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Inherited blood disorders, genetic risk and global public health: framing 'birth defects' as preventable in India

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ABSTRACT

This paper engages critically with the global assemblage framing sickle cell and thalassaemia disorders as a 'global health crisis'; and the promise of genomics, largely DNA-based carrier/pre-conceptual screening, prenatal diagnosis with a view to terminations, deployed in framing a solution to these historically racialised spectrum of diseases as essentially preventable. Sickle cell and thalassaemia are recessively inherited, potentially life-threatening haemoglobin disorders with significant variation of severity, often needing life-long treatment. I argue that the re-classification of inherited blood disorders (IBDs) under 'prevention and management of birth defects' by the WHO in 2010 can be read as an ethical moment within the 'globalising turn' of IBDs and the use of genomics in addressing structural inequalities underpinning health in low- and middle-income countries. Using an Indian case study, the paper aims at first examining the language of risk through which genes and IBDs are mapped onto pre-existing populations (e.g. caste and tribe) as discrete, categories. Second, it discusses the likely social and ethical ramifications of classifying these recessive gene disorders as essentially preventable, despite cheaply available diagnostic tests and treatment options available in most countries in the South.

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Introduction

Anticipating the philosophical reverberations of the notion of genetic error (mutation) introduced at the turn of the twentieth century, Canguilhem (1991, 172) poignantly observed, 'To be sick is to have been made false, to be false, not in the sense of a false bank note or a false friend, but in the sense of a "false fold" or a false rhyme'. We have since identified 437 mutant genes related to 286 severe childhood recessive disorders, using relatively cheaper and efficient new generation sequencing. The idea of genetic error as a 'false fold' or a 'false rhyme' now implies that it can and must be 'undone'. Preimplantation diagnostics and genome editing techniques pose unique questions for how we address embodiment, genetic risk, inheritance, impairment and disability (see Masae, this collection). Equally, stem cell transplants and gene therapies open up new frontiers of a 'moral economy of hope' (Rose and Novas 2005). The challenge facing anthropologists

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that I find particularly exciting, as outlined by Margaret Lock is: how to recognise the materiality and centrality of biological difference to human health and wellbeing, while critically engaging with the imminent dangers of molecuralisation of race and its implications for essentialising, dehistoricising and depoliticising the biology of human difference and structural inequalities underpinning health (Lock 2012, 131; also see Gibbon 2016; Pagano 2014; Calvo-Gonzalez 2013; Fullwiley 2007; Palsson 2007, 152–162).[1]

This paper engages with the global assemblage framing sickle cell and thalassaemia – a closely related spectrum of two historically racialised, recessively inherited blood disorders (IBDs) – within a 'crisis rhetoric' of contagion in public health being extended to non-communicable diseases across low- and middle-income countries (LMICs; see Parkin, Krause and Alex 2013; Reubi, Herrick and Brown 2016). More specifically, it focuses on the use of genomics, largely DNA-based carrier / antenatal/pre-conceptual screening and prenatal diagnostic tests (with a view to terminations), deployed in governing these disorders as essentially *preventable* in LMICs (WHO 2002; 1994). I argue that the re-classification of IBDs under *prevention and management of birth defects* by the WHO (2010) can be read as an ethical moment within the 'globalising turn', aimed at addressing structural inequalities underpinning health in LMICs. It unravels 'competing truth claims' seeking to address the burden of disease, death and the suffering of children within the context of international and national developmental goals (Shiffman 2009). An Indian case study is used to analyse how the language of risk, prevention and elimination of IBDs, silences the racialisation of historically marginalised ethnic/social groups embodying these 'deleterious genes' and the threat they seem to pose to public health within a specific national context (see Calvo-Gonzalez 2015; Thomas and Clarke 2013; Cavalcanti and Maio 2011; Tapper 1999).

In this paper, significant differences in the broader histories of sickle cell and thalassaemia, briefly touched upon later, are ignored so as to focus on the space carved by international and national policies where these disorders are placed together.[2] My analysis draws on three main data sources collected over the past four years in anticipation of a grant for a detailed ethnography[3]: (i) policy documents related to IBDs within central, state and international domains, (ii) scientific papers and community surveys (often citing data from the Indian Council of Medical Research (ICMR) or the Anthropological Survey of India) and (iii) media reportage of recent events and policy issues raised by prominent health activists and non-governmental organisations (NGOs). In particular, I have shadowed Sickle Cell Society India (SCSI) – interviewing key members, observing four community engagement events in Maharashtra (December 2016), and observing their participation at the 3rd Global sickle cell congress in Bhubaneswar (February 2017). My objective is not to validate a particular truth claim rather to identify some of the 'therapeutic gaps' (as in Simpson 2007) being addressed through diverse forms of activism, and state and non-state partnerships in view of particular, local health interventions (Biehl 2016; Simpson 2007).

The two aims of the paper are to discuss the likely social and ethical ramifications of classifying a complex, heterogeneous spectrum of recessive gene disorders as essentially *preventable*, and focusing on the potential *suffering* of infants and children (excluding adults), despite cheaply available diagnostic tests and treatment options available in most countries in the South. Second, I want to analyse the seemingly contradictory influences

of the policies and practices of different actors on the governance of health and reproductive rights of marginalised populations in poorly regulated healthcare systems in countries such as India (Gammeltoft and Wahlberg 2014; Unnithan-Kumar 2009; Chattoo 1991). In problematising the notion of prevention of 'birth defects', one is not contesting the importance of the materiality of IBDs or the suffering of children, especially within the context of extreme poverty (see Das 2015; Das and Das 2006). Instead, as Didier Fassin reiterates:

> … saving babies, … and bringing assistance … is a collective responsibility … . But the fact that this is beyond dispute does not imply that we should not challenge the way the mission is conducted, the implicit logic it reveals, the specific interests it may serve, and the contradictions and misconceptions that it may provoke. (Fassin 2013, 128)

One of the major contradictions explored by Fassin through his work on AIDS in South Africa, and Veena Das in her study of health of the urban-poor in India, relates to the abstract notion that all lives are equal and must be saved, and how international humanitarian policies on aid and state interventions and distribution of resources, in practice, reflect different values placed on life and 'letting die' (Das 2015, 181–202; Fassin 2013, 2007 following Foucault 1991, 2003).

Before outlining the Indian policy context, a note on the reclassification of IBDs is helpful to set the global scene.

Crisis rhetoric, politics of classification, and (in)visibility of suffering

In her evocative ethnography of 'sickling' in Senegal, Fullwiley outlines the struggles of clinicians, patient advocates and NGOs, since early 1990s, in challenging the political neglect and invisibility of sickle cell by the World Health Organization and the United Nations (Fullwiley 2011, 9–10). IBDs have since been reconstituted as a 'global health crisis' posing specific challenges and solutions for high-prevalence countries in the South (Piel et al. 2014; Weatherall and Clegg 2001; WHO 1994). David Weatherall, a renowned haematologist trying to raise the profile of IBDs (paradoxically), observed:

> … It has been estimated recently that if the survival rate of children with sickle cell anemia in Africa increases to only one half the African norm, more than 6 million Africans will be living with sickle cell anemia … . We are, in effect, sitting on a *genetically determined time bomb*. It is time for action. (Weatherall 2010)

Importantly, this impending crisis is perceived to have significant implications well beyond the borders of high-prevalence countries in the South, as can be gleaned from the following excerpt from a widely cited Lancet paper, forecasting the redistribution of sickle gene as a global phenomenon (co-authored by Weatherall):

> … . International migrations can also have a long term effect on public health through the introduction of deleterious genes into populations in which they were previously absent … (Piel et al. 2014, 1)

(Further on)

> In the absence of a curative treatment for sickle cell disorders, … prevention programmes are essential strategies to reduce the subsequent long term economic and health burden. Rather

> than suggesting *strict immigration policies*, our findings emphasise the need for an *international* approach to prevent such genetic health disorders globally. (Piel et al. 2014, 6 my emphasis)

Needless to say, the 'global assemblage' IBDs as a 'crisis' can be read in several registers of competing 'truth claims' (Shiffman 2009, 608), situated across a contingent, heterogeneous, unstable, partial, and contested field (Ong and Collier 2005, 11–12). Despite different bio-political underpinnings of interventions for the prevention and management of IBDs, three sets of issues framed within the neoliberal project of global governance of health and 'humanitarian morality' emerge (Thomas and Clarke 2013): (i) a concern for the welfare of affected children in LMICs; targets for reducing IBD-related infant and under-five morality, (ii) the economic logic of reducing the long-term costs of care, anticipating greater demand for treatment as more children are diagnosed and survive to live with such genetic disorders, and (iii) a public health approach to prevention focusing on potential carriers, who themselves are 'healthy' but can 'pass on' the disease to their children through reproduction. Hence, carriers reify body as a 'frontier of risk' (Lock 2012) and have been the focus of state control and prevention policies (Tapper 1999; Cavalcanti and Maio 2011). Such articulations reflect a configuration of influential actors and strategic epidemiology that shapes the 'biolegitimacy' of particular rights related to health rather than empirical evidence reflecting the needs of those affected per se (Fassin 2012, 51). For example, while sickle haemoglobin affects10 per cent of the population in Senegal, 30 per cent of state health budget is committed to HIV/AIDS programmes (Fullwiley 2011).

Previously, the International Classification of Diseases (ICD) 10 included thalassaemia (D56) and sickle cell disorders (D57) in Chapter III, covering 'diseases of the blood and blood forming organ', rather than Chapter XVII on birth defects and chromosomal abnormalities. Subsequently, the 63^{RD} World Health Assembly report on birth defects included IBDs in the list of the 'most common serious congenital disorders'. Here, both genetic and environmental congenital disorders ae lumped together, making a broad case for prevention – an ethically contentious issue that cannot be explored here. More specifically, the document links *prevention* of IBD-related *births* to the Millennium Development Goal (MDG4) of two-thirds reduction in under-five mortality by 2015. It emphasises several interventions for preventing births, before outlining standard treatments and benefits of newborn screening- an important preventive strategy aimed at early diagnosis, known to produce better treatment outcomes with reduced mortality for children (WHO 2010).

Humanitarian concerns about potential suffering of children in LMICs, where 70–90 per cent of affected babies are expected to die before the age of five, are based on an assumptions that no treatment is available or economically feasible (for a critique, see Fottrell and Osrin, 2013 [on Piel et al. 2014]; Fullwiley 2011). On the contrary, newborn screening for sickle cell in Ghana, with the use of antibiotics for preventing known infections, and adequate treatment and compliance for beta thalassaemia in India, show that average life expectancy around 55 years can be achieved, comparable with outcomes in the North (Grosse et al 2011; Agarwal 2004). The likely reverberations of a focus on prevention (of births) for particular populations will now be explored through the specificities of an Indian case study.

Mapping genes onto cast, tribe and race: the 'shifting metonymies' of haemoglobin variants

India provides an important conceptual link to the broader history of globalisation of IBDs, and the discursive practices through which complex genetic mutations are mapped on to pre-existing 'populations'. The point at issue here is not that some of the gene variants resulting in IBDs might be more common among certain ethnic groups or regions of the world/India.[4] Rather, in mapping genetic differences on to existing social divisions, genomics both sustains and challenges ideas of descent, ancestry, origin, ethnicity and nation (Calvo –Gonzalez 2015; Beaudevin 2013; Carter and Dyson 2011). As cogently argued by Kent, Santos and Wade (2014, 737):

> These genomic techniques involve the concept of biogeographical population: a set of people thought to have evolved a genetic profile in a given location and transmitted to their descendants. A key question is how to define such populations - given that humans share 99 percent of their DNA – and whether these populations relate to modes of social classification, such as ethnic group, race, nation, region, community, and so forth.

In their classic article, Lehman and Cutbush, first documenting the presence of sickle cell gene in India, summarised the thesis of its 'African' origin as follows:

> The aboriginal tribes were chosen as the group in whom a search for African blood features appeared most likely to have positive results (Nilgiri Hills, South India). … . These findings lend support to the idea of an Indian migration to Africa in prehistoric times… (Lehmann and Cutbush 1952, 404)

The story of the 'Indian-Arab haplotype' is central to destabilising the notion of sickle cell as the archetype of a racialised, black disease – if only to be replaced by a mesh of local idioms of caste, tribe, race, ethnicity and class. Equally, the Indian case study also challenges the notion of genes and genetic disorders as stable, mutually exclusive biological categories (also see Beaudevin 2013). Thus, while 6–7 common mutations account for 80–90 per cent of the mutant alleles associated with significant forms of sickle and thalassaemia, clinical literature highlights the molecular heterogeneity of around 64 mutations, with complex homozygous, heterozygous and double heterozygote forms – some less benign than others (Verma, Saxena and Kohli 2011).

It is fascinating to note how the debates surrounding haemoglobin variants (causing IBDs) in India mirror, what Mukharji (2014, 145) evocatively describes as, the myth of origin and, 'the shifting metonymies of Blood group B'—perceived as a genetic marker of racial groups and caste hierarchy at the turn of the twentieth century (see Sen 1960). Ever since the first Anthropological Survey of India (1950s), data on incidence of IBDs by *jatis* (sub-caste) and tribe is cited in studies by clinicians as well as physical anthropologists. The legacy of sickle cell being essentially a 'tribal disease' persists, despite evidence of significant variations within tribal groups, following similar kinship and (consanguineous) marriage patterns (Urade 2012; Mohanty and Das 2011). This is not the place to engage in a semantic discussion on the pre, colonial and post-colonial intersections of caste, tribe, race, religion and ethnicity in relation to the strongly contested nationalist theories of Dravidian – Indo-Aryan races. Suffice it to mention here that the *adivasi* (so called aboriginal) or tribal groups sit awkwardly squeezed between the dominant notions of caste/Hindu society

on one hand and nationalist/civilizational and developmental discourses on the other (for a broad overview see Xaxa 2003; Bates 1995).

The colonial history and administrative function of categories such as 'scheduled caste', 'scheduled tribe' and 'other backward classes' invoke notions of race, ethnicity as well as socio-economic 'backwardness' (see Nigam 1990 on the Criminal Tribes' Act 1871). Subsequent to several tribal movements over land rights, loss of livelihood, and authoritarian public health interventions, since independence, these categories have served as a basis of anti-discrimination laws and reservation policy in education and employment, guaranteed under Article 341 (1) of the Indian Constitution (see Berreman, 2009). Hence, 'strategic essentialism', in Glick Schiller's phrase (2005), is important for seeking *recognition* and redressal of socio-economic inequalities at a policy level – albeit one that both subjectifies and objectifies the minority ethnic/religious group in question (see Xaxa, 2003).

Irrespective of these features, the intriguing question for this discussion remains: what purpose do these categories serve in clinical literature? The following excerpt from a paper on the challenges of genetic counselling in tribals, using 2001 Census figures, is illustrative:

> There are many (pre/agricultural/nomadic) tribal groups identified for their specific biological constitution, anthropogenetic characterization, distinct cultural and linguistic patterns and confines geographical localization… In many tribal groups distinct Negroid feature of appearance is seen (e.g. Jarawas, Ongs of Andamans…) whereas in many, mongoloid origin is traced (Khasi, Garos of North East)… . … Studies done on blood groups and immunity related genes have shown … sets of alleles which are exclusive to certain geography and ethnic groups. (Mohanty and Das 2011, 562–63)

However, like others, the authors go on to concede that

> Earlier postulations … of HbS gene being only limited to tribal and lower caste population have been changed as the gene has been found in almost all the communities … with preponderance among the Indian tribes. In Orissa, the gene is prevalent among the general castes (0.3–20.7%), scheduled castes (0–8.9%) and scheduled tribes (0–5.5%). (ibid, 563)

Even when social and geographical mobility of tribal groups is recognised within clinical and policy documents, the threat of the mutant gene spreading to urban geographies and miscegenation looms large (Ghosh, Colah and Mukherjee 2015, 506). While 635 tribal groups, living predominantly in inaccessible rural and forest areas, constitute 8.8 per cent of the Indian population, they represent over 25 per cent of the poorest across India. Their lives are still characterised by disproportionately high levels of malnutrition, anaemia, common infections as well as higher infant mortality rates of 100 per thousand rather than overall 80 for India, marking the 'local biology' of the disease (Jan Swasth Sahyog 2016). It is not surprising that the Editor of a special issue on tribal health, in the *Indian Journal of Medical Research*, qualified IBDs as 'poor man's diseases' (Singh 2015; also see Colah et al. 2015, 510). The importance of these structural features of poor health indices of tribal children for prioritising prevention of IBDs over better and accessible care will be discussed later.

Locating IBDs within health policy in India: the 'seeping in' of the local and the global

To provide a broad policy overview, India is estimated to have the largest number of carriers of IBD in the world, around 42–45 million of a population of 2.1 billion.

Approximately 7500–12,000 babies with Beta thalassaemia and 15,000–25,000 babies with sickle cell disorders are born each year (Colah et al. 2015).[5] The epidemiological picture is characterised by striking inequalities in access to appropriate, long-term healthcare across public and private sectors, especially for the poor, rural and tribal communities living at the margins of the state- as suggested earlier (Government of India 2016b; Chatterji and Gunjan 2007). Even though cheap diagnostic kits and generic drugs as well as curative bone-marrow and cord- blood stem cell transplants are widely available at several state and private healthcare centres across India, only 5–10 per cent of children with thalassaemia receive optimal care (Malik et al. 2010; Chandy 2008).

Lack of access to cash and affordable healthcare pushes roughly 39 million Indians below the poverty line (Reddy et al. 2011). As elsewhere in the world, access to treatment has been a central feature of health activism since mid-1999s, with public-private partnerships mediating the role of giant pharmaceutical companies (Nguyen 2005). However, following Biehl, we must ask, are there ways in which these affiliations, '… endow states with new (sometimes abusive) powers while also diversifying claims to citizenship'? (2016, 130). I want to foreground this question by analysing how the two main constituencies – (state) public health policy, and NGOs and online patient communities – represent the needs of people with IBDs and engage with policies of prevention outlined earlier.

It is important to note that right to healthcare is a positive rather than a protective right within the Indian Constitution. However, since the 1990s, in response to several public interest litigation cases, the Supreme Court has treated *right to health* as an extension of the fundamental *right to life and dignity* guaranteed under article 21 of the constitution (see for example, Archive Indian Express, 19/12/2013, for one such petition filed by parents of an 8-year old: http://archive.indianexpress.com/news/hc-seeks-reply-from-govts-aiims-on-free-treatment-for-thalassemia-patients/). Individual states are responsible for maintaining data, providing healthcare and regulating professional practice, though both state assembly and parliament can legislate on health policy. There are no national policies related to IBDs in India, though periodically these might be nested within larger health programmes. For example, the National Rural Health Mission (NRHM) (set up in 2005 to help the states achieve the Alma-Ata target of universal health coverage) focuses on vulnerable groups, and reducing under- five and maternal mortality rates, in line with the (expired) MDGs 4 and 5. Closely related *Rashtriya Bal Swastha Karyakam* (RBSK, national child health and early screening and intervention programme for 0–18 years, 2013) covers 30 conditions, and item 30 includes congenital disorders and IBDs. States and Union Territories, however, have the option of including screening and intervention policies, based on local epidemiology.

Similarly, the Working Group on the Disease Burden for the 12th Five-Year Plan (Section 2, item 21), covers prevention and management of IBDs within programmes of prevention and rehabilitation of disability, highlighting cooperation between state and NGOs, perceived as representing the interests of patients (Government of India 2012). These NGOs, however, are often set up by local clinicians/activists working closely with the state and/or the ICMR. Following a consultation, the National Health Mission recently published guidelines on prevention and control of IBDs which, however, are more on literature from Cyprus and elsewhere than the needs of

local patient populations across India (Government of India, 2016a). In letter, the guidelines refer to the WHO recommendations on ethics of non-directive counselling, informed consent and cultural sensitivity about plural reproductive norms and disability (National Health Mission, 2016). The reality of how screening and counselling are actually implemented at state and local levels, especially in rural and tribal areas with high levels of minimal literacy, has received little attention (Mohanty and Das 2011; Patra and Sleeboom-Faulkner 2010, 73–75).[6]

Gujarat Sickle Cell Anemia Control Society is a good example of the 'bioavailability' of vulnerable groups (cf. Cohen 2004) within the space carved by the NRHM, as well as the state-NGO partnerships outlined in the 12th Plan above. The Society was set up in 2011 by a group of clinicians in the state service to 'better integrate' the Sickle Cell Anemia Control Programme (Gujarat Health Government portal n.d). Supported by the NRHM and the local health authorities, the plan was piloted in 5 districts in South Gujarat in 2006, later extended to 12 tribal districts involving 446 centres by 2013–2014. The team worked in collaboration with the Indian Red Cross Society, and *Valsad Raktdan Kendra*, a local (NGO) blood centre catering to the needs of sickle cell affected families since 1984. The three main goals of the Programme were (i) to eliminate *all* births related to SCD by 2020 (MDG4 target), (ii) prevent deaths from SCD, and (iii) to improve the health and quality of life of people suffering from these disorders (Gujarat Health Portal, nd). Implemented by the epidemic branch of the Ministry of Health, it was called sickle cell *swa* (self) *surakhsha* (protection) *abhiyan* (movement) (Patel et al. 2013). The target of reducing under-five mortality (MDG4) was translated into a rhetoric of *no births of children with SCD by 2020*; while attempts at reducing maternal mortality (MDG5) resulted in an increase in institutionalised births, leading to a higher number of prenatal diagnoses and terminations carried out for sickle cell. Antenatal carrier screening was 'offered' to all women on *Mamta divas* (mothering day) designated for immunisation in the tribal areas (Department of Health and Family Welfare (nd), 22). On a positive note, the policy included newborn screening, access to free treatment and follow up for children and adults diagnosed in tribal areas. The Commissioner for Health received a national award for successful outreach in the tribal areas, portraying a success story.

However, there has been little discussion on how the antenatal and newborn screening was implemented alongside community screening of children and adolescents, promoting an ethic of *genetic exogamy*. Gujarat is not the only state where carriers are advised to match their genetic *kundali* (profile/ test result) rather than *janam kundali* (horoscopes, widely used by Hindus constituting 80 per cent of the population) in arranging marriages. The catchy soundbite pre-empts the potential risk. Two carriers together have a 25 per cent chance in each pregnancy of having a homozygous baby (or 25 per cent risk of having a normal baby and 50 per cent chance of having a heterozygous/carrier). Despite positive, though contradictory, promises of cash rewards for those willing to marry a person with sickle cell anaemia, community screening can reinforce stigmatising attitudes, especially towards young girls and women who might face greater discrimination within their community (Patra and Kumar 2010; Gupta 2010; Chattopadhyay 2006).

The current Prime Minister, Narendra Modi (Gujarat Chief Minister, when the above policy was implemented), has endorsed similar projects at a national level. The most extensive of these being the *Jai Vighyan* (celebrating science) thalassaemia control programme, based in six high-prevalence cities, supported by the IICMR (Mohanty, Colah and Gorakshakar 2008). Furthermore, the Ministry of Tribal Affairs planned to screen 5 million tribal children across 10 tribal dominated schedule V states, starting with schools and hostels run by the Tribal Welfare Department and community groups, advising them against marrying a carrier (*The Economic Times*, 4 May 2015). A glimpse of the relationship between the state health officials and these tribal groups, in the following report, is reminiscent of the Raj:

> In tribal society the different socio-cultural activities revolve round gods and spirits… . (assuming they are endogamous) Those who were detected to have sickle cell gene, were asked to tattoo their hands in the form of god and they were told that they should not get married to another individual with similar god. This worked out well amongst young tribal adolescents of Satpura hills among whom the selection of partners is still done by young girls and boys themselves. (Mohanty and Das 2011, 567)

The economic logic of such national 'missions' is summarised in a Delhi Ministry of Health Report, stating that the public health costs of treating about 2000 children born with thalassaemia each year in Delhi (100,000–120,000 rupees a year) are 'unbearable'. 'It would therefore be preferable to prevent the birth of a thalassaemia child. This can be achieved through screening of pregnant women and school children for thalassaemia carrier state' (Ministry of Health 2014; also see Gupta 2010, 48). The use of mandatory carrier screening of pregnant women, with a view to identifying 'high risk' couples, who are advised termination following a positive diagnosis, in conjunction with provision of free blood and chelation therapy offered in state hospitals in Delhi and Gujarat, is a good example of 'benign authoritarianism' (cf. Das 2015, 200–201). Needless to say, some health professionals are critical of the ethics of population screening in remote, rural areas, where no treatment or follow up is provided (personal conversation Yogesh Jain, Director JSS, London, 28 April 2017).

The tensions inherent in the notion of *eliminating* genetic disorders, and carrier screening of children and young adults, however, are equally reflected in the practices of NGOs and online patient support groups. In Maharashtra, Rotary Club of Mumbai (supported by TIF, staunch supporters of prevention) and We Care Trust run carrier screening programmes in schools and colleges, persuading head teachers and college principals to 'motivate children' to undergo screening. They also organise community campaigns, advertising car bumper stickers with the message – 'check your blood not horoscope – to nip thalassaemia in the bud' (We Care Trust, homepage, http://www.wecaretrust.net/). Clearly, these NGOs fill in important gaps in state provision for information and social support -though, sadly, with little reflexivity about how their own practices might reinforce the negative imagery of IBDs and associated notions of impairment and disability within the wider society.

While sickle cell organisations are fewer in number and less visible virtually, despite fighting for small pots of money locally, they might work together with n a larger thalassaemia organisation (as in Delhi and Bangalore). These NGOs can provide practical support, subsidised tests, treatment and welfare advice, as well as act

as a pressure group for health issues of equity and change (see Unnithan and Heitmyer 2012). Some of the battles fought by small organisation, such as the SCSI, are quite exemplary, as explained below.

SCSI and Ramteke's crusade for justice and equity: taking on the state

I first met and interviewed Sampat Ramteke, a retired superintending engineer and President SCSI, in March 2015, at his residence in Nagpur. Ramteke's journey into the world of sickle cell, prompted by his son's illness, is documented in a short tele-film entitled (translated), I kept walking along with life (www. Sampat ramteke/ me *Zindagi ka saath nibhata chala gaya*). Born into a poor scheduled caste (Mahar) agricultural family from a remote village in Chimur, Chandarpur District, Ramteke did exceptionally well to get a diploma in engineering, progressing to a senior position in a coal company. His biographical details are central to the aims and functioning of SCSI. Ever since his son's diagnosis about two decades ago, he has worked ceaselessly to raise awareness about the condition, lobbying for better medical and welfare support especially for the rural and socio-economically deprived families. His tiny office is lined with meticulously filed correspondence with bureaucrats and newspaper cuttings related to his work. Rather than the logistics of how this tiny organisation of seven executive members operates in relation to the state, without external funding, I want to focus on some of the policy interventions they have successfully lobbied for.

Ramteke explained how one needs to 'get under the skin' of appropriate legislation, and the perseverance and political acumen required in fighting the bureaucracy, to achieve a goal that might take years. One of the eight 'schemes', proposed by SCSI and now implemented by the Maharashtra government, was to provide a free bus pass to parents/patients living in remote villages, to help them travel to a treatment centre. A trip costing a family roughly 400 rupees can, at times, make the difference between life and death, in accessing timely care for children prone to 'crisis events' (*Times of India*, Nagpur, 11 December 2015). Furthermore, following advice from SCSI and an expert panel, Maharashtra State Secondary and Higher Education Board, since 2013–14, have kept a provision of 20 minutes extra time for each question to be availed by sickle cell patients/students writing their class X and XII Board examinations (*Times of India, Nagpur Today*, 10 June 2013). More importantly, in January 2013, SCSI challenged the exclusion of sickle cell from the (Draft) Rights of Persons with Disability Bill (RPWD) 2012, at an important hearing of the National Human Rights Commission on the issues of scheduled castes and scheduled tribes. At that stage, thalassaemia and haemophilia had been incorporated within an expanded, original list of disabilities drafted in the RPWDB Bill, 2012. The relative invisibility of sickle cell, within such policy contexts, largely reflects its clinical variability, periods of intermittent painful crises and adverse health events interspersed with stable periods where patients may not see a doctor for months or even years. In contrast, the need for regular blood transfusion and chelation treatment brings families and patients with β thalassaemia into greater contact with health professionals, blood banks and NGOs that are better resourced and urban centred.

Taking recourse to metrics, Ramteke convincingly argued that sickle cell causes multiple disabilities, affects nearly 1.4 million children and adults, twice the number

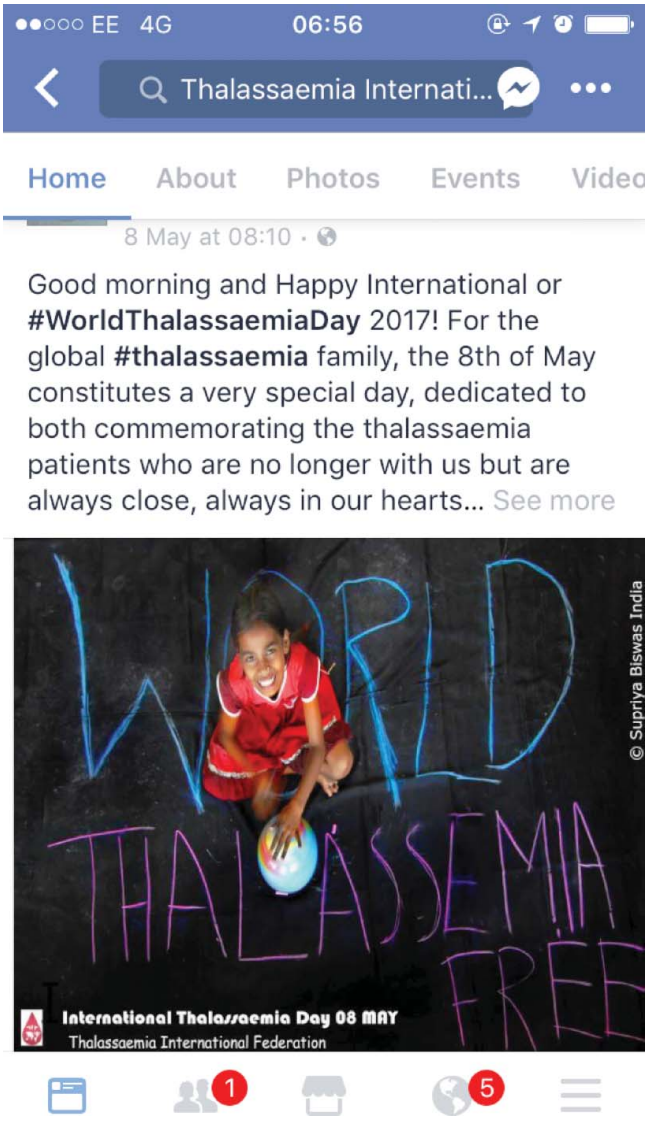
affected by the other two disorders put together, largely from remote, rural and tribal areas. (*Times of India*, Nagpur, 29 January 2013). In a significant move, he approached the Chair of the National Commission on Scheduled Castes and the Parliamentary Committee on Scheduled Castes and Scheduled Tribes (Times of India, Nagpur, 19 April 2013). Subsequently, the revised RPWD Bill of 2014, providing significantly enhanced rights and entitlements for people with disabilities, was extended to19 conditions including sickle cell (Kala and Shankar 2015). On the day the Bill was passed (16 December 2017), we were in Gadchiroli for the state sickle cell week. The sense of pride and jubilation was palpable in the team, as friends and colleagues kept ringing to congratulate Ramteke over his success.

Interestingly, in our conversations and public meetings, Ramteke underplays the notion of sickle cell being a 'tribal disease'. In his *marg darshan* (literally, path showing) speeches at community awareness events that I attended, he would pose a (retrospectively rhetorical) question to his audience, 'Which *jati* (caste) do you think is most affected by sickle cell?', or 'Why do you think, people get this disease?' At times, the response was anecdotal reference to people who eat 'gaye ya baiel ka mas' (beef/ bull, denoting 'other', lower castes or tribal people contravening dominant (idealised) Hindu norms of a diet free of meat and/or beef. He then pulled out an extensive list of castes/*jatis* and tribes affected by sickle cell, based on published scientific reports; reiterating that sickle cell can affect people from different religious, caste and ethnic backgrounds.

Shiffman uses 'policy window' for a moment in time when global (national/local) interventions are favourable to a cause, and particular sentiments are deployed for a greater impact (2010, 2045). Ramteke researches his 'facts' and uses every 'policy window' to galvanise support across several platforms – welfare rights of children, women, the disabled as well as the marginalised SCs and STs—with his 'pen power' and sheer perseverance. Ironically, one of his 'missions' is the implementation of legislation similar to the infamous Sickle Cell Anemia Control Act 1972, introduced by President Nixon. The Act, deemed central to achieving full citizenship rights for black Americans during the Civil Rights Movement in the USA, also generated resistance to the widespread discrimination in education and employment, and carrier screening perceived as a form of 'racial genocide' (see Wailoo 2017; Tapper 1999; Duster 2003). However, Ramteke is not alone in his belief in mandatory carrier and antenatal screening as a progressive step towards achieving a 'sickle cell free' India. I turn briefly to this theme and its contradictions in the penultimate section below.

Contradictions within a crisis rhetoric – the promise of genomics and a nation free of thalassaemia?

On World thalassaemia Day (8 May) this year, Shobha Tuli, President,[7] Thalassaemics India, called for a national policy on thalassaemia to prevent, control and provide treatment across India – the designated 'thalassaemia capital' of the world (Afhshan Yasmin, *The Hindu*, Health, 'Time for a national policy on thalassaemia', 7 May 2017). Namitha K. Malur, a Bengaluru based health researcher and activist (herself a thalassaemia patient),[8] updated her Facebook profile with the following message: 'On the eve of the world thalassaemia day I wish for thalassaemia free India' – echoing the message posted on the TIF website.



(Image 1. Source Facebook status, TIF, 8 May 2017).

In response to an intensive campaign led by Namitha and the Thalassaemia and Sickle cell Society, Bengaluru, the Karnataka state government announced a series of measures on the World Thalassaemia Day, including free transfusion and treatment for thalassaemia, sickle cell and haemophilia patients irrespective of income, and free antenatal screening for pregnant women (up to 12 weeks). At a press conference following the announcement, Namitha outlined the demands of her constituency: (i) a national policy on IBDs, (ii) full inclusion in Disability Bill to avail 4 per cent reservation in jobs and education (currently limited by the level of certified disability), and (iii) full inclusion in the national rare diseases policy (the *New Indian Express*, 9 May 2017). The reference to inclusion of IBDs under rare diseases policy is strategic. The policy, drafted by Namitha and her colleagues from several institutions, in March 2016,

highlighted the need for public-private investment in diagnostics, orphan drugs and curative gene therapies, for an estimated 70 million patients across India (*The Times of India*, 2 March 2016).

I find the juxtaposition of images of gene therapies and orphan drugs alongside metaphoric images of an epidemic of carriers spreading the disease, and the disablist reverberations of elimination of thalassaemia (or sickle cell), disturbing and hard to grasp. Similarly, a flurry of online posts in praise of a recent Bill on compulsory premarital screening, passed in the Pakistan National Assembly, did not touch upon the thorny ethical issue of mandatory carrier screening and its social ramifications (see Raz 2010). I am not denying that Namitha along with other academics, or indeed other patient activists, might be having these debates elsewhere. Indeed, I am aware of the several forums on difference and disability supported by Namitha and the Centre for Health Ecologies and Technology (where she works).

We saw how, despite their contrasting urban/rural bae and styles of activism, both Ramteke and Namitha adopt forms of 'strategic essentialism', increasingly taking recourse to disability rights legislation in fighting for the rights of people with IBDs. However, in uncritically advocating or appropriating state policies prioritising prevention aimed at eliminating the disease – the glaring contradictions related to how these policies reproduce forms of 'stratified disability' are completely ignored (cf. Ginsburg and Rapp 2013, 161). Some of these engagements reflect a broader ethical dilemma, earlier intimated in Canguilhem's idea of 'undoing a false rhyme' – i.e. the expanding use of genomics and genetic tests seem to 'erase the very category that you are trying to preserve' (Friedner and Weingarten 2016 for a review).

Concluding reflections

Earlier it was suggested that a language of epidemic and carriers reifying the body as a 'frontier of risk' (Lock 2012) might silence the racialisation of historically and socio-economically marginalised ethnic groups caught at the margins of the benevolent and repressive functions of the state. India, in particular, has a long history of state abuse of abortion and sterilisations as a means of controlling the re-productivity of such communities (Jeffery and Jeffery 2011; Hodges 2006; Chattoo 1991). Given their economic vulnerability, it is not difficult to imagine how the political (in)visibility of 'tribal health' in general and IBDs in particular might constitute a space where the public health targets of prevention and population control overlap. This is brought to sharp relief in a paper by R S Balgir, a well-cited senior scientist (at the time, Deputy Director (ICMR) Regional Medical Research Centre for Tribals, Jabalpur). Looking at the incidence of sickle cell and other haemoglobin variants in a sample of 81 Dhelki Kharia tribal families from Sundargarh district in Orrisa, Balgir observes:

> The poor, illiterate tribal communities, which are at the verge of extinction, can not afford even the minimum standard of living and the treatment of an affected child is beyond their expectation in India. The practical deprivation of infrastructural health facilities, lack of adequate resources for treatment and lack of any source of entertainment in their isolated habitat in the dense forest cover are the added disadvantages of the tribal communities in India. *Reproductive pleasure and sex life is the only entertainment source* under such environmental conditions.

(further on)

> … the tribal people go on producing children (2-6 children) regardless of their resources. If the couple inherits any defective gene(s), those abnormal genes go on multiplying in the community because of a large number of offspring productions. (2010, 360, my emphasis)

Balgir concludes that 'There is an urgent need to contain the spread of preventable IBDs in the underprivileged tribal communities in India', by limiting the family size and preventing new births with screening, counselling and prenatal diagnosis (361). Despite the high infant mortality rate in the state, and the structural deprivation outlined by the author, the national policy norm of the two child family is advocated as the hallmark of development and women's welfare. Furthermore, given the financial constraints of modern life, all eligible (middle class and better educated) couples desire that, 'every child born should be normal' (my emphasis, ibid, 362).

Indeed, the pressures of reproductive outcomes and prevention further complicate the Indian case study when we think of how state sponsored genetic technologies might legitimise the phenomenon of sex selective terminations of female foetuses affected by IBDs (personal conversation with Yogesh Jain, 28 May 2017; see Gupta 2010; Ghai and Johri 2008; for a wider discussion see Unnithan-Kumar 2009; Patel 2007). Equally, the implications of an intersection of gender, genetics and disability set against vicissitudes of extreme poverty shaping 'local biologies' of IBDs remain to be explored (cf. Locke and Kaufert 2001).

In critically engaging with state policies of prevention, I do not wish to oppose and romanticise family and community as benign and benevolent (Chattoo 2014; Das and Addlakha 2007). Anthropological evidence points to the contingent and varied human practices supporting abortion and neglect of fragile or physically impaired infants and children, especially in communities facing extreme poverty and hunger (e.g. Denham, 2017; Allotey and Reidpath 2001; Scheper-Hughes 1996). Nevertheless, analytically, we must treat negotiation of individual reproductive decisions including the use of prenatal technologies as distinct from state interventions for prevention of genetic disorders. Not surprisingly, all the success stories of prevention represent authoritarian regimes and some form of collusion between medicine, state and the Church/religion, going right back to the thalassaemia eradication programme first introduced in Cyprus in 1974 (Kyriakedes 2016), and later imported to several Islamic states including Pakistan.

Historical evidence suggests that prevention of births within the context of racialised/ethnicised disorders often shifts resources away from care – reinforcing existing inequalities in health as well as discriminatory attitudes towards difference and disability (see Gammeltoft and Wahlberg 2014). Even though this seems less visible in the current policy documents from India, we saw how the clinical literature, and anthropological and census surveys (underpinning policy) reflect highly racialised notions of genes, assuming caste/tribal groups as well as the diseases they embody to be stable, biological entities. In following the WHO reclassification of 'preventable birth defects' as an ethical moment in global public health, two main conclusions can be drawn from the Indian case study. First, as a result of the reclassification, both the differences in history and the complex molecular heterogeneity of thalassaemia/ sickle cell disorders is erased. This, in turn, legitimises a policy focus on prevention – reinforcing forms of stratified

reproduction as well as disability related to recessive gene disorders. Second, this erasure works towards sequestrating meaningful debates on the social and ethical reverberations of state policies on prevention. Hence, a critical engagement with the notion of children's suffering highlights a systematic neglect within policy and practice of the long-term treatment, education, employment and welfare support needs of millions of adults living with these disorders.

I want to leave the reader with a passage in *Affliction*, where Das reflects on a lack of consensus in literature on how we might judge the ethical basis of state interventions, especially when these relate to the poor, disabled or historically marginalised communities (2015, 200). This, she notes, has replaced the earlier notion of public health where the demarcation between the infectious and non-infectious diseases also delineated the boundaries between the public and the private. She asks:

> When would the kind of paternalism that defines such default conditions as provision of clean drinking water slip into authoritarian control over individual rights? Given that public health historically has been in close alliance with police and military operations and that even now the most spectacular success stories of public health have emerged from strongly authoritarian regimes (China, Rwanda), what place can we make to discuss cases in which individuals prefer … liberty or dignity, over heath narrowly or even broadly defined? (Das 2015, 200–2001)

Notes

1. This is not to underestimate the role of epigenetics, and the social, environmental and material factors in explaining phenotypic difference, in the so-called post-genomic era (see Lock 2012 for a commentary).
2. I am ignoring the contrasting positions on prevention adopted by the Global Sickle Cell Disease Network (GSCDN) and Thalassaemia International Federation (TIF), and how these may or may not impinge on the policies and practices of the NGOs at a local/ national level in India (see Bivins 2015, 304–367).
3. *Inherited blood disorders, globalisation and the promise of genomics: an Indian case-study* (2016–2019), with colleagues Karl Atkin (York), Veena Das (JHU) and Maya Unnithan (Sussex) (Inherited blood disorders…: an Indian case-study).
4. The incidence of IBDs is higher in malaria endemic regions of the world; carriers are believed to have developed a selective protection against *Plasmodium falciparum* that causes malaria (Piel et al. 2014, 2).
5. Several local NGOs have been involved in screening, treatment and counselling for IBDs in the tribal areas, long before the visibility of IBDs at an international level, e.g. Tribal India Health Foundation, Gudalur, in the South and the Maharashtra Arogya Mandal in Pune.
6. Shobha Tuli is also the Vice President of TIF – who support national control programmes for the prevention and treatment of thalassaemia across countries (www.thalassaemia.org.cy/about-tif/). In contrast, the GSCDN focuses on research and clinical care to improve the lives of children living with sickle cell and their communities (www.globalsicklecelldisease.org/). However, TIF has now widened their base to cover sickle cell and other rare genetic disorders and has a significant online representation of patient and community groups across the world.
7. In August 2016, Namitha started an online petition submitted to the Union Health Minister (.@JP nada:save our lives.), raising the issue of shortage of Desferal, a blood chelation drug, produced by Novartis (a Swiss multinational) and the need to list it as an essential drug in the state.
8. I have also read several posts about families struggling with treatment costs and premature deaths of young people in their 20s due to lack of affordable chelation therapies across Pakistan

and rural India. Perhaps, in scenarios of high levels of poverty and lack of access to basic treatment, *prevention* operates in a different moral economy of care?

Ethical approval

Ethical approval for the larger project was granted by the respective Ethics Committees of the Department of Health Sciences, University of York and the Institute for Social-Economic Research on Development and Democracy, Delhi (local research collaborator in India).

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