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4 Precarious Lives, Uncertainty and the Politics of Hope

Engaging With Novel Therapies for Blood Disorders in India

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Introduction

This chapter explores the local, experiential context within which those affected by or caring for a child with thalassaemia choose a particular, so called, *novel* therapy, involving the use of thalidomide and hydroxyurea, which remains controversial within clinical literature and practice. Thalassemia is an inherited blood disorder that causes serious chronic anaemia. The novelty of this treatment circulates within a wider political economy of hope (Good et al. 1990; Novas 2006). A lack of consensus in clinical practice on the safety and efficacy of thalidomide in treating thalassaemia brings home the significance of the hierarchy of methods through which evidence is selected to legitimise innovation and change. However, the processes of (re)constitution and regulation of clinical trials is not the focus of discussion here. Instead, the aim is to analyse the motivations and therapeutic journeys of those seeking this novel treatment despite uncertainty of outcomes and significant financial costs. Theoretically, the analysis hinges on the concepts of potentiality and precarity with uncertainty/hope as the mediating term—drawing our attention to the "ordinary, chronic and cruddy" aspects of everyday milieu within which the materiality of the disease, illness and caring are negotiated (Das 2015; Povellini 2011: 13).

Scientific controversies surrounding the legitimisation and routinisation of new technology and medical interventions can be placed within the remit of "an anthropology of potentiality in biomedicine", following Taussig et al. (2013: S3–S12; also see Bharadwaj 2018, among others). In their eloquent Introduction to the special issue of *Current Anthropology* (2013), they trace etymological roots of potentiality in Greek (*potentia)* and early Latin (*potens*/ *potence*) implying power/ force/ possessor/ possible/ capable and so on. Interestingly, "potentiality of the negro" was a phrase appropriated during the civil rights movement between the 1960s and 1970s. Hence, the very act of framing something as potential (or controversial) is a political act, invoking ethical choices about how we engage with life and death, health and well-being. The

historical shifts in our understanding of an embryo as a person is a classic example. Both as a theoretical concept and an object of study, potentiality reminds us that biomedical knowledge and practice is a dynamic space of contestations over truth, safety, risk and efficacy of treatments (Ford 2019).

Precarity, as a concept, is akin to potentiality since it reflects an inherent uncertainty of outcomes of interventions/ treatments that will only be revealed in time. In tracing its genealogy to the Marxist theory of labour, it implies a generic sense of ontological uncertainty. Here, we are using precarity more specifically to the context of (self)care, following Hyde and Willis (2020). As observed by Anne Allison (2014) and others, precarity of care invites a focus on the present, short-term goals rather than a distant future. At the same time, uncertainty of outcome leaves a door open for hope and resilience in the face of a serious illness, whilst reinvigorating investment and hope in innovative therapies (Hinton and Kirk 2017; Good 2010: 275; Brown 2003).

This next section, following a note on methods, outlines the clinical controversy surrounding the use of thalidomide in treating thalassaemia within the Indian context. This is followed by a case study outlining the quest of a father from a North Indian village, seeking this novel therapy for his two children popularly known as *Jhanduwalla ilaj*—set against the backdrop of the struggles of rural families seeking routine care in state hospitals. The third section, takes us right into the clinic of the practitioner, tracing the nuances of his motivation for offering what he called a "novel therapy" with a view to filling a therapeutic gap (Simpson 2007). In the concluding section, I pick up the conceptual threads to analyse the place of *jugaad* (disruptive innovation) as a practice that arises from and mediates the therapeutic space carved by the precarity of caring and the potentiality of an "operational cure". Before we move to the controversy surrounding the use of thalidomide in thalassaemia, a brief description of the methods and the field is important in setting the scene.

A note on methods and the field: Setting the scene

The arguments and analysis presented here draw on a multi-sited ethnography of public health policies and experiences of inherited blood disorders in India, carried out between 2017–2019.[1] The larger sample included 49 households from three ge-

1 This research was funded by the Economic and Social Research Council (ES/ 15665/1, https://www.york.ac.uk/sociology/research/current-research/inherited-blood-disorders/). I am grateful to all the participants who shared their lives and therapeutic journeys with us. My special thanks to Karl Atkin and Maya Unnithan for their contributions to the project; colleagues at the Institute of Socio-economic Research on Development and Democracy (ISERDD) for their invaluable skills and help fieldwork; and Prayas for their support. I owe a deep intellectual debt to Veena Das for decades of inspiring conversations and what I have borrowed from Affliction. This chapter has benefited substantially from the insightful comments and suggestions of the MAAH panel, especially Rikke S. Andersen and the two Editors.

ographical areas, where a child or an adult had the condition. This chapter is based on case-studies of five families (from the same field-site, S3) who pursued the novel therapy, using in-depth interviews with adult patients and family carers. Each family was interviewed at least twice and followed up on phone during the pandemic. The case studies were written specifically to analyse their engagement with risk and the circumstances within which a decision was made to opt for or discontinue the new treatment. It is important to mention that my initial framing of the novel therapy as being *controversial* has been important in shaping a shifting analytical space and my appreciation for the specificity of the innovative spirit, a point to which I shall return.

We cannot understand the parental quest for a cure and engagement with therapeutic uncertainty related to novel treatments without first locating the disease in its social milieu. The materiality of the disease is enmeshed within persistent struggles of families, marked by striking levels of poverty and inequalities in accessing basic healthcare provided free by the state (Chattoo 2018). Despite cheap diagnostic tests and treatment options available across public and private sectors, including bone-marrow and stem cell transplants promising a cure, only between 5–10 percent of children with beta thalassaemia receive optimal care in India (Parmar et al. 2017). Paradoxically, whilst state healthcare is free for everybody, in principle, 70 percent is accessed in the private sector with huge variations in quality across both the sectors (see Das and Mohpal 2016).

Thalassemia it is an inherited blood disorder that results in severe/ chronic haemoglobin deficiency. Standard treatment involves a strict life-long regimen of red cell transfusions every 3–4 weeks, supplemented by injectable or oral chelation drugs to extract excess iron from the body (caused by the transfusions). The relentless chronicity of the transfusion-chelation routine is painful, involving iatrogenic risks of blood borne infections and iron overload potentially affecting vital organs over time. Some of the parents from a small town in our sample travelled between 70–200 miles to a larger treatment centre to avail safer blood for their children, whilst most had tried several folk, ayurvedic and spiritual remedies, hoping for a cure.

News about new treatments such as stem cell transplants, gene therapy and new medicines travels far online, via *WhatsApp* chat groups conversations at treatment centres where parents/carers and adult patients form close "family like" ties (see Unnithan et al. 2023). That is how I first heard about *Jhanduwalla* (place pseudonym) *illaj* (treatment/ cure), involving a prescription of thalidomide, when I started fieldwork at Site 3. I had not heard of such a treatment for thalassemia either in India or the UK. A quick online search lead me to a clinic advertising the use of thalidomide as a "novel therapy" and an alternate to transfusions. Initially, I was suspicious about yet another "quack" taking advantage of carers who were desperate for a cure. The novelty of this treatment was already framed as part of the historic controversy sur-

rounding the scientific credibility of the use of thalidomide reflected in the clinical literature, for reasons explained below.[2]

Novel treatment: Controversy, efficacy and safety of thalidomide

Thalidomide remains shrouded in the scandal of birth disorders and miscarriages caused in a cohort of pregnant women who were prescribed the medicine for morning sickness between mid 1950–60s. New versions of the drug are in use for treating epilepsy and malignant blood cancers. A review of clinical literature suggests that some clinicians are less ambivalent regarding the use of thalidomide in thalassaemia and dismiss its efficacy as purely anecdotal (see Manglani and Kini 2017). Others recognise its benefits in raising foetal haemoglobin levels, justifying its use with varying degrees of caution in selecting the "ideal candidates", for whom the benefits override the increased risk (see Chandra et al. 2021). Given the genetic variants, baseline patient characteristics, diagnostic histories and socio-economic factors underpinning outcomes, predefining the "ideal patient" or a single treatment protocol sounds unrealistic. It is difficult imagining how boundaries of risk and safety defined in Europe or North America can be applied to under-resourced healthcare settings being described here. This is not to undermine the importance of setting the bar high and the need for oversight of protocols at a local/national level.

Thalassaemia International Federation (TIF), an influential organisation with a strong clinical focus, who work closely with the WHO and have a wide international membership base of patients' and carers' representatives, posted the following statement on their Facebook page on 30th June 2018:

> TIF has increasingly been receiving questions from patients about the use of Thalidomide in the treatment of thalassaemia, based on the information that some clinics have been treating patients with this drug. TIF wants to clarify and insist that there are no controlled clinical studies to support the use of Thalidomide as a standard of care for the treatment of thalassaemia. The potential that Thalidomide may have as a treatment option for thalassaemia is, currently, only based on case studies. This means that Thalidomide has only been tested in a limited number and specific groups of patients across the world, mainly in India and China, and so results on its efficacy and potential side-effects are limited and not representative.[3]

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2 I would like to thank my colleague, Vaibhav Saria, for his contribution to the literature search on thalidomide.

3 https://thalassaemia.org.cy/news/tif-on-thalidomide/

The above statement by TIF was followed by a potted history of thalidomide and its teratogenous side effects, without adopting a formal stance against the use of the drug in thalassemia and sickle cell disorders.

In a similar vein, Sankalp Foundation, one of the leading non-governmental organisations (NGOs) providing clinical care and stem cell transplants for thalassemia patients in Karnataka (India), reviewed the current evidence on thalidomide. They agree that while thalidomide has been reported to enhance red cell production, the safety and efficacy of the drug (for thalassemia) is debatable. Rather than outrightly discrediting use of thalidomide, Sankalp strongly recommend seeking informed consent, communicating the risks to the patients and reporting any adverse events and deaths.[4] Interestingly, neither Sankalp nor TIF referred to a large retrospective cohort study describing the outcomes of a specific protocol used in India, perhaps, since it was not part of a clinical trial (Ramanan and Ketki 2017).

To summarise, the use of thalidomide in treating thalassemia as a highly contested site of therapeutic innovation and policy regulation highlights two important issues: Firstly, given the practical limitations of governance of medical practice (due to scale and complexity of the federal healthcare structure), the notion of informed consent is compromised across healthcare settings in India. Second, as suggested earlier, the use of thalidomide as an experimental therapy in thalassaemia has been reported from other countries. Hence, criticisms of its use in India might be attributed to "epistemic prejudice and geographies of innovation", following Centellas et al. (2019: 3). Based on their ethnography of birthing practices in a poor state like Mississippi in the USA, they define epistemic prejudice as:

> […] an orientation toward globally relevant knowledge production and influence that denies or underplays local complexity, practice, and insight. […] We find that epistemic prejudice enables certain assumptions to become taken-for-granted truisms about the world; it facilitates the construction of "facts" on shaky, uncontested, or invalid foundations. Simultaneously, it serves to silence local innovation and creativity, making a kind of paradox of the local, a place that is both so unique and so failed based on cosmopolitan standards that it barely deserves to be taken seriously and therefore has no generalizable insights to provide to other locations. (Centellas et al. 2019: 3)

The process of legitimisation and routinisation of new technology/ medical treatment based on trials is beyond the scope of our discussion here. The question I want to pose is: what motivates a clinician to try novel treatments in which the efficacy and safety are (yet) not well established? This is assuming that an established clinician with a thriving business has a lot at stake and will not jeopardise her reputation

4 https://www.sankalpindia.net/news/thalidomide-thalassemia#main-content

(see Bhardwaj 2015). Second, we must also try and understand the circumstances and rationale underpinning the decision of parents and (adult) patients who choose to accept the (risks) unknowns associated with such treatments? Finally, how does my own framing of the history of thalidomide "controversy" shape the arguments I am presenting here? The "evidence" seems to have already shifted since I wrote the first draft of this chapter for the MAAH workshop in Autumn, 2021. Rather than provide a linear summary in the retrospect, I want to stay with the flux and potentiality of the intervention as I navigated my way through the field. Let us now turn to the therapeutic journeys of parents/patients in pursuit of this novel treatment within a wider political economy of hope (Good et al. 1990; Novas 2006).

Seeking *Jhanduwalla ilaj*: Precarity of care, uncertainty and hope

Around the time I started fieldwork at Site 3, (2017–18), I heard stories about some of the families in our sample following *Jhanduwalla daktar ka ilaj (doctor's treatment identified by place)*.[5] Given the porousness of the complementary medical systems, health beliefs and knowledge practices, it is common for practitioners across health systems to prescribe allopathic medicines (see Das and Mohpal 2016). Interestingly, only five out of our sample of 59 thalassaemia households had chosen *Jhanduwalla ilaj,* through their hospital network rather than being referred by their clinician. Even though their personal circumstances varied, they came from the same state (Site 3). The following case-study provides a synopsis of what I defined earlier as precarity of caring, especially in rural areas, in securing regular transfusions they considered to be safe, in the first instance.

In April 2018, Rajan Singh (ISERDD colleague) and I went to meet Prakash and Rani, Papu and Hansa (their children who were under18 and had thalassaemia). They lived in a village about nine miles away from the District hospital in town (Site 3), tucked away from the bus route along the highway. Whilst we were finding our way across unmarked village streets and houses without numbers, Papu met us half- way and recognised Rajan from his previous visit. The family lived in a relatively large, *pucca* (concrete) house (a sign of being relatively better off), with a mud *chullah* (oven) used for heating water in the courtyard. His paternal grandmother, in her long customary *ghoonghat* (veil) covering her face, welcomed and invited us to sit on a *manji* (jute-string-bed), as we waited for Prakash. It was coming to the end of the Winter-harvest season and most of the men and women were busy in the fields, we were told. Rani only made a brief appearance to serve us water and refreshments, assisted by Papu, but did not join in the conversation, given the local custom of deference

5 The names of places and participants have been anonymised throughout the chapter.

women must show to generation and gender. Her mother-in-law, however, was listening carefully and occasionally interjected. We were soon joined by Prakash, one of his brothers, nephew and a neighbour who sat in listening but did not contribute to the discussion.

Clearly, Prakash was the main carer who navigated the medical system, accompanied his children for their hospital appointments and looked after their medications. His nephew helped him financially and whenever they needed help in taking the children to the hospital. There was a sense of desperation in Prakash's voice as he described the routine of taking time off farming to take Papu and Hansa, on public transport (subsidised for patients), for their monthly transfusions to the state hospital about 80 miles away. At times they stayed overnight, involving further expenses. This is a journey they had to undertake every 2–4 weeks since, at the time, the district hospital closer home did not have a blood separation machine. He preferred the long journey to the city hospital, to access separated blood for the children, knowing the harmful impact of whole blood transfusions. Co-ordinating their treatment schedule with the demands of farming, however, was not easy despite the practical support from his nephew. Prakash recollected the time when Hans's transfusion was delayed due to the pressures of harvest taking priority over her routine care.

Prakash was moved to tears when he echoed what I had heard from other parents. He did not know how long his children would live, perhaps 20–25 years, he ruminated. It was quite sad to hear him say, "[…] sewa karunga, dil se, jab tak hen"! (literally, "I will serve them with my heart and soul, until they live"). This expression of *sewa* (care) is a reversal of what parents expect from their children as they get older. He had tried spiritual remedies, votive offerings and other treatments to no avail. At times, he was upset at his *kismet* (poor luck) at having two children who had a difficult, painful condition for which they would need transfusions all their lives.

Unfortunately, such a prognostic vision of a brief life, reinforced by the knowledge of other families losing a child in their 20s, affected the life choices for children with thalassaemia. Papu said that he had not been able to continue school beyond the 8th standard since he found cycling both ways quite tiring. Instead, he now helped his mother with the household chores and went to the fields with his father. In contrast, Prakash said proudly, "Our daughter is really clever and very good at her studies. She needs our support and we are focusing on her education now. We don't expect her to do any housework. You will meet her. She will be back soon".

So, how did he first hear about the *Jhandhuwalla ilaj*, I asked. Prakash responded:

> All the friends at the hospital and the […] group (naming the city) talked about it. Then we were invited to the camp (educational meeting) on 7th May [world thalassemia day] by the Society [the main patient support group based in another city] and parents were talking about it. Then four of us [parents] from the hospital

> decided to travel to jhandhuwalla (a distance of 580 miles, a journey over 24 hours by bus and train).

Prakash and the children had met the doctor three times, in person. The first time, they travelled as a group of four (affected) families. The consultation fee was 3.000 rupees (for both) and the doctor was nice and patient. He explained everything in detail using a graph, showing how the hb (haemoglobin) would behave, coming down before registering a steady rise. Several tests including a DNA analysis were ordered to confirm the type of thalassemia the children had, each costing 7500 rupees. They were (re)diagnosed as having thalassemia *intermedia* (which often has a milder course and is believed to respond better to thalidomide/ hydroxurea treatment). The differences in types of thalassaemia and pros and cons of the new treatment were explained to him. Rajan and I were shown the notebook they had been given. It was in English with hand-written translation in Hindi and explained in detail how to take the medicines daily, monitor pulse and other signs and a schedule for regular blood tests.

The first batch of medicines was provided for four months and the family were hopeful of the treatment being effective since Papu and Hansa were weaned off transfusions. On their second visit, the doctor was a bit brusque when Rajesh raised the issue of not having enough cash on him. He was told in no uncertain terms, "You can either take these medicines or go back to transfusions." Eventually, the clinic administrator agreed to an electronic transfer of money so that medicines would be couriered to the family. By the time of their third visit, he had spent a substantial sum of nearly 3.5 lakh (350.000) rupees and he realised that spending 20.000 rupees a month, with additional costs for regular blood tests for both the children, was not sustainable in the long term. Hoping that this treatment would work, he had taken out a loan from the bank. Unfortunately, that year, the harvest had been disappointing, followed by COVID-19 a couple of years later, making it difficult for him to repay his loan.

Like most parents, Prakash was desperate to try any new treatment for his children. He believed that stem cell transplants carried an 80 percent risk of death, even though it promised a cure. It was a difficult choice for him to discontinue the treatment, given that both the children had benefitted from it for 18 months. Prakash speculated, "If only the doctor had specified that these medicines were to be taken for 2–3 years, I would have managed the finances". We do not know what the potential treatment outcomes might have been, had the family had enough money to persevere with the treatment. On a positive note, in May 2022, I learnt that the blood separating machine at the local hospital was finally operational, making the treat-

ment routine emotionally and financially less challenging for Prakash and other parents like him.[6]

Reflections on other potential endings, limits of hope

Meanwhile, doubts about the long-term benefits of *jhanduwalla ilaj* had surfaced in the group, as one of the patients suffered an adverse reaction and had to revert to transfusions. Such incidents had an impact across families who shared a treatment routine and were bound by a kinship of caring (see Unnithan et al. 2023). Ravi's parents, for instance, said that they had discontinued the treatment due to concerns about side effects. Ravi, a frail young man in his 20s, however, added that the treatment was "too expensive anyway". Given their lower-middle class background, it is not clear to what extent their decision might also have been related to competing financial commitments. It is an important aside that, whilst Ravi struggled with his studies at college due to his poor health, his sister was being coached privately to sit for the highly competitive, examination for entry into a medical school. Families with limited resources had to prioritise their needs, often resulting in subtle differences in caring practices. In both Papu's and Ravi's family, education of the healthier/brighter sibling was the focus. When I asked how they made such ethical choices, middle class parents usually claimed that they treated both/ all their children the same.

What we can say with some confidence, however, is that access to cash or the ability to take a loan, often informally from kin or from a bank, rather than severity of the illness *per se,* played a significant part in decisions related to starting and discontinuing the novel treatment. For instance, in contrast with Prakash's situation, Pawan, who was in his late 20s and training to be a teacher when I met him in 2019, came from a relatively better off farming family. He had been pursing *Jhanduwalla* treatment for over a year, even though he had milder form of thalassaemia (intermedia) needing intermittent transfusions. When asked how he was doing, Pawan replied, "Ab me theek hun" ("I am fine now/at the moment"). I asked him what he meant by the term *theek hona* since, in Hindi, it can mean both getting better or being cured. He was clear that in his case cure meant not needing blood. He did not have any concerns about the safety or the expenses related to the treatment and wanted to continue as long as it worked, and his father supported him financially, whilst he invested in his training.

Vibha's father was the only parent of the five families that we followed who had access to scientific papers on clinical trials and new medical interventions, having

6 Some of the accounts of the second/ third visit to the family are reconstructed after I had interviewed Dr Dev in 2018.

worked in the pharmaceutical industry. They shopped around online to save money on the prescription each month and maintained regular contact with the doctor online and by phone during the pandemic. Her family had the added advantage of cultural capital that helped in better communication with the doctor, greater confidence in knowing the pros and cons of the medicines and better resources for addressing their doubts. Even he did not broach the subject of the scientific controversy regarding the use of thalidomide, despite mentioning the research he had been following in the field. Vibha's parents were protective gatekeepers and did not want any negative information being filtered to her. On both the occasions, contact was mediated through parents who sat in on both the interviews. What mattered to Vibha and her parents was that her condition was well controlled since she started *Jhanduwalla* treatment. In Spring of 2022, it had been four years without any adverse effects. Vibha had since finished her studies and moved on in life.

Vibha's family were different from the other four in that their cultural capital enabled them to seek information and exercise choice about the potential risks of the novel treatment, economising on costs by looking for safe but cheaper brand of the same medicine in the market. Using Pierre Bourdieu's concept of cultural capital, we can understand the significance of embodied, objectified, and institutionalised forms of cultural capital (e.g., dispositions, values, knowledge, books, technology and educational qualifications) as being central to the perpetuation of class based, structural inequalities (1986: 17–20). The role of cultural capital has been central to debates on the complex intersections between structural inequalities underpinning vulnerability to ill-health, health seeking behaviour and outcomes of care (see Baru and Murugan 2016; Abel 2008).

Whilst these social determinants do not impact on who inherits thalassaemia, the inverse relation between social class and the susceptibility to ill-health and adversity in general have a cumulative impact over time. This was more visible in Sabiha's case who unfortunately died while still in her mid 20s, following an illness caused by dengue, a common infectious disease. The last time I talked to Sabiha on phone was in Summer 2021. She sounded quite cheerful and said that since she was continuing with *Jhanduwallah* treatment and had not had transfusions for two and a half years. She had had two-three serious events resulting in emergency care that she did not consider significant. When I first met her in 2018, Sabiha looked and felt quite ill. Her iron overload was very high, her tummy was swollen due to an enlarged spleen, and she had little appetite. What she described were signs of a poorly managed thalassemia as a child. She spent most of her time in her room barely having the strength to move, until it was time for her next transfusion in two weeks. Even though her mother complained about the *Jhanduwalla ilaj* being expensive, the family owned a small business and managed to chip in.

In Spring 2022, I learnt that Sabiha had developed dizzy spells and fever [dengue] in Autumn 2021. She was critically ill and admitted to the Intensive Care

Unit for a few days, and never returned home. I went to commiserate with the family. It was *iftiari*, the evening time to open the fast during the holy month of Ramazan. Her mother was in the kitchen and did not come out to meet me, her silence marking her mourning. Her brother described the events preceding her death and kept repeating, "[…] she was doing well (*who achi thi*) until she developed fever […]. It was our oversight (*hamse bhool ho gayi)*." It took the family a few days to realise that she could be seriously ill with dengue (given her thalassemia). They should have rushed her to the hospital earlier. He would always regret that she did not live to see his wedding—an event that she had told me, she was so looking forward to. In taking on the blame for what he saw as a lapse of judgement on their part, we are reminded that better educated parents or siblings might have read the critical signs in relation to her underlying condition serious or sought clinical advice from a network of friends to evade her death.

Given a better sense of what this *Jhandhuwalla ilaj* entailed, I was ready to meet Dr Dev at his clinic in Spring 2018, to find out more about his perspective and practice.

Therapeutic innovation, private market and the role of medical pioneers

Dr Dev's online profile highlighted that he was an established specialist in his field, affiliated with several national and international clinical bodies. He had already published several papers based on his clinical practice, ranging from leukaemia to sickle cell and thalassemia. His clinic was in a busy part of the old city, in a building that housed other clinics, a courier service as well as a furnishing house. Given that 70 percent of healthcare is provided in the private sector, these are familiar sights across India. The clinic was custom-built and well organised with rows of patients waiting to be seen. I started by asking Dr Dev about his training and interest in thalassaemia. He responded:

> In fact did my first transplant in 2006 […]. We have done identical, haplo transplants for thalassemics. We have done cord [blood] and all of them have unique challenges. And what I feel is that they are not the perfect option. Why do I feel so? There are ten thousand children who are born every year [with thalassaemia]. Around eight thousand three hundred are dying every year because of lack of transfusion or lack of chelation. […] we are doing some two or three hundred transplants a year. How can that be an ideal treatment? The standard of care should be something which will cater to majority of the population.

A conjectural estimate of children dying of thalassaemia each year appears as a rhetorical device in aid of his case for a novel treatment, as revealed later. Appar-

ently, thalassaemia was common in his community and the death of a child in the extended family (a decade ago) made him think:

> […] that we should have a solution for somebody who cannot have a transplant. And talking about ideal things (protocols), about transfusions, in this country is probably talking about a bullet train […] (next to impossible).

So, what would an ideal treatment protocol look like, in his view, I asked. Dr Dev was critical of any notion of universal protocols premised on the scenario in Italy or the UK. He showed me a diagram demonstrating the progression of the disease and the treatment scenarios, and explained:

> […] This whole pharmacological induction of fetal hemoglobin comes in and that's how I started in 2009, with an interest with hydroxyurea. And then we had this graft failures with our transplants, thirteen of them, whom I wanted to pull out of transfusion, and that's how I stumbled upon thalidomide. It is not my innovation […]. Eglar Lopez has already done […] and it's just that our doctors are blind to it. They just want to talk about the phocomelia (rare foetal anomaly of limbs) which occurred in 1960s to pregnant ladies. Our kids are not going to get pregnant? If they are going to get pregnant, we have […] women, [options] by stopping the medicine and have got normal pregnancies.
> So we are mixing up two issues. The issue today in India or in the world for thalassaemics is that: a) transfusion is not free, b) it is not safe, and c) it leads to iron deposition, ultimately leads to all this [complications and organ failure—pointing to the diagram on his desk]. After the age of ten years you get all this. This is a British diagram but in India I feel this curve is here […]. And by twelve to fourteen years of age we have cardiac events and kids have just died […]. So what it means is that India has a bigger problem.

Due to these premature complications caused by poor clinical management, Dr Dev said that the outcomes of stem cell transplants were also poor and that the aim of clinicians should be to improve their lifespan and quality of life rather than a cure. On a more philosophical note, he later added, "cure is always operational", an important statement to which I shall return.

The pace of the interview was set by his swift thinking and counter questioning, highlighting the scale of the problem and potential solutions that cater to the maximum number of people (principle of equity of care) and are sustainable economically. He went on to criticise the "tunnel vision" of established clinicians who are not willing to take any risks:

> […] Today we have more than, we have stopped counting them (patients)…more than the number in England […] *here in one single centre.* So that's what I feel that

> going forward […] we need to understand the needs of the patients. Idealism has to be kept away from practicality because we need to know […] for example, we were calculating the economic impact of thalassaemia on Indian economy. My rough estimate, which maybe exaggerated, […] approximately *two billion dollars* (his emphasis).

Steering the conversation away from the neoliberal logic of how much each patient costs the state, I asked him, what he considered to be an ideal regimen with a view to preventing iatrogenic effects of standard treatment. His rehearsed response sounded like a perfect marketing pitch for his new treatment:

> There is nothing ideal. Everything is imperfect. The transplant is imperfect, the transfusion is imperfect, the Chelation is imperfect because chelators also cause renal failure, eye, ear toxicity[…]. why do I choose this (thalidomide) […] here in my clinic?: a) This you can take at home, b) […] you can treat a larger pool of patients.

Towards the end of the interview, I was brave enough to finally broach the subject of his thalidomide/ hydroxyurea prescription. He reminded me, again, that he did not invent the combination of these drugs, others had published their results from Italy and elsewhere. This provided a certain legitimacy for the scientific rationale in the absence of a clinical trial, even if reinforcing the Eurocentric epistemic prejudice of credibility of science. The following excerpt from his interview captures Dr Dev's rationale:

> *S:* Yeah, but they are always very small numbers (referring back to the studies from outside India). One patient here and a case-study there and that's why there is a lot of scepticism about the use of Thalidomide.
>
> *Dr Dev:* […] You look at the Elgar-Lopez's (paper) […] and 17 years of her use […] (publication). So, moral of the story is that it may not be a policy today, it may become a policy tomorrow. When I started in 2009 with Hydroxyurea, people said, "Don't use Hydroxyurea". Now they are saying that everybody is happy using Hydroxyurea in this country [commonly prescribed in treating sickle cell disorders]. It's just passage of time […]. See, data has to be accumulated. If we just sit on the side-line, nothing is going to be done. Somebody has to jump in and do the thing. Now you will say, "Start a clinical trial". See off-label drug use, you know it [is used] in England, you know it in USA. Pediatricians do it. So this is one of the off-label drug uses.[7] […] from my limited data, I can see, it is benefitting the patients. So […] why should I put them at risk of HIV, Hepatitis B, Hepatitis C and

7 It is not uncommon in India for a drug to be prescribed by clinicians which might still not be approved by the state regulatory authority. For example, at the time, Hydroxyurea was

> iron overload by giving transfusions? Leave alone the pain, the cost and everything else.

One can certainly not fault Dr Dev's theoretical logic about the scale of suffering and the iatrogenic effects of transfusions within the Indian context. His concerns aligned closely with the motivations reflected in the therapeutic journeys of the parents/ patients we met in the previous section. Strictly speaking, he sought informed consent in principle by explaining risks in relation to the type of thalassaemia, the costs of each treatment cycle and laboratory investigations. Equally, the written instructions provided to the family highlighted signs of critical events needing medical attention from a doctor. The geographical distance from the clinic meant that follow up consultations were arranged on phone, while medicines were delivered by post—far from an ideal situation. There is a certain *laisse-faire* attitude to managing risk on both sides, the doctor, and the patients/families, that is best encapsulated in the spirit of *jugaad* (making do/innovating with little to hand). *Jugaad* has been defined as "disruptive innovation", finding solutions for seemingly insurmountable problems that are far from ideal, which might be considered unsafe or even unethical in other healthcare settings (see Kaur 2016; Birtchnell 2011). Indeed *jugaad* is, "[…] often celebrated as an almost national trait and Indians often pride themselves in being able to navigate suboptimal contexts and marshal available resources, in order to find compromise and solutions that somehow work" (Broom et al. 2020: 24).

Going back to my initial scepticism, I wanted to know what motivated clinicians like Dr Dev to face a reputational risk and criticism from peers in practicing, what Bhardwaj critiques as *badnam* (bad/unethical) science (Bharadwaj 2015). What I had not considered was that they might consider themselves to be moral pioneers with a vision, rather than simply exploiting a gap in the market (see Rapp 1988). This is not to deny the role of the market and profit underpinning Dr Dev's thriving private practice. He was not providing the treatment free of cost to patients who struggled, as we learnt from Prakash's account. Nor was he promising a mass cure. In fact, analytically, what is fascinating in his approach is that he defines all cure as operational (provisional) and both risk and treatment protocols as being relative to a therapeutic milieu.

Concluding reflections

In contrast with the post-modern notion of risk as colonising the future (Giddens 1991), precarity draws our attention to the "ethics of immediacy" (Mittermaier 2014,

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still awaiting approval, even though doctors were able to prescribe the medicine subsidised by the state.

as in Hyde and Willis 2020: 299). In the narratives of families seeking *Jhanduwalla ilaj*, we saw the complex intersection of the materiality of the disease and the socio-structural factors (financial and cultural capital) determining the potential outcomes that unfold in time. The uncertainty of what the novel treatment entailed, both in terms of its composition and outcomes, left the door ajar for hope of, what Dr Dev called, a "functional cure".

However, none of these patients or family carers appeared as passive victims of exploitation at the hands of a "guileful maverick" to borrow Bharadwaj's phrase (for a critique, see Bharadwaj 2018: 15; 2015; Sleeboom-Faulkner and Patra 2011). They had actively chosen to try this treatment without a clinician's referral. We had a glimpse of how patients and family carers struggled to access safe care, moving between hospitals, across cities, changing doctors, pursuing unknown treatments remotely. Irrespective of their level of literacy or lack of knowledge about the medicines, they were not pursuing a miraculous cure. What they were aiming for was freedom from the relentless transfusion routine and the known dangers of iron overload, hoping to prolong life. They were not engaged in the wider processes of knowledge production (research) or governance of thalassaemia and, instead, operated within a very different political economy of hope than envisaged by Novas and others (op cit: 291).

It is fair to say that, arguments for democratisation/decentring of knowledge production and sharing, so well represented in the collection edited by Bharadwaj (2018), for instance, reflect a middle class bias in research. To engage with the clinical/scientific knowledge on trials, risk, and evidence in order to make informed choices about treatment or cure with uncertain outcomes, requires cultural and financial capital. The lives and journeys of the families shared here remind us that most of these parents and patients were unaware of the historical controversy surrounding thalidomide and the potential risk of infertility due to the use of hydroxyurea. They weighed the known, often irreversible, iatrogenic effects of standard treatment and an (perceived) imminent risk of death against the hope of an "operational" cure. The significant financial hardship and potential adverse health outcomes were balanced by the safety-net of state healthcare. If they had to revert to transfusions, they would simply go back to their state hospital and continue receiving free care.

Given the Indian context above, Dr Dev's critique of idealism and universal treatment protocols makes perfect sense, carving a space for therapeutic novelty as "pragmatic improvisation" that he considered to be "frugal, flexible and inclusive" (see Prabhu and Jain 2015: 3). Even though he did not claim credit for developing it, the innovation was embedded in how he practiced it so that it reached patients living hundreds of miles away, without regular follow up visits. The families were responsible for monitoring the treatment, getting the tests done and communicating the results to the doctor either on phone or electronically, unless they lived locally. It was left to them to understand the script of signs signalling an impending health

event and seek immediate medical care closer home. There was something common to this *ad hoc* attitude to risk on both the sides. It resonates with what Veena Das, in her study of the urban poor in Delhi, so eloquently describes as the expectation of things going wrong or failing that is seen as being "normal". She writes, "The lives of the poor are strongly defined by living this normal—yet remaining attentive to the critical" (Das 2017: 222; also see Miller 2014). Even though Sabiha's brother regretted that they had not initially taken Sabiha's fever seriously, she was eventually admitted to the ICU.

Finally, as Dr Dev had predicted, there have since been other publications on the use of thalidomide from India, some from researcher-clinicians in the state sector. It is likely, that the novelty will be routinised, as better markers for risk assessment and safer protocols emerge. Whether and to extent such treatments actually helps address the scale of structural inequities in health across India, remains open to discussion.

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