, WhatsApp, and YouTube, where he makes bold criticisms of biomedicine as the ‘Medical Mafia’ and advocates that cancer can be cured through strictly natural methods. Dr Vinod set up this meeting

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[1] When a person is suffering and in a challenging situation, a Malayalam speaker may use this proverb to help inspire them to develop a more optimistic perspective. Malayalam is the language of Kerala, South India. Malayalis are the Malayalam speakers of Kerala.

[2] First promoted in India as part of M.K. Gandhi’s anti-colonial project, nature cure uses the metaphor of vitality to frame the body as having a natural wisdom that works to non-invasively restore health and balance. Practitioners in Kerala refer to this medical tradition as naturopathy, nature cure (*prakr̥ti cikitsa*), natural life (*prakr̥ti jīvitam*), or natural living (*prakr̥ti jīvanam*). In Malayalam, natural living (*prakr̥ti jīvanam*) is most used, and at once refers to individual therapies, natural farming, and environmental advocacy.

[3] As a public figure, Mohanan Vaidyar’s name has not been changed. All other names of persons and institutions have been changed.

[4] Mohanan Vaidyar shifts between identifying as a nature cure or *prakr̥ti jīvanaṁ* healer and as a *nāṭan cikista* practitioner. This latter term means ‘local therapy’ and may also refer to other non-professionalised folk healers. Before he passed away from COVID-19, he was jailed several times for spreading controversial information about vaccinations. For more information, see:
https://culanth.org/fieldsights/covid-19-in-kerala-nature-cure-social-media-and-subaltern-health-activism.

as a creative care strategy: he wants Rakesh to receive a new naturopathic prognosis and care regimen, to replace looming doubt with trust.

With the goal of learning more about naturopathic caregiving, I, as participant observer, join Dr Vinod and Rakesh on this trip, along with Rakesh's brother and Sajitha—the young doctor-in-training at Swasam. Ever perceptive, Dr Vinod is aware of her fondness for Rakesh; by bringing her along, he aims to create the conditions for them to connect. He acknowledges that if they get married, it will bring a double improvement: Sajitha will rise from her marginalised caste and class position, and Rakesh will gain what Dr Vinod calls the '*faith*' (*viśvāsaṁ*) necessary to get well.

The trip begins. Helping Rakesh into the passenger seat, Dr Vinod says, '*What your body needs to get cured, he* [Mohanan Vaidyar] *will say*.' To speak about cure, Dr Vinod uses the verb '*disease change* [*rēāgaṁ māṟuka*]'. This connotes a more gradual end-goal of illness transcendence; he does not promise that any specific intervention or mind frame will ensure a sudden freedom from disease.

Introduction: Living with illness uncertainty

This article foregrounds the ethical stakes of rehabilitation. I demonstrate how alternative medicine in India hinges on diverse approaches to interpersonal care and narratives of possibility, even if practitioners publicly align in political stances and orientations to the body. While Mohanan Vaidyar and Dr Vinod both publicly identify as nature cure healers, their charisma, care strategies, and expressions of empathy differ greatly. With a magnetic presence, Mohanan Vaidyar claims to be a '*food adulteration consultant*', uncovering the poisonous contents of popular modern commodities: Tang juice contains paint chips; store-bought ayurvedic medicines are laced with pesticides; and pre-made masala powders cause cancer. Well versed in social media, he also provides how-to videos for Malayalis on reversing bad health habits and solving chronic conditions—as mild as pimples and constipation, and as serious as cancer and diabetes. In all this, Mohanan Vaidyar—like other nature cure healers—identifies as a Gandhian, committed to manifesting the principle of *swaraj* (self-rule) in everyday life by supporting persons' self-governance in individual and community life.[5] While Dr Vinod also holds a similar official orientation toward local living, his prime concern is not

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[5] Drawing on Gandhi's reinterpretation of European naturopathic literature through the lens of yogic theory, nature cure healers in Kerala teach that the body is 'a microcosm of the larger world', imbuing Gandhi's assertion that humans have a responsibility to act in harmony with nature, in relation to their own concerns of stewardship and toxicity (Slate 2019: 4).

public. Instead, he aims to rehabilitate his patients within their social worlds, so that they learn to live with faith (*viśvāsaṁ*) in their life paths. And unlike Mohanan Vaidyar, Dr Vinod is not so liberal in promising complete cures, nor does he univocally place responsibility on patients when their health conditions do not improve.[6] Instead, he is more like a palliative care physician, striving to 'see through the patient's eyes' as he relieves suffering (Banerjee 2020: 91).

In making this argument about the limits of public categorisations of medical systems for representing on-the-ground care strategies, I also demonstrate how nature cure therapy, despite hinging on narratives of self-healing, is not rooted in liberal conceptions of autonomy and independence, nor does it primarily serve as a reactionary critique of failed biomedical interventions. In Kerala, this medical tradition instead invokes a 'radical scalar integration of ethical stakes for self and society', making the independent detoxification of bodies a politicised space for negotiating environmental and social change (Mathias 2020: 257). In addition, practitioners like Dr Vinod move beyond the overt political realm, to ask how the process of detoxification is embedded in a patient's wider social world. This runs counter to contemporary biomedical regimes, which have been said to 'hollow out the self', where 'society is reduced to a conventional middle-class vision in which individual threats are removed from local worlds, to be managed by drugs and other new technologies of the person' (Biehl *et al.* 2007: 11). Dr Vinod consistently works in counterpoint to biomedical processes, undertaking interactions and narratives that acknowledge personal histories, vulnerabilities, and local cultural values. As he restructures patients' lives, he attends to their prior histories and the specific arrangements of kinship, caste, class, gender, and voice shaping their experiences. In this way, Dr Vinod is sensitive, recognising how illness may come to be 'diffused throughout an existing social field, all the while absorbing, augmenting, or hardening prior vulnerabilities' (Banerjee 2020: 80).

To represent the relationality underpinning Dr Vinod's care strategies, I focus on two of his patients: Rakesh and Soumya. In both of their lives, Dr Vinod addresses their situational challenges, emotional concerns, and structural barriers, with the aim of instilling in them a newfound subjunctive mood. Counter to the 'world-destroying' nature of illness and loss (Scarry 1985), this hopeful orientation toward reality allows for 'traffic in human possibilities rather than certainties, keeping alive multiple perspectives, emotions, and moods as a way to cope with

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[6] While nature cure practitioners often claim that faith plays a role in recovery, they do not necessarily blame those who encounter disability or death. Rather, as nature cure practice hinges on the notion of detoxification from social and environmental toxins, healers often link illness causation to factors outside of one's control. In this way, healers commonly articulate a vision of the embeddedness of humans in their environment, where toxins and environmental changes play a defining role in explaining health challenges.

the harm of disease' (Banerjee 2020: 7). Hence, the subjunctive mood indexes strategies through which illness sufferers draw upon an available body of cultural knowledge so to 'emplot' their condition in relation to possible desired outcomes (Good & Good 1994: 838). For Dr Vinod's more chronic patients, these strategies are critical, given the ways in which feelings of illness uncertainty have prevented them from ascribing clarity and meaning to their experiences (Mishel 1988). As I will demonstrate, Dr Vinod's 'subjunctivising' tactics are personalised to particular social worlds: rather than apply a single blueprint of action for inspiring his patients to focus on 'as-if' outcomes as opposed to terminal prognoses, he recognises how needs are always grounded in the 'temporality of individuals and families and communities' (Good & Good 1994: 841). Empathic and receptive, Dr Vinod's therapeutic interactions intervene in kinship ties and social inequities, to transform feelings of doubt and uncertainty into those of trust and possibility, where one accepts the space of indeterminacy surrounding illness diagnosis.

In examining how Dr Vinod works within patients' social worlds to instil in them indeterministic outlooks, I draw on and expand the work of philosopher Havi Carel. In *Phenomenology of Illness*, Carel (2016: 2) explores the 'existential, ethical, and social dimensions' of illness as a lived experience. Chronic illness causes perceptions of space and time to shift, and so demands philosophical attention concerning how one understands 'the world, [and their] fundamental beliefs, habits, and expectations' (4). By approaching illness as a philosophical tool, Carel improves our understanding of a concrete aspect of human experience. To illuminate the relational dimensions of illness experience, I engage with Carel's specific argument on how illness breaks down certainty concerning everyday embodied experience. Carel argues that, because of chronic illness, bodily doubt comes to the fore and radically modifies experience in three ways: loss of faith in one's body, loss of transparency, and loss of continuity (96). While Dr Vinod acknowledges how his patients' illnesses influence their perspectives of these factors, he works 'within and through the fragile social ties within which … disease[s] often takes shape' (Banerjee 2020: 141); in doing this, he does not accept chronic illness experience as unitary. Like an anthropologist, Dr Vinod asks how what it means to live and to die is rooted in a particular time and space.

To examine how naturopathic caregivers like Dr Vinod frame illness experience in terms of interpersonal action, I methodologically engage with the genre of narrative phenomenology. According to Cheryl Mattingly (2010: 7), this method 'not only recognizes the macro structural dimensions of our social existence (the way discursive regimes are embodied and played out in everyday social practice) but also foregrounds the personal, intimate, singular, and eventful qualities of social life'. The following ethnographic scenes draw on narratives collected from semi-structured interviews and participant observation across thirty months of continuous fieldwork and Malayalam language study from 2014 to 2017, where I lived in a nature cure hospital-home, attended health camps and demonstrations, and followed patients and healers across living contexts. Findings are also based on two follow-up returns in 2017 and 2019. Rooted in a person-centred analysis throughout, each scene constitutes an instance of what Cheryl Mattingly has termed ‘moral laboratories’. These are the metaphorical realms, revealed through interpersonal interactions, that serve as spaces for social experiment, moral critique, or personal transformation, enabling the unfolding of lives and ongoing moral becoming (2014: 17).

Scene 1: Generating trust

Dr Vinod brings spirited conversation to our three-hour drive, sharing jokes, singing songs, and narrating the phone call he had with Mohanan Vaidyar that morning. Rakesh is quiet, resting in the passenger seat. Without air conditioning, the smell of overripe plantains permeates the car. Given Dr Vinod’s height, his head of carefully combed hair, parted to the side, nearly hits the jeep’s roof. His white beard is well maintained, just as are his collared shirt and khaki slacks. It is hard to imagine that the tiny briefcase on his lap holds all he needs to travel from district to district for days at a stretch, to teach classes, visit patients, and to provide raw food cooking demonstrations. In his shirt pocket is a bamboo pen, inscribed with the face of Gandhi, signalling that he, like other nature cure healers, is politically committed to *swaraj* or self-rule.[7] Sajitha, dressed in a new *kurta* dress set, braids her freshly washed hair; the smell of coconut oil lingers. Entering her mid-twenties, she has been working for Dr Vinod for a year. Knowing her challenges back home, Dr Vinod insists that she live full-time at Swasam.

It was not difficult to find Mohanan Vaidyar: his house is on a street named after him. He is routinely in the media, whether to promote organic farming or to critique biomedicine. And he is a familiar face among the police; his promises of quick cures have resulted in more than one death. Yet even though he is famous, Mohanan Vaidyar’s medical lineage remains unclear. He uses the title *vaidyar*, which is reserved for hereditary medical experts, but has not confirmed any genealogical authority. Amid these uncertainties, his home remains simple and welcoming,

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[7] In the text *Hind Swaraj*, Gandhi outlines the necessary steps for Indians to develop freedom from British rule. He argues that, to exert passive resistance, Indians must exercise Swadeshi or homegrown self-reliance, and thus refuse all trade and dealings with the British. A key part of this is not consuming non-Indian products, which nature cure healers in Kerala consistently emphasise in their health and political undertakings.

without the ostentatious decorum of other houses in Kerala, built on huge plots of land due to the help of remittances from family abroad. Instead, it reminds me of Dr Vinod's natal home, constructed and organised according to the *vastu śāstra*, the traditional Indian science of architecture.[8]

As we get out of the jeep, Mohanan Vaidyar stands on the other side of the ten-foot-high gate. All in white, he wears a *muṇḍu*[9] and crisp, linen shirt. His smile in person is as beaming as it is online. Yet unlike his videos, I notice that his hair is dyed black, the grey roots coming through. As Dr Vinod greets Mohanan Vaidyar, he also helps Rakesh get out of the car, bracing his arms. Once we pass through the gate, we enter another world. I soon learn that the porch we sit on is also his stage when giving twice-weekly lectures. Patients and their kin from across Kerala make the long trek here to receive a consultation, with medical biopsies, X-rays, and urine samples in hand. He brands his method as '*kitchen medicine*', claiming that women's home-remedies are the most original source of health authority.[10] In the same way that Samuel Thomson reworked botanic and domestic medicine in 18th-century United States into his brand of Thomsonianism (Cayleff 2016: 18), Mohanan Vaidyar aspires to reframe indigenous and home therapeutics in relation to his own proclamations surrounding natural diagnosis, cure, and prevention. Yet, while Thomsonianism provided space for women to become respected practitioners, Mohanan Vaidyar's feminist interventions stop at the claim that women are a traditional resource for authentic medical knowledge.

Even though the trip has been orchestrated for Rakesh's benefit, Mohanan Vaidyar does not focus on him for the first hour. Instead, he provides us with an impromptu lecture. The topic: India's colonial history of medical corruption. Laid out on a side table are several laminated reports, blown up to triple their size. Such artifacts are common for his speeches. Mohanan Vaidyar first shows us a printout of the 1835 Macaulay's Minutes for Education, which he claims involved the British trying to systematically destroy Indian knowledge of science and literature.[11] Here, he asks

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[8] While others link this method to Hindu beliefs, Dr Vinod frames it in a more ecumenical way, in relation to following the universal principles of natural living or *prakṛti jīvanam*.

[9] A *muṇḍu* is a male garment worn in Kerala that is made of a rectangular piece of cloth. It is wrapped around the waist and legs and knotted at the waist.

[10] When Mohanan Vaidyar uses the term '*kitchen medicine*', he refers to women being a source of authority in therapy, on the basis that they are food providers, who are intimately familiar with spices, herbs, and their functions.

[11] British historian and politician Thomas Babington Macaulay presented this text in 1835, to establish the need to impart English education to Indian 'natives'. In it, he framed Indian knowledge, languages, and scientific research as worthless. He wrote that: '… a single shelf of a good European library was worth the whole native literature of India and Arabia'. For more information, see: http://www.columbia.edu/itc/mealac/pritchett/00generallinks/macaulay/txt_minute_education_1835.html.

Rakesh to read out the line, ‘We have to educate a people who cannot at present be educated by means of their mother-tongue.’ Mohanan Vaidyar then translates that statement into Malayalam, to make his wider argument that, like such English language initiatives, teaching English medicine—biomedicine—is part of an ongoing colonial project.

Moving fast, Mohanan Vaidyar then shows us an agreement form that he claims chemotherapy patients must sign in India. He asks me to read out the English-language disclaimer, where it claims that the ‘surgery will not guarantee any cure’. Mohanan Vaidyar adds in Malayalam: ‘*There is a better chance at cure with naturopathy because improvement is certain!*’ Building on this, Mohanan Vaidyar ends by showing us printouts of The Drugs and Cosmetics Act of 1940, The Drugs and Cosmetics Rule of 1945, and The Drug Prices Control Order in 1995, as well as a list entitled, ‘51 Diseases and Ailments which a Drug Must not Purport to Prevent or Cure’. He asks me to read out the list, which includes diabetes, blindness, arteriosclerosis, glaucoma, hernias, and leukemia, among others. These illnesses, Mohanan Vaidyar tells us, are what natural and herbal remedies are best suited for. While Dr Vinod would not publicly disagree with these statements, he would not tell patients about them.

Only after that unexpected class does Mohanan Vaidyar turn his attention toward Rakesh. ‘*What is his prognosis?*’, Dr Vinod asks. Mohanan Vaidyar sits down next to Rakesh, gruffly taking his left hand in his own and placing his right fingers on Rakesh’s inner wrist. For a few moments, he performs a pulse reading, though it is not clear whether he is employing the categories of interpretation found in Ayurveda, Kerala’s long-standing medical system. After a pause, Mohanan Vaidyar places his fingers around the delicate skin surrounding Rakesh’s eyes. He opens them wider, all while holding a piercing gaze. From there, he tells Dr Vinod: ‘*It’s pancreatic stones!*’

Mohanan Vaidyar relays the plan: Rakesh will stay with him, receiving herbal remedies for as many days as he needs, to let the pancreatic stones pass through his body. Once he is better, he will return to Dr Vinod’s hospital-home to fully recuperate. Throughout this, Rakesh appears in a daze. He then pulls Rakesh up to stand—much less gently than Dr Vinod does—to show him where he will sleep.

After the meeting, we all go on a drive to a roadside fruit stall. This will be our last moment with Rakesh until his treatments are complete. Drinking coconut water, sitting on a bench, Dr Vinod tells Rakesh, ‘*You have a prognosis now. This is good! Soon you will return to work. You will buy your mother a car!*’ Dr Vinod understands Rakesh’s need to fulfil his gendered role as the only son.

Clutching the coconut, Rakesh appears doubtful. He asks, ‘*What if it does not work?*’ Rather than affirm or deny the fact that his situation is indeterminate, Dr Vinod reframes his question in terms of a subjunctivising narrative, where transcending his illness is possible, even if things remain uncertain. Here, trust or faith is a necessary basis, but not the sole determiner, of health improvement:

> *If you have faith, you may improve … You will provide for your family. If you still have pain, we can visit an English doctor. I do not go to those doctors, but their tests may ease your mind. At our hospital, masala* [mixture] *medicine is an option. You will improve!*

Providing relational care

The stark differences between Dr Vinod and Mohanan Vaidyar highlight the diversity of nature cure as an alternative medical system: while they publicly align in terms of their political values and critiques of biomedical authority, their approaches to caregiving differ. Dr Vinod invites Rakesh to maintain an unstructured orientation to the future, even if it involves not staying true to Mohanan Vaidyar's public-facing anti-biomedical stance. By drawing attention to what he calls masala medicine (a mixture of medical techniques, including biomedicine), Dr Vinod gives Rakesh therapeutic options that other nature cure advocates would critique. This is not contradictory, as Dr Vinod's aim is not to publicly combat other medical systems, but to personally support Rakesh's return to normalcy. At the less-visible level of interpersonal care, Dr Vinod personalises treatments in a way that is receptive to the vulnerabilities, orientations, and hopes surrounding his patients' social worlds.

To help Rakesh generate faith about his body, Dr Vinod draws attention away from what Carel (2016) has framed as the contingency and fallibility of our bodies. By introducing him to Mohanan Vaidyar, Dr Vinod strives to create the conditions for Rakesh's body to function again—or to at least create a space where Rakesh feels such recuperation is possible. According to Carel (101), the vulnerability and hesitation that an ill person experiences on a bodily level 'amounts to a disruption of one's sense of belonging to the world and the disappearance of the sense of ordinariness'. When one loses faith in the capacity of one's body to function as it has in the past, it reveals how one's previous bodily certainty was an 'epistemically ungrounded tacit belief', as opposed to being reasoned. Carel frames this loss of faith in one's bodily capacities in terms of one doubting whether one can ever again 'pursue everyday goals and plans' (102). In counterpoint to this uncertainty, Dr Vinod approaches Rakesh's predicament in relational terms; he recognises and responds to the fact that his illness has caused a loss of faith in his socially-situated life trajectory.

While Carel sees lived doubt as disrupting everyday intentional action, Dr Vinod goes a step further to consider everyday interpersonal action, addressing how

Rakesh's therapy must involve conscious, pragmatic efforts to generate trust in his ability to fulfil reciprocal social roles. On one level, Carel's approach to bodily doubt aligns with Elaine Scarry's (1985: 6) canonical analysis of how pain causes a reversion to 'the pre-language of cries', whereby words become insufficient for articulating one's illness experience. In doing so, Scarry demonstrates how pain may produce doubt in one's capacities and relations to the point that it creates an 'unbridgeable chasm between the person who witnesses and the one who suffers (Banerjee 2020: 9). Like Scarry, Carel foregrounds how the bodily doubt that arises from illness disrupts faith in one's immediate capacities to act and intend; neither ask how socialities cohere and transform around illness experiences.

Dr Vinod extends Carel and Scarry's approach to illness experience; he recognizes how illness-related doubts grow out of prior social histories, and come to put pressure on maintaining acceptable intimacies. His approach is pragmatic. Aligning with philosopher William James' orientation to meaningful action, he pushes against fatalistic ideas that the universe is already mapped out with finality. Intervening in a long-standing free will debate, James (1884) offers a two-stage model of indeterminism. In the first stage, we face chance as we consider alternative future possibilities. In the second stage, we make choices that limit chance, granting consent to one future possibility. When we choose between random possibilities, we redefine the past as unalterable and make space for spontaneity. Gesturing toward the complexities of sociality, James challenges claims that meaningful action results from automatic social norms and given logical reasons. As with James' view of choice-making as being both individual and shaped by contexts, Dr Vinod guides his patients and their families to come to terms with the facticity of illness, death, and change. In this way, Dr Vinod supports patients' cultivations of an 'as-if' subjunctive mood, not as a simple tactic to motivate intentional action, but because it serves as a valuable way to cope with the 'ever-present stakes of a threatened real' (Banerjee 2020: 42).

As expressed in their conversations, Dr Vinod is sensitive to the moral weight of Rakesh's condition. He is aware of dominant masculine norms in Kerala, where men are deemed providers, generating income and value through work. Like a palliative care worker, Dr Vinod is attuned to the 'broken kinship worlds' (Banerjee 2020: 71) shaping many of his male patients, whose lack of mobility causes them to make explicit their dependence on the gendered work of everyday care. He is aware that Rakesh is motivated to transcend his illness, so to move away from *payyan*-hood (young immature status) towards full adult status as a householder. In Kerala, this life-stage transition is defined by 'the combination of marriage, fatherhood, and showing ability as a "provider"' (Osella & Osella 2000a: 120). It is in this fragile context that Dr Vinod strives to bring momentum to and generate clarity in Rakesh's prognosis and life-stage progression.

Scene 2: Forging transparency

Two weeks later, Rakesh returns. He is energised. Looking at Rakesh's face, Dr Vinod notes: '*You have become fresh* [*fresh āyi*]!'[12] Like the subjects of the nature cure magazine testimonials that Dr Vinod encourages his patients to read, Rakesh declares that he has regained his vitality. He is a new man.

The day after Rakesh's return, I spend the morning with him and his brother Rahul. Hair still wet, Rakesh wears a bright blue track suit, as if he had just returned from sports practice, and not a therapeutic steam bath. As in all spaces at Swasam, his hospital room is sparse: a narrow wooden bed, a thin mattress, a desk, chair, and a terracotta pot for water. The green cotton pillowcases and bedsheets serve as the only evidence that this room is in a hospital rather than an ashram or monastic centre; it is the same colour and material used across all public hospitals in Kerala.

I sit on the only chair in the room. Green and plastic, it is broken at one arm; this is a rented property, and Dr Vinod doesn't have the finances to make this a refined institution. Rahul and his brother sit on the bed, playing Snake and Ladders. Unlike the sense of random chance in this game, Rakesh is now facing life with a renewed sense of possibility. The late morning sun glides into the room from the window, lightening the walls. Like that sun, being around Rakesh feels rejuvenating. Unable to contain his excitement, Rakesh hands me a cloth, folded into a ball, and directs, '*Look inside!*' The fabric in my hands feels warm to touch. I open it, part by part, as Rahul hovers his hands around, concerned that whatever is inside will fall out. Once opened, I see what looks like tiny pebbles.

'*What is it!*', Rakesh asks, in a tone that conveys he knows more. After several failed answers, he tells me that these rocks are proof that he is cured; they are the pancreatic stones. During his two-week regimen of raw food and herbal remedies, Mohanan Vaidyar confirmed that this condition was the result of eating adulterated food. Rakesh expands on this cause, placing culpability on his experiences living in Bangalore. He references his college life, where he drank alcohol and ate restaurant food, and more generally became exposed to environmental toxins. After all, it was there that he started to develop his digestive issues. With the cloth in my hand, Rakesh validates the purported cause of his depleted vitality; he now has physical evidence.

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[12] In Malayalam, the English word 'fresh' is often used to describes a state of feeling clear and renewed.

Fast forward two weeks, and Rakesh's ebullient hope has waned. The water and herbal therapies are not working. Sajitha has even started to give him Boost meal replacement drinks—not part of any nature cure regimen. His bodily transparency has been replaced by what his body felt to be prior to Mohanan Vaidyar's intervention: broken, tired, and slow. Once again, Rakesh returns to feeling like he is '*in a waiting room*', unable to act with purpose. It is a quiet Tuesday night, and I walk into the staff dining room. I stop at the doorway once I see Sajitha at the table. She is crying, using her shawl to wipe away tears. Across from her is Dr Vinod, and right next to him is Sajitha's mother. I soon learn why they have gathered. In a paternalistic spirit, Dr Vinod had phoned Rakesh's mother to propose that he arrange their marriage, in lieu of Sajitha's father. Rakesh's mother assured her that no dowry would be necessary; her care is gift enough. Yet, despite hoping that the marriage will renew Rakesh's will to live, Dr Vinod is realistic; he affirms that if Rakesh gets any sicker, Sajitha may become a widow. As they weigh the pros and cons, Sajitha mourns her future.

Later in the week, Dr Vinod sets up a hospital meeting. All the staff, long-term patients, and family members gather outside near the herbal garden. Dr Vinod holds Rakesh's shoulder, acting more like a father than a doctor, while he narrates the romance, '*Rakesh and Sajitha have found each other through nature cure, it is fate!*' He then declares the dates of the weddings; one will be near Swasam and the other will be up north with Rakesh's family. As Dr Vinod continues his speech, he makes no reference to Sajitha and Rakesh's divergent social positions, nor to the possibility that Sajitha may experience early widowhood. Instead, the focus is on trusting in a future where the two can care for each other.

Providing kinship care

By coordinating Rakesh's marriage, Dr Vinod aims to reconfigure his illness experience, which has become marked by a lack of transparency and continuity. According to Carel (2016: 99), for a person who is chronically sick, '[their] body's taken-for-granted capacities become explicit achievements'. This directly contrasts the experience of the healthy body, where one's embodied state is rarely 'the thematic object of experience' (Leder 1990: 10). When one is well, one's body is expected to perform complex actions, all the while maintaining concentration and being pain free. Rather than hold any such taken-for-granted attitude, someone in Rakesh's state must consciously modify their habits so to mitigate any health risks; what once required little thought now involves strategic planning and concern. Aware that illness creates such 'areas of dramatic resistance in the exchange between body and environment' (Leder 1990: 13), Dr Vinod crafts interpersonal solutions that look away from highlighting the body as an explicit problem. According to Carel (2016: 100), 'medical encounters usually focus on the dysfunction at hand, thus becoming unpleasant reminders of bodily incapacity or disease progression'. Rather than contribute to the ongoing explicit thematisation of Rakesh's body as a problem, Dr Vinod helps him to experience it as transparent and easy to understand. To do so, he first introduces him to the charismatic, hopeful world of Mohanan Vaidyar. When that is not successful, Dr Vinod switches tactics. He subtly guides Rakesh to visit biomedical doctors for further treatments, yet does not draw attention to these actions. Instead, he strives to instil in him a sense of trust and continuity by directing his attention towards an impending wedding. Dr Vinod knows that for Rakesh, getting married is a prerequisite for any life-stage progression.

Attuned to personal contexts, Dr Vinod works within the 'shifting, local relational worlds within which … disease appears' (Banerjee 2019: 504) to foster in his patients a sense of body-environment transparency. In examining cancer secrecy in India, Banerjee highlights the processual nature of non-disclosure; it does not operate as a binary choice between concealing and revealing, nor between knowing and not knowing. Rather, 'weaving between disclosure and non-disclosure [allows] interlocutors to inhabit the space of the "as-if"—of living in a subjunctive tense' (499). Similarly, Dr Vinod guides Rakesh's daily life at Swasam, never disclosing a finalised understanding of his body; he only provides an indeterministic assurance that his body has an underpinning recuperative capacity. To facilitate Rakesh to live 'in the present, as if the future was not already pre-ordained' (502), Dr Vinod crafts creative interpersonal interventions, with the aim to reconfigure lingering feelings of illness uncertainty, where the body is seen as a thematic problem to be worked upon.

Emergent in Dr Vinod's patient–care interactions are ethical sensibilities that encourage patients to craft new stances concerning personal responsibility, illness transcendence, and community belonging. In creating such space for Rakesh to get out of 'living in prognosis' (Jain 2007), Dr Vinod also reworks kinship, marriage, and caste norms. Ester Gallo (2021) has argued that in Kerala, inter-caste unions have become a troublesome presence in middle-class family culture. On the one hand, 'real' kinship in Kerala has largely been associated to ties made through blood and marriage, leading to the reaffirmation of caste and religious membership. On the other hand, 'fictive' kin-like relations are those that allow for the traversing of caste–religious boundaries, if they do not lead to marriage or genealogical bonds (93). In arranging an inter-caste marriage between Rakesh and Sajitha, Dr Vinod challenges historical norms that regulate the boundaries between kinship domains. He is aware of the public judgements that may come from this union, ones which claim to lament the erosion of traditional hierarchies. By offering this unconventional care union to Rakesh, Dr Vinod aims to create the conditions for him to cultivate feelings of body-environment transparency, life stage continuity, and trust.

Scene 3: When doubt returns

One night in August, nobody slept much. Soumya almost stopped breathing. A seizure. The other patients in her room, next door to mine, said that her skin turned white, '*like a ghost*'. It took over an hour for the ambulance to arrive. Before the other patients and I knew what to do, Dr Vinod ran down the two flights of stairs, outside the kitchen, and into the patient quarters. I heard him trip over shoes by the doorway, placed away from the reach of stray dogs. A family history of seizures was not listed on Soumya's intake form. In fact, Sajitha had not even recorded her family's emergency phone number. After all, nothing like this had ever happened at Swasam. It was unprecedented.

At the time of this tragic incident, Soumya had been staying at Swasam for almost three weeks. When she first arrived, she was quiet and resigned, careful to wear long sleeve shirts to hide the dialysis insertion points on her arms. Soon, she wove herself into this community, only leaving for weekly dialysis sessions at a private hospital in town. Many nature cure healers in Kerala won't accept a dialysis patient because of the risk. Post-dialysis bodies generally need high protein and low potassium, the opposite of the raw food diet that Dr Vinod often prescribes.

Up until this moment, Dr Vinod had been successfully forging trust, transparency, and continuity in Soumya's life, providing her with purposeful activities to help her see her future as workable, with normalcy in sight. Aside from intricate diets, herbal medicines, mud baths, and reflexology sessions, he found a tutor to help with her now-on-hold college studies and invited several young women living nearby to accompany her for yoga classes. Things were looking hopeful and each day during consultation, Dr Vinod's presence would remind her of that.

The morning after Soumya is taken away on a stretcher, I see an older patient—a retired professor—reading on a bench outside. Like us all, he is shaken by last night's events. Quietly, he tells me: '*This is what it is like in India. Ambulances are late, people are left to die. There is little value for human life in this country.*'

I go upstairs to visit Dr Vinod. Today he is supposed to give a raw food cooking demonstration, and I have been planning to attend. When I reach the second floor, however, I know that the event is off. Hunched over a table, Dr Vinod is ironing his shirt. Before he notices my presence, I see that he has been ironing the same spot, over and over. His white beard is unkempt, a sign of a sleepless night. Usually, Dr Vinod brightens any space, but all I see is sorrow. His words are sparse: '*My mind is not well* [*manas śeri alla*].'

Dr Vinod undertakes intensive moral projects with his patients, in ways that greatly diverge from other nature cure practitioners in Kerala, despite their unifying categorisation as part of the same governmentally instituted medical system. In co-creating recuperative projects, he delves into the non-medical nuances of their lives, reframing interpersonal concerns so that their futures are perceived as workable and their bodies as sources of trust. At the same time, inherent in these tactics is the ever-present possibility of doubt. When his initiatives fail, he must face the facticity of death and loss, which pushes against his public stance that one can transcend all illness through non-biomedical means. Dr Vinod not only creates the conditions for patients to commit to a lifestyle that accepts the sea of indeterminism surrounding them; he is affected by the fact that success in these contexts is never complete. In rehabilitation, trust and doubt are never far from each other.

Like a palliative worker, Dr Vinod cultivates an empathy for his patients that also involves recognising the limits of his interventions. When he internalises such failures, he does so privately. As in Dr Vinod's hospital, Banerjee (2020: 118) demonstrates how the pain clinic in Delhi comes to stand in as 'the space of hope for dying well, the provisional rubrics of a compassionate response to those who had been denied timely treatment'. Here, empathy comes to be improvised in a space that demands recognition of the inevitability of death. Banerjee highlights how the research initiatives of palliative workers appeal to narratives of transcendence to 'look past the dispiriting conditions of everyday failures and toward the resilient capacities of a mind strengthened by the development of its spiritual capacities' (119). Yet at the same time, palliative workers' interventions are embedded within conditions of infrastructural pressure; working long hours and receiving patients who have received piecemeal and provisional treatments, these healers face limitations that are beyond their individual control. Healers like Dr Vinod face a similar tension between publicly employing hopeful narratives of illness transcendence, and privately recognising the on-the-ground limits of such claims.

Dr Vinod always foregrounds the possibility that patients will improve, and yet this distracts from a reality of inequality and lack. Patients often come to his hospital-home after facing barriers and blame in other biomedical contexts, and when they arrive, supplies and care options are rudimentary at best. However, Dr Vinod does not place 'responsibility and blame on already vulnerable patients' (23). Rather, he works to normalise and de-individualise chronic diseases, by interpersonally attending to the ways that such conditions create barriers in patients' lives. Yet, despite his hopeful approach and attention to the way that illness folds into persons' social worlds, Dr Vinod must face moments where pain and illness become intractable, unable to be transcended. It is in these moments that Dr Vinod witnesses the gulf between his discourses of transcendence and his practices of empathy. Even though he declares that illnesses can always be improved upon, there are limits.

Conclusion

In February 2018, renowned Malayali oncologist Dr V.P. Gangadharan criticised a message circulating in WhatsApp, which supposedly claimed that cancer can be cured through natural means.[13] In response, Dr Gangadharan said to *The News Minute*: '[Patients] take these messages seriously, and the real sad fact is that some patients even stop medication, believing that there are alternative ways to cure the disease. We cannot blame them for trying to find hope in anything they see.' He then adds, 'We, doctors, have no difficulty in clearing the doubts of the patients.'

Through this criticism, Dr Gangadharan indirectly homogenises alternative practitioners in Kerala into one unified group, who all manipulate vulnerable patients to mistrust biomedical treatments. However true this may be at times be, this claim distorts the multiplicity of healers under the umbrella of alternative medicine and nature cure therapy in Kerala, who each hold diverse moral stances and care strategies. On the one hand, there are those like Mohanan Vaidyar, who oppose themselves to biomedicine, and who often propose miraculous possibilities of healing through non-invasive means. On the other hand, there are more empathetic healers like Dr Vinod, whose real focus is on supporting patients' small acts of transformation. Rather than get publicly involved in binarising debates between alternative and biomedical traditions, Dr Vinod instead intervenes in his patients' social worlds, assauging vulnerabilities and supporting choices that acknowledge the limits of cure. In doing so, he may engage with discourses of nature cure as a self-directed practice, but his care strategies are not rooted in liberal notions of autonomy. Rather, he addresses how chronic illness care must be folded into the recuperation of already-vulnerable social worlds.

With a relational approach to illness experience, I have engaged with Carel's (2016: 93) framing of bodily doubt to illuminate how Dr Vinod responds to his patients in a way that is attuned to how 'the natural confidence in [their] bodily abilities are displaced by a feeling of helplessness, alarm, and distrust'. At the same

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[13] For more information, see: https://www.thenewsminute.com/article/don-t-fall-fake-cancer-cure-messages-my-name-oncologist-dr-gangadharan-75854.

time, I move beyond Carel's individualist framework of bodily doubt, which unifies chronic illness as rendering all bodies unable to carry out tasks with transparency and faith. Rather, Dr Vinod's care strategies hinge on a recognition that first-person experiences of illness are embodied in relation to structural barriers and situated vulnerabilities. Like a social scientist, Dr Vinod does not separate Rakesh and Soumya's illness experiences from the interpersonal, co-produced contexts of meaning in which they act. Aware of and empathetic to his patients' social worlds, Dr Vinod gently intervenes in their lives, forging social ties that support them to develop faith, transparency, and continuity—even if he faces limitations in the process.

Rather than being irrational or simply reactive to suffering, Dr Vinod's care tactics align with a Jamesean model of indeterminism and choice-making. According to William James' (1892) open future account of the universe, history is contingent on how free will is used. There are no laws or initial conditions that would allow one to deduce the state of the universe at a later point, because there are many possible ways that people will employ their free will to create future experience. Rather than experience unfolding like predetermined links on a causal chain, he claims that there is a gap in the causal chain, which can only be filled through the self freely determining how to act (James 1892). This feeling of choice makes life tingle with what he calls 'tragic zest': though it means that we have the freedom to mould our future, it also means that we are responsible for how the future develops. For moral reasons, James asserts that free will is genuine, even though it could be an illusion. The 'cash-value' or merit of this 'Will to Believe' outlook is that we are more likely to interact positively with others, appreciate their value, and create a more moral world in which we identify as responsible, free agents (James 1892). Like an Jamesean indeterminist, Dr Vinod undertakes narratives and actions that support his patients to hold a subjunctive mood, whereby they face illness uncertainty, perceiving life as neither predetermined nor fatalist.

The Malayalam proverb cited at the beginning of this article—'If things come down, they will also definitely go up'—draws attention to Dr Vinod's hopeful orientation to time and improvement, which he aims to imbue in his patients. Even though he publicly declares cure to be a complete transcendence from one's original prognosis, possible without the help of biomedicine, his interpersonal care tactics are far more subtle and attentive to one's embedding in social worlds. For his patients, Dr Vinod continually instils a more open perspective to reality, where things that have 'come down' will always 'go up', suddenly and at any time.

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The centrality of (mis)trust in pandemic preparedness in Sub-Saharan Africa: a conceptual framework

Catherine Grant

Abstract: Trust is central to pandemic preparedness and the degree to which the population has trust in policymakers and health authorities during an outbreak is based upon historical and social context as well as policy decisions. This paper aims to translate complex ethnographic knowledge into a conceptual framework to simplify multiple temporalities and spatialities of trust. This model is based on the literature, consulting experts and experience conducting research and providing technical assistance in a policy environment during the 2014–16 West Africa Ebola outbreak and the 2019–23 COVID-19 pandemic. Trust varies according to past and present decisions and realities and the model focuses on the complexities of trust depending upon populations' historical experience with medicine, (in)effective health systems, social context, colonial history, (dis)trust in public authority and social determinants of health. The world is increasingly interconnected and transdisciplinary and new approaches are needed to deal with these changes. A holistic, context-driven approach which forefronts the importance of gaining the trust of populations and addresses the new problems created during modern experiences of pandemics and epidemics is key to future preparedness efforts.

Keywords: Trust, Ebola, COVID-19, Africa, conceptual framework, transdisciplinary.

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Introduction

Research on trust has shown that it is important to gain a population's trust whilst preparing for and during a pandemic and this is not only about trust in medical providers, but is also bound up in trust in governments, communities and societies (Grant 2014, Leach *et al.* 2022, Storer & Simpson 2022). It is a complex issue and anthropologists have noted that a discourse of trust/mistrust can be deployed in a nebulous way to account for difficulties encountered in policy interventions (examples are given in Coates 2019, Leach *et al.* 2022, MacGregor & Leach 2022). It can serve as a vague proxy for a set of uncertain, complex, contextual and behavioural factors that hinder implementation. However, to fully discuss the concept we must first reflect on some of the key issues around understanding and discussing trust. Leighton and Roberts (2020) outline that too often the common-sense understanding that knowledge = trust dominates; this is that understandings of trust see it as a problem arising from a lack of knowledge or inappropriate calculation of risk, whereas in reality such framings are too reductionist. As Storer and Simpson (2022) argue, trust is a far more illusory and nebulous concept to be defined and resolved through simply providing populations with information in attempts to promote trust.

Understandings of trust need to be interrogated in order to be able to use the concept in practice. Though trust was central in classical sociology, for example in the works of Max Weber, Talcott Parsons and Gabriel Tarde, it was rarely interrogated directly, 'functioning instead as a sort of black box at the heart of social theory' (Carey 2017, Misztal 1992, Parsons 1970, Weber 1947). Trust is a precondition for collective human existence. Therefore each of human and social sciences separately insists on the importance of the presence of trust. For example, economists see trust as the foundation of all economic transactions and political science as the cornerstone of the legitimacy of government (Carey 2017). Indeed, trust does not imply a utopian vision but is rather a pragmatic concept and gives us a window not only into the empirical dilemmas of pandemic policy, but into wider questions of the context in which this exists and the interplay between these factors: for example care, social cohesion, stigma, inequality and freedom (Storer & Simpson 2022). This is the area this article will explore.

Whether trust is viewed as an etic (culture-general or universal) or as an emic (culture-specific) concept (Earley & Mosakowski 1996, Triandis 1994), the intersection of different levels or meanings of trust has implications for research into how context factors influence how policy decisions are reached and enforced in the outbreak climate. Lack of trust has been interrogated by Citrin and Stoker (2018: 50), who define mistrust and distrust as follows: 'mistrust reflects doubt or skepticism about the trustworthiness of the other, while distrust reflects a settled belief that the other is untrustworthy'. Mobilising the concept of mistrust highlights the importance of transdisciplinarity in public health policies and practices to understand these interactions and how trust might be impacted in different contexts as trust is multi-faceted and complex, so needs to be considered beyond usual disciplinary boundaries. Biomedical science alone cannot 'end' epidemics, which are in large part socially driven and need to be viewed within the entire context in which they exist, and this article looks at the importance of trust within this (Bardosh *et al.* 2020, Blassnigg & Punt 2013, Darian-Smith & McCarty 2016, Gasper, 2010).

Mistrust during pandemics is associated with poor satisfaction with healthcare, lower uptake of medical recommendations regarding health behaviours or treatments, reduced quality of life, and worse health outcomes, and economists, epidemiologists and policymakers all recognised and wrote of its importance in recent outbreaks (Benkert *et al.* 2019; Birkhäuer *et al.* 2017, Leach *et al.* 2022, Storer & Simpson 2022, Thornton 2022). There must be 'trust between holders of knowledge, process facilitators and the eventual users of knowledge' for effective health policy to be well received by the community (Chambers 2006: 8, Storer & Simpson 2022). Trust is also self-referential in character—if only we had more trust, we could build more trust, then we would have more trust. However, despite its continual repetition in policy documents, trust remains an illusory concept and even scholars struggle to 'speak to the relational connotations of the concept' (Storer & Simpson 2022). Trust can also be used by policymakers to blame, exclude and stigmatise communities who are considered non-compliant: for example, by being vaccine hesitant (Leach *et al.* 2022). Trust is often taken for granted in healthcare policy, but building trust within communities involves tacit listening, acknowledgement, social support, and coalition-building. However, this is complex and a danger in some places is that exclusionary hierarchies might be enhanced, and vulnerable and marginalised populations further excluded (Sarafian 2023, Storer & Simpson 2022).

Trust is often associated with doctor–patient healthcare encounters; however, the pandemic has refocused the role of trust in broader social contexts (Chan 2021). Bollyky *et al.* (2022) found that higher levels of government and interpersonal trust had large, statistically significant, associations with fewer COVID-19 infections. This corroborates findings of research done before COVID-19 that also found an association between trust and compliance with public health guidance (Gilles *et al.* 2011, van der Weerd 2011,). Therefore transdisciplinarity is key as it is problem-based and concentrated on the practical applications of knowledge in the real world where issues tend to be multifaceted and call for multiple analytical perspectives

(Darian-Smith & McCarty 2016). Transdisciplinary scholarship also considers how knowledge is constituted in the first place as a replication and outcome of particular worldviews, ideologies and cultural biases. According to Rosemary Johnston, transdisciplinarity ‘overtly seeks ways to open up thinking to “maps of unlimited possibilities”... to create mindscapes that are unfettered by traditional patterns and procedures’ (Johnston 2008: 229–30). For example, generally during a disease outbreak the world prioritises health protocols above environment and economic considerations (Grant *et al.* 2023). An example of the impact of not thinking in a transdisciplinary manner, and focusing on containing the outbreak is in Uganda where COVID-19 restrictions included many very restrictive and militarised lockdowns and forced hospitalisations, implemented in a context of political oppression surrounding national elections, and in which symptomatic Covid cases and local levels of mortality remained very low—thus damaging livelihoods and fuelling resentment and distrust amongst local populations (MacGregor *et al.* 2021, Parker *et al.* 2020).

A key issue when dealing with pandemics is that reciprocal trust (populations trusting authorities and vice versa) needs to be pre-existing amongst the majority of the population and be maintained with policies that garner adherence by the population. Securitisation, the use of military and harsh enforcements as well as war metaphors in political communications to the public appeared prominently during Ebola and COVID-19. For example in Malawi and Uganda, COVID-19 occurred alongside national elections and was layered with everyday mistrust in leaders, so people questioned whether health measures were connected to struggles for power, and open to manipulation by leaders seeking to avoid scrutiny or steal elections (Atuhura 2021, Grant & Sams 2023, Parker *et al.* 2020, Storer *et al.* 2022). If people do not already trust medical personnel and the government, it will be much harder, but still possible, to gain support for difficult policies, e.g. lockdowns. However, even with trust existing beforehand, if policies are not considerate of populations, they may lose trust (see Figures 1 and 2). Low public trust in sources of information among the population was linked to low societal compliance, and the involvement of local authority figures who command trust could lead to better community engagement (MacGregor & Leach 2022). In much of the world, public health is a local, community-based endeavour and so interpersonal trust (trust within communities) plays a large role (Bollyky *et al.* 2022).

This paper can begin to give insight into what needs to be put in place pre-pandemic and how to put trust at the centre of policy-making during pandemics. Fortunately, the author believes that trust is something that can be fostered, even in a crisis. Bottom-up community engagement which comprises cross-disciplinary collaborations and interventions, including true partnership with local communities, giving voice to differing narratives and gaining trust, will lead to a true understanding of contextual realities and how to create policy for the situation. This can be useful in making context-specific policy decisions that are based on the lived reality of the population rather than using 'one size fits all' approaches or 'copy and pasting' policies from other contexts, which makes it harder for trust to be gained in a specific context (MacGregor *et al.* 2021). There has been learning between Ebola and COVID-19, but it could go further to ensure we are better prepared for the next pandemic and these findings can assist in attuning interventions to different contextual realities and therefore ensuring that they are proportionate, considerate to vulnerabilities and social inequalities and socially just (Leach *et al.* 2022, MacGregor *et al.* 2022). While there has been research in high-income countries showing the importance of trust in explaining individual precautionary behaviours related to COVID-19 (e.g., Borgonovi & Andrieu 2020, Ye & Lyu, 2020), few studies have addressed this in Sub-Saharan Africa (Yu *et al.* 2023).

Methodology

This research used in this paper is based on twelve years of experience working on research and policy on zoonoses and pandemics both as a researcher and providing technical assistance. Research projects the research was conducted in include the Dynamic Drivers of Disease in Africa Consortium (2011–16) and the Pandemic Preparedness Project (2019–23) and work providing technical assistance to policymakers included through the DFID Human Development Resource Centre (HDRC) (2011–12) DFID High-Quality Technical Assistance for Results (HEART) (2012–16), FCDO K4D (2016–19), the Ebola Response Anthropology Platform (2014–16), Social Science and Humanitarian Action Platform (2023–) and the Covid Collective (2023)[1]. During this work the author provided advice on how to engage with crucial socio-cultural and political dimensions of outbreaks, consulted and interviewed experts and used evidence to improve the impact of development policy and programmes. During the Ebola outbreak, the author went to policy meetings at the UK Department for International Development (DFID) and a report she wrote was used by the British Army and DFID when discussing issues of trust amongst local populations and how to incorporate these, showing increasing awareness of these issues (Grant 2014). It was recognised in the *Annual Review of Anthropology* that this report 'challenge(d) conventional wisdom by arguing that international experts'

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[1] The dates given are the dates during which the author was involved, not the dates the projects and organisations existed for.

misconceptions about West Africans' responses to the epidemic were an important factor impeding the effectiveness of the response' (Abramowitz 2017).

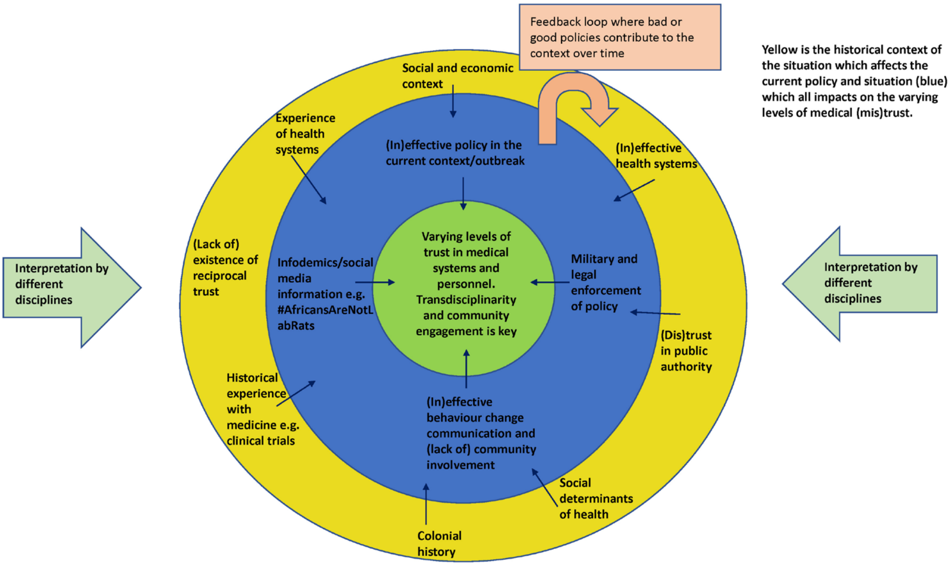
In addition to synthesising data collated through this immersive approach, experts were consulted to provide key papers and a rapid literature review was conducted according to the method outlined in Grant and Longhurst (2016). This approach was also used for rapid policy research by HEART and ERAP. Initial searches were done and then a snowball sampling approach was used, adding keywords as the literature was accessed and a reference list of key documents was used to find the most relevant literature. The initial key words used were 'trust', 'pandemic' and 'Africa'. Science Direct, Web of Science and Google Scholar were searched and the selection criteria included articles published between 2011 and 2023 focusing on Sub-Saharan Africa, and peer-reviewed journals were prioritised.

Drawing on this complex milieu of intersubjective and published experience, this paper will now present a conceptual framework showing how trust varies according to past and present decisions and realities, using the Ebola and COVID-19 pandemics as examples. It shows how trust was constructed or deconstructed depending upon populations' historical experience with medicine (e.g. Parker *et al.* 2022), (in)effective health systems (e.g. El-Sadr & Justman, 2020), social context (e.g. Schmidt-Sane *et al.* 2022), colonial history (e.g. Mutombo *et al*. 2022), (dis) trust in public authority (e.g. Parker *et al.* 2022) and social determinants of health (e.g. Ripoll *et al.* 2022). These contexts in turn influence how policy decisions are reached and enforced in the outbreak climate, the (in)efficacy of behaviour change communication, and how infodemics and social media (mis)information are contributed to and received.

Conceptual framework

The yellow section of this figure outlines the importance of the historical, social and economic context of the situation. Literature and experience have shown the areas highlighted in the model to be key to understanding how these issues affect current policies and realities (blue section). By feeding these issues (yellow section) into policy and involving multiple actors and narratives and considered community engagement, this enables policymaking that considers contextual realities and is attentive to social differences and vulnerabilities (the blue section of Figure 1).

Central in this model and emerging in the synthesised material is that key to increasing trust is that external actors undertake committed community engage-



Yellow is the historical context of the situation which affects the current policy and situation (blue) which all impacts on the varying levels of medical (mis)trust.

Figure 1: (Mis)trust in pandemics: a conceptual framework.

ment. This should comprise transdisciplinary collaborations drawing together all of these issues and harness mobilisation, knowledge and inventiveness ‘on the ground’, hearing from people about their priorities for and experiences of health and livelihood issues both current and historical (the yellow section of Figure 1). Doing this will release the pressure of disciplinary interpretation (green arrows), which are separately only able to consider part of the picture.

Taking this approach should increase the levels of trust in medical policy (green section of Figure 1) (Grant *et al.* 2015, 2016, forthcoming, Sams *et al.* 2022, Schmidt-Sane *et al.* 2022). There is also a feedback loop; poor policies impact on context over time and help contribute to and build histories. Figure 2 shows how the two layers interact with each other.

Each epidemic experienced has resulted in learning, but focusing on the centrality of trust in policymaking can ensure the design of the most effective preparedness policy (see Figure 2). Figure 2 shows the centrality of trust and how to analyse at what point trust has been lost in various contexts and whether long-term structural change or policy change is needed to address the issues and increase trust levels.

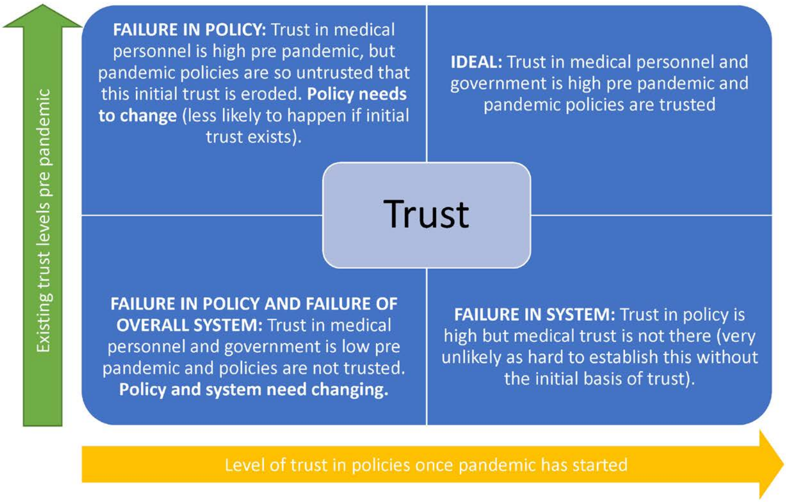


Figure 2: Conceptual framework on (mis)trust in policy-making and social contexts during pandemics.

Discussion

When analysing trust, the first place to start is to understand the long-term structural issues. This model points to a multi-layered production of mistrust in space and time and each section below discusses a different part of the model.

Part 1: Long-term structural issues (yellow section of the model)

Social and economic context

Historical injustices and socio-political issues inevitably shape interpretations of disease and trust in government, authorities and medical providers. This context shapes the ideology and narratives of a nation or region. For example, when epidemics circulate (through viral agents) in historically marginalised communities, widespread resistance has been reported, which has been interpreted as indicative of mistrust in response and a view of government, as either the cause of the disease, or a neglectful responder (Démolis *et al*. 2017, Ripoll *et al.* 2022). Fairhead (2016) also describes precarious ‘social accommodations’ that need to be made during a disease outbreak, that is, established norms of cooperation and coexistence that were violated throughout an outbreak: for example, the medicalisation of burials during Ebola when previously they were handled within communities and using important rituals which were interrupted by Ebola regulations on burials. Previous research has also shown that corruption contributes to lower trust in government and social institutions, which might reduce compliance with public health guidance and policies (Bollyky *et al.* 2022).

An example of policy which did not account for these issues is when the Governments of Sierra Leone, Liberia and Guinea responded with bans and fines for burying, sheltering or treating suspected Ebola patients and corpses (Richards *et al.* 2020). People resisted the response teams to continue traditional burials, which fuelled the epidemic with some burials becoming 'super-spreading' events. However, the importance of burial practices cannot be overestimated, as they are closely controlled by the male and female societies who are central to local and regional politics (Grant 2014). Medical teams wishing to prevent traditional burials will likely be intervening in domains of power and 'secret' knowledge that lie at the centre of the socio-cultural context of the area (Wilkinson 2014). Mistrust is often cited by authorities as a way of pushing the biomedical, dominant culture against traditional beliefs, reinforcing histories of medical experimentation, injustice and oppression, and systemic racism; all too often, trust is expected before trustworthiness can be established (Jaiswal & Halkitis 2019). Further fuelling rumours was the focus on the biomedical crisis that COVID-19 had created without considering economic and livelihood issues. By instituting lockdowns without fully considering the economic impact on poor, marginalised and vulnerable people, public authorities lost trust among the populations (Grant *et al.* 2023). Another example of how these issues come together to manifest in reality is widespread reportage of vaccine fears. To give a couple of examples, in Guinea the pumping of disinfectant in markets was thought to be pumping virus, and when a COVID-19 vaccine was announced, rumours circulated about conspiracies to depopulate the world, starting with Africa (Grant & Sams 2023, Leach 2014).

By considering the whole context, including social, economic and livelihood, political and cultural, instead of only prioritising the biomedical crisis situation, more holistic and well-rounded policies can be developed, gaining the trust of the population as their lives and livelihoods are considered, not only their health (Grant *et al.* 2023, MacGregor *et al.* 2022). Unsettled national politics, distrust of foreigners fuelled by decades of extractivism and lack of respect for local cultures need to be considered when thinking about how to gain the trust of populations (Leach 2015).

When planning long term, these issues ideally need to be addressed on a wider structural level and, once they are, policy attentive to these histories and culture can be made to a gain the optimum level of trust in populations (Figure 2). There is no short-term fix to these issues, but improvements could be made by considering the four policy-making points (Figure 1, blue area) and considering local contexts

(Figure 1, yellow area) while ensuring effective communication and appropriate enforcement. For example, burial practices could be modified during an epidemic and people are generally open to these modifications, partly because indigenous protocols prescribe such modifications, for example adaptions to burials accepted during Ebola (Grant 2014). In this way, understanding and responding to local experience can be very effective and increase trust and positive responses (moving into a more positive box in Figure 2) (Hewlett & Hewlett 2008).

Colonial history

For decades, people living in colonised states were subjected to coerced medical interventions that were in many cases neither safe nor effective (Lowes & Montero 2021). For example, Lowes and Montero (2021) analysed the effects of French colonial policies, which included forced examination and injections to treat and prevent sleeping sickness with severe, sometimes fatal, side effects, in Cameroon and French Equatorial Africa between 1921 and 1956, and they found that greater exposure to colonial policies significantly reduces present-day vaccination rates and trust in medicine. So, nearly one hundred years later, descendants still live with the effects of this historical trauma, resulting in less trust in modern times (Lowes & Montero 2021). Storer and Anguyo (2022) also make the point that successive historical deceptions have been practised by state and medical actors in some areas, bringing the issue into modern times. Kovacic *et al.* (2016) and Shaw (1997) suggested that involving elders in policy-making meant that decades later positive, trusting memories of approaches could be fostered. By considering these issues, the four policy areas (blue in Figure 1) should be considered carefully to ensure that policy-making is trusted as much as possible in this difficult context.

Resistance and mistrust must be understood through consideration of historical structural violence (Benton & Dionne 2015, Hirschfield 2017, Wilkinson & Leach 2015). Benton and Dionne (2015) argue that the transatlantic slave trade, the colonial period, 1980s structural adjustment programmes and civil wars in the 1990s were types of imperialism that helped create the context that intensified the spread of the 2014–16 West African Ebola outbreak. An example of this is Sierra Leone, which was used as a central port in the slave trade and then as a mining colony for the British Empire; therefore a substantial proportion of their encounters with outsiders were primarily extractive (Wilkinson & Leach 2015). This colonial history played out in the Ebola epidemic which took hold in Sierra Leone in 2014; reports were rife of instances of community resistance to medical intervention, mistrust and avoidance of healthcare centres, and stigmatisation of health workers and survivors showing that memories of these histories last a long time, and therefore trust should be central to modern policies to begin to build better future relationships (Enria *et al.* 2016).

(Dis)trust in public authorities

Levels of trust will vary depending on the historical and social issues described above as well as public health paradigms. For example, public authorities[2] which historically have not held back from curtailing individual rights in the interests of protecting populations from infectious diseases will be viewed differently by the population and will need to consider different policies and communication methods to gain public trust (see Figures 1 and 2). Additionally, recent experience of policies and public authorities will shape trust levels. For example, questionable practices in the Ebola response in the Democratic Republic of Congo (DRC), including payments to security forces, renting vehicles at inflated prices, and corruption, may have jeopardised humanitarian operations and put lives at risk (Freudenthal 2020, Ripoll *et al.* 2022). The outbreak experience existed alongside existing complex protracted difficulties and many public figures and authorities tried to advance their own agendas, though this is often challenged by populations (Kirk *et al.* 2021).

Levels of trust in different public authorities may vary: for example, Lipton (2014) wrote about the situation in Sierra Leone during Ebola and found that while many people were proud of being law-abiding and respectful to authorities, there was a widespread mistrust of the motivations of the police and army, who are often badly paid and gain an income through bribes and fines. However, he found that in a crisis to survive people are forced to encounter and engage with certain actors and that policies were respected (Lipton 2014). Traditional practices such as secret societies are an institutional structure that people understand, and trust, and can be effectively used in times of crisis (Grant 2014). When thinking about gaining trust, these nuances need to be understood and used to ensure effective policy and communication of policy giving authority to trusted groups (Figure 1).

Trust can also be different in different authorities. Research findings showed that people had low trust and confidence in policing systems and state institutions and felt the state lacked a coherent plan, but they had more trust in public health offices, medical professionals and the emergency committee. (Collyer *et al.*

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[2] The term ‘public authority’ refers to formal government and state instruments created by legislation to further public interests, such as the police, army and various sanctioned forms of local administration (Kirk & Allen 2021).

2021). They also found that preventative policies were more accepted if carried out in cooperation with local civil society organisations which were 'closer to the people', thus showing how policy can be adapted when context is understood (Figure 2).

Some examples of policies that have increased mistrust in public authorities and shown a lack of contextual understanding include padlocking churches shut in Uganda during COVID-19. People complained that 'people with authority have hidden our God from us. We would be going to church as we ask help from God about this disease. … But now God is hidden from us. You can see how it is a problem …' (Baluku *et al.* 2020).

Epidemic preparedness and response are not neutral, technical endeavours, but are profoundly shaped by geopolitical processes and by formal, hybrid and informal public authorities on the ground. These processes and authorities are likely to profoundly shape the future course of COVID-19 (Parker *et al.* 2020). A key lesson for preparedness is to decentralise, to trust local negotiations and to be flexible in implementation, responding to local conditions. This may help address the lack of trust people had in formal institutions because of the nature of an often predatory, autocratic state (Scoones 2023).

Historical experience with medical systems and personnel

Given violent and extractive colonial histories, often conducted under the guise of the 'greater good', there have been issues surrounding trust for decades ,with a particular concern around new treatments (Mutombo *et al.* 2022). Crane (2013) highlights the complexities of the HIV/AIDS epidemic in Uganda and how global health science both generates and relies upon inequalities, even as it strives to end them, when new treatments are disseminated to Africa. When COVID-19 vaccines were offered as a new solution, people questioned whether they were being used to experiment on or worse exterminate Africans and also wondered what the role of international actors was in this. This was discussed on social media, using hashtags such as #AfricansAreNotLabRats and raised in particular the question of trust in knowledge and how knowledge carries authority (Grant & Sams 2023).

Rumours such as these, whether originating online or in person, are articulations of mistrust, and produce more mistrust in the context of colonial legacies (Richardson *et al.* 2019). Rumours and mistrust can have huge impacts: for example, in 2003 three states in Nigeria boycotted the polio immunisation campaign because the political and religious leaders told parents the vaccines were 'corrupted and tainted by evildoers from America and their Western allies', believing 'modern-day Hitlers have deliberately adulterated the oral polio vaccines with anti-fertility drugs and … viruses which are known to cause HIV and AIDS' (Jegede 2007).

Trust also seemed key for the COVID-19 vaccine, as in some places, there was evidence of mass absenteeism when the vaccination team arrived. In others there was an enthusiastic turnout. The variations seem to relate mainly to the existing state of trust in government medical services (Leach *et al.* 2022). Vaccine confidence also grew when the vaccines were delivered by trusted local providers, and local differences between villages in health service experience affected uptake (Leach 2022).) Community approaches in Africa have continually adapted throughout the post-independence period. Over time, responses have begun to include aspects of biomedical practice, giving hope to vaccines being increasingly accepted. Health policy is not imposed onto a blank canvas, but rather onto long-term attempts of populations to resist disease (Aluma *et al.* 2022).

(In)effective health systems

Trust in health systems is based upon beliefs and experience. Communities have diverse beliefs around disease, which can overlap or diverge with biomedical models, and this leads to health systems that have a plurality of health providers including biomedical, faith and traditional healers (Ripoll et al 2022). People may have very good reasons to mistrust the biomedical healthcare system, be it due to underfunding and structural issues or cultural beliefs. A study in Uganda found that distrust in the Ministry of Health is prevalent among frontline health workers; there is a lack of trust in the organisation's coordination role in service delivery and this affects healthcare delivery to patients, interrelations and provider cooperation (Akello & Beisel 2019).

Pre-existing ideas about health actors matter since this trust level is important during pandemics as it informs how people respond to new risks. However, levels of trust in health systems can change during outbreaks. Even if trust levels were previously high, heightened anxiety and a change in service levels can lead to distrust (Figure 2). So, when thinking about communicating and enforcing policies this needs to be considered. Fragile health systems were overwhelmed with the surge in cases at the peak of the COVID-19 outbreak, meaning essential health services (for example, reproductive health services) were disrupted in many African countries due to an imbalance in supply and demand (WHO Africa 2021).

Trust levels can also change due to fear during an outbreak. For example, in Sierra Leone doctors are generally respected, and people are normally keen to seek medical attention at pharmacies and hospitals if resources permit. However, during the 2014–16 Ebola outbreak, there was a widespread distrust of hospitals and treatment facilities. People feared being wrongly diagnosed with Ebola, and either harmed by the treatment process or worried that they would catch Ebola in hospital. In part, this attitude stems from a distrust of the motivations and the capabilities of the government during the crisis, who many feel willingly benefit at the expense of ordinary people (Grant 2014, Lipton 2014). Field research in Uganda also showed that distrust moved across generations and outbreaks; people reported not trusting the government during COVID-19 vaccine campaigns because they had had experiences of the Ebola vaccine making them sick, so people avoided the vaccine (Baluku *et al.* 2020).

This experience goes back through the history of outbreaks. Trust levels can change and reflect experience of previous outbreaks. For example, Hewlett and Hewlett describe the situation in Gabon in *Outbreak Ethnography*. Local people were reluctant to talk about what had been happening or admit that people had died from Ebola due to a lack of trust in health policy and systems. Villagers, priests and local government officials supported the denial, even though laboratory tests indicated Ebola. Distrust of the international team was not surprising given local people's experiences with French and American teams during the 1996 outbreak, where blood was taken, but results not given, leading to rumours of blood or body parts being sold for profit (Hewlett & Hewlett 2008). Other communities in the 2014 outbreak also believed that, whenever international health teams visited, 'the communities [were] hit by illness' (UNICEF 2016, Fassassi 2014).

Despite colonial histories, most people want and value outside help, as long as feelings of mistrust are not amplified, but it is important to have a sense of the local institutional fabric and healthcare workers should make activities transparent and develop trust and rapport with local people. Working with communities could include regular community meetings to explain control efforts and walking in the community and acknowledging local people help. Social mobilisation is a key component because all stakeholders should be involved to enable pooling of resources and optimising the management of epidemics (Chippaux 2014). Past experience has shown that health education and social mobilisation efforts should target women and women's groups as they often care for the sick and perform burial practices (Grant 2014). Secret societies, which are male and female societies who are central to local and regional politics, are also often one of the most well-trusted institutions (Grant 2014). Collaboration with communities is needed to find solutions: for example, being creative with traditional rituals to identify new burial practices that meet cultural needs and infection-reducing protocols; and in how treatment units are located and designed (Leach 2014).

Social determinants of health

Different people and institutions will be trusted by different social groups, depending on the social and political histories of the affected communities (Figure 1, Ripoll *et al.* 2022). Different groups are affected differently by and are vulnerable to different infections, illness and levels of mortality by virtue of social roles and practices. Cultural logics refers to communities' own models of health and illness, explanations of epidemic emergence, as well as local capacities to respond. Mistrust may be a response to current and historical differences in healthcare and society as a whole and may play a role in COVID-19 inequities (Bogart *et al.* 2021). Vulnerability, power differentials and exploitation are involved in the concept of trust in healthcare (Bhattacharya *et al.* 1998, Fugelli 2001). Low interpersonal trust is most correlated with income inequality and government corruption, suggesting those who are economically and socially disadvantaged and confront a society stacked against them might be naturally less inclined to trust others (Abascal & Baldassarri 2015).

When considering how to make policy to deal with the context, it is important to consider that, while the centralisation of response may benefit coordination, decentralisation of response activities carried out by affected communities and promoted by local trusted actors can promote trust and increase the uptake of services. Understanding the political dynamics of a response and identifying how different response actors and activities are perceived by different social groups in a context is crucial (Ripoll 2022). For instance, in the 2018 DRC Ebola outbreak it was realised that local people felt uncomfortable engaging with external actors so they set up *comité cellules*—structures of locally elected, trusted community members who facilitated action plans at the local level (Oxfam International 2021, Ripoll *et al.* 2022).

Part 2: Outbreak policies (blue section of the model)

(In)effective policy

When a virus emerges with high potential for spread, governments must be able to convince citizens to adopt public health measures. Doing so often requires behavioural change, from mask wearing and physical-distancing rules to following quarantine policies (Bollyky *et al.* 2022). Policy can be ineffective if it does not understand the context, and the levels of trust in its populations. If levels of trust are low to begin with, it makes it harder to gain high compliance with policy. For example, a study on Ebola in DRC showed lack of trust in government was associated with less compliance with government-recommended mitigation strategies, such as keeping physical distance and accepting vaccines (Vinck *et al.* 2019).

(In)effective communication and (lack of) community involvement

If the government and health teams do not take hold of the narrative on outbreaks and people are forced to work out the facts from the rumours and then decide the best course of action, they are more likely to ignore government directives rather than follow them. Especially if they risk greater difficulties, such as following lockdown rules to the detriment of their livelihoods (Baluku *et al.* 2020). Reinforcing knowledge networks that allow the exchange of validated information (not just from health sources) across communities and into the diaspora is important. These exchanges help build trust between different sources of expertise, avoiding anxieties such as those around vaccines (Scoones 2023).

An example of how misleading information can spread in the absence of trusted correct information is the misunderstandings of policies in Uganda, such as the emphasis on handwashing as a preventive measure led to rumours that the COVID-19 attacks and spreads through hands. This led to a belief that if washing with alcohol sanitizer is the remedy, then drinking a locally brewed gin would be a cure (Baluku *et al.* 2020)

When people are forced to make desperate and dangerous decisions to ensure the survival of their families and livelihoods based on media reports and whispers of information whilst still recovering from and facing the threat of Ebola, COVID-19 and other diseases, trust is eroded and a community already wary of the system, when faced with poor policies and poor communication, fall into the lower-left-hand box of Figure 2.

Military and legal enforcement of policy

Coercive government responses to epidemics lead to resentment and mistrust. For example, compulsory cremation in Monrovia at the onset of Ebola in 2014 led to mistrust in the response and the proliferation of secret burials (Abramowitz 2017). Also, during the COVID-19 pandemic, it has been argued that its impact had been exacerbated by military involvement: for example, comments from South Africa argued that the ‘heavy cross’ of COVID-19 had been made heavier by military involvement (Grant & Sams, 2023). Others referred to the COVID-19 pandemic as a ruse for increased control of the population. There were many examples of violent enforcement of lockdowns and other restrictive policies. For example, before there was any official communication or local experience of COVID-19, a Ugandan village experienced extreme social unrest: ‘this corona is making our people be beaten by the Army men’ (Grant & Sams 2023).

During COVID-19, heavy-handed ‘preparedness from above’ forced people to ‘prepare’ in a way that impacted them negatively. COVID-19 measures in Uganda included a succession of restrictive and militarised lockdowns and forced hospitalisations, in a context of political oppression and national elections, during which time COVID-19 cases and mortality in Uganda remained very low (Parker *et al.* 2020). This damaged livelihoods and increased resentment and distrust amongst local populations, for example in rural areas market closures and people not being able to reach farms where they grew their food (Baluku *et al.* 2020, MacGregor *et al.* 2021). Village fieldwork discovered women being beaten, men being fined (and wondering if these are official fines or to line the pockets of the military) and facing extreme threat to their livelihoods (Baluku *et al.* 2020). These villages have a history of repeated externally imposed disease problems and to increase trust, an improved overall system and improved policy-making, communication and enforcement would be needed (blue section of Figure 1). This has happened in other epidemics: for example, stories of structural violence during Ebola helped explain why the epidemic became an epidemic of fear—of ‘Ebola panic disease’ not just Ebola virus disease and trust in agencies and communities were key to control efforts (Leach 2014).

When considering how to enforce policy, it is important to consider that the WHO model of response, and the way it has been enacted in developed countries, for example through lockdowns, can be experienced differently in different contexts. In Uganda, soldiers were the first prioritised group for vaccines, and allegedly there was 100% compliance. This only increased its association with a distrusted militarised state (Parker *et al.* 2019). Responses from below, supported by community-led communication, which make sense to people and are more ethical and humane, could change the experience of this, and future, disease burdens into something more manageable for these villagers, as there would be increased trust and compliance and less need for excessive enforcement of policy (Baluku *et al.* 2020, Grant 2018, MacGregor *et al.* 2022)

Infodemics and social media (mis)information

Once these policy considerations have been made, the challenge then moves towards replacing ‘wrong’ with ‘right’ information, in world that is increasingly connected by social media and technology, and restoring perceived lack of trust in public health institutions. A shift in the COVID-19 pandemic was the idea that the public face an excess of information and are vulnerable to mis- and disinformation and there needs to be ‘infodemic management’ (Grant & Sams 2023, Sams *et al.* 2022). Whilst social media use was also widespread during previous outbreaks, for example, Ebola, Zika, and Nipah, the lack of human contact during the lockdowns made it an even more important connection (Grant & Sams 2023).

Technology and social media were used on an immense scale to keep people informed, productive and connected during the COVID-19 pandemic. Social listening and infodemiology can be used to make practical improvements by translating data into actionable insights based on community sentiment. Social media can have a role in amplifying and gaining access to unheard voices and narratives that emerge, especially during lockdowns, as usual social contact is halted. However, caution is needed, as the ‘infodemic’ also continues to undermine the global response and jeopardise measures to control the pandemic.

Social media has changed the way organisations communicate with their stakeholders as well as providing new opportunities for stakeholders to engage in direct dialogue both with organisations and with each other. Social media documents in real time the cultural and political–economic contexts, community responses and reactions. A deficit of trust in medical science, and/or in those developing or delivering technologies can be amplified during ‘infodemia’, but communication and engagement can strengthen and build trust (MacGregor & Leach 2022). This shows the importance of a transdisciplinary approach, looking from both a biomedical and social perspective, ensuring different actors work together (Grant & Sams 2023).

As mentioned above, rumours and mistrust can cause a real impact, such as the polio vaccine being banned in parts of Nigeria, and social media can amplify rumours such as viral tweets suggesting that the COVID-19 vaccine was developed to cause harm and reduce the world population (Grant & Sams 2023). Knowledge of these rumours can help plan a response. There is an opportunity to use social media, WhatsApp groups and other new technology and communication tools to communicate messages to communities, understand and hear rumours that are circulating and get access to real-time data on what conversations are being had around outbreaks.

Conclusion: the role of interdisciplinarity and social science in understanding how to gain trust and provide solutions

Research has shown that trust during pandemics is not only about trust in medical providers, it is bound up in trust in governments, communities and societies. This is tied up in arguments for transdisciplinary policy that understands that trust during pandemics, and indeed pandemics themselves are not just biomedical issues, but social ones as well. De Ver Dye *et al.* (2020) recognised that ‘COVID-19 is equally—if not more—a socially driven disease as much as a biomedical disease’. Even before COVID-19, researchers had long noted the connections between socio-economic inequalities and infections, and there is growing recognition that policy makers need to consider social, political and economic issues as key to pandemic preparedness and response (Bardosh *et al*. 2020).

The conceptual framework presented in this paper brings together all of these issues and shows the interrelationships between historical and social context and policy decisions and how trust is central to the interplay between these and the outcomes of epidemics and pandemics. Thus, showing that adopting context-blind approaches to epidemic response that ignore local realities and do not consider the levels of trust in government, policy, authorities, medical personnel and in wider society reinforces deep social and economic issues. This further inhibits trust in communities, leading to lower compliance with government policies and contributes towards a further destabilising of trust in that context for the future. To address these issues, policies should be sensitive to the historical and social context and be considerate of the choice of enforcement measures and how they are communicated and discussed. This allows communities to trust in the policies and the context creating reciprocal trust between authorities and communities and paving the way for increased compliance and buy-in in the future.

Controlling and reducing the human costs of pandemics, requires knowledge of social, economic, cultural and political processes, including drivers of trust, vulnerability and risks amongst different parts of the population. Of course, there are difficult decisions to be made: for example, when policies might be detrimental to trust but might be effective to save people’s lives, for example during the COVID-19 lockdowns (Grant & Sams 2023). To advance the field, we need to use evidence to underpin inclusive, appropriate, tailored and responsive interventions which should be led by a range of actors and even emerge ‘from below’ (MacGregor *et al.* 2022, WHO 2022). A transdisciplinary approach looking at both biomedical and social drivers of disease with a focus on bottom-up community engagement, giving voice to differing narratives, would be more effective at preventing the spread of disease while mitigating other negative outcomes. Interventions can be attuned to different contextual realities, ensuring that they are proportionate, considerate to vulnerabilities and social inequalities and socially just. Hearing from people about their priorities, or concerns about other prevalent health and livelihood issues, is key to a proportionate and effective response that people understand and trust, alongside an approach involving multiple actors and narratives.

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