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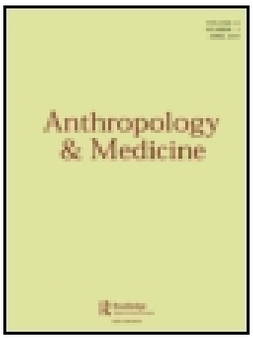

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'Only parents can understand the problems and needs of children with thalassaemia': parental activism for thalassaemia care in Northern India

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ABSTRACT

Evolving knowledge of genetics and improved clinical care have re-shaped life choices for those suffering from chronic, incurable conditions and their families. Yet the realisation of care requires complex navigation to access vital therapies which is often difficult for individuals or their family carers. In the article, we explore the struggles and strategies of parents of children with thalassemia (a genetically inherited blood disorder) in a North Indian city, who have come together to ensure better long-term health of their children. A focus on the ways in which families come together and remain apart in their quest for guaranteed access to life-saving substances such as filtered blood, provides insight into the diversity of bio-social strategies at work. It is not only family relationships and kinship, we suggest, but bio-sociality itself which is reshaped with the advent of new rights-based languages, evolving therapies and state support which hold out new possibilities for young people with thalassemia to live as normal a life-course as possible.

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Thalassemia; kinship; blood; parental activism; India

Introduction

It was a hot, Saturday morning in August when Mr Bhairav ushered us into the corridors of the private hospital and into the day ward reserved for thalassaemia patients in Jaipur. We were greeted by a cool breeze from the whirring fans and a clean space with 25 beds occupied by young girls and boys connected to an infusion machine. Blood transfusion was part of their monthly routine of living with their inherited blood condition, thalassemia, referred to as *khoon chadhne ki bimari* (literally, a condition where blood (*khoon*) must 'rise' (transfuse). Accompanied by their parents, children and young adults greeted each other as they settled down to receive blood and browse on their mobile phones. Parents gathered to share the latest information on therapies. The ward emanated cheer, hope and the possibilities for arranging social events. (field-notes, Jaipur city, August 12, 2017)

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Mobilising for young people with thalassaemia

The evolution of genetic knowledge and improved clinical care are re-shaping the life and care choices for those with chronic or incurable conditions; generating 'new consequences for the politics of life today' (Rose 2013:3). By focusing on the work of a parent-led organisation called the 'Society', set up to support children and young adults with thalassaemia in a North Indian city, we examine and contribute to anthropological understanding of the diverse ways in which the therapeutic economy in the era of genetics is constituted, as 'individuals call on networks of obligation and reciprocity to negotiate access to therapeutic resources…' (Nguyen 2005:126). Following Rabinow, we acknowledge the myriad ways in which society and sociality are reshaped through knowledge-practices of genetics and a variety of related micro-level, biopolitical practices and discourse (Rabinow 1999 [1996], 2005: 188). Building on Rabinow's powerful analysis of the changes brought about in identity and advocacy as a result of the new genomics, we suggest that parental success in accessing medical resources shapes a future where the underpinning rationale of such activism may itself become obsolete. As conflicting values and inter-generational tensions arise over time with rising opportunities to live longer, parental mobilisation itself faces an uncertain future.[1]

In the article, we explore thalassemia (a genetically inherited blood disorder) with specific attention to efforts at mobilisation for care (Rapp and Ginsburg 2011). Parents confronted with their child's genetic disorder not only re-think their kinship practices as caring but develop, as Rapp and Ginsburg suggest, new forms of activist intervention (Rapp and Ginsburg 2011) and new ideas of self as advocates. In a context where despair is so palpable, hope (Mattingly 2010) plays a critical role, we suggest, in shaping and sustaining such activism. As a substance, 'blood' has polyvalent significance, acting as a metaphor for kinship, inheritance, religious morality and healing (Copeman 2009, 2016; Carsten 2011, 2019); all of which come together in the context of the mobilisation of thalassemia care described in this article.

Parents and family-members we met referred to thalassemia as a condition of great stigma and, much as Douglas (1966) describes, perceived it as a threat to the purity of the reproductive order. In addition, as a material therapeutic resource beyond metaphor, blood transfuses (literally) life for the thalassemia recipient. In the article, we also employ 'blood' in a third sense, and following Mol's work on anaemia, use it to signify a fluid conception of action (Mol and Law 1994; Mol 2002).[2] Ensuring access to blood requires a constant enactment or 'service' (sewa) of parental mobilisation.[3] It is through the continuous voluntary caring work in the wards and in policy discussions and campaigns, that the flow of blood is metaphorically suffused with 'sewa' and hope that flows between parents and children.

In India, family and kin-based mobilisation around thalassemia is somewhat distinct from other forms of health activism (for Rajasthan, see Unnithan and Heitmeyer 2012, 2014; Unnithan 2019). Differences include types of networking processes, action pathways selected and a focus on a specific condition. Such mobilisation, we argue, is similar to, and yet distinct from other forms of parental activism linked to genetic disorders and chronic disabilities (Singh 2018: 173, also see Cystic fibrosis Trust, UK Thalassaemia Society, Rapp and Ginsburg 2011; Ginsburg and Rapp 2017). The thalassaemia mobilisation we encountered was both India-specific in its caste and religious adherence and the middle-class orientation of parents who, as in other countries, became health advocates for their children.

Background and methods

It is estimated, between 10,000 and 15,000 babies with beta thalassaemia are born each year across India (Government of India 2018) who require life-long medical care. An inability of the red blood cells to produce sufficient haemoglobin manifests in severe anaemia during the first 4–12 months of life which, if left untreated, causes premature death. Babies with thalassaemia require life-long monthly blood transfusions and iron chelation to deal with the iatrogenic iron overload caused by the frequent transfusions. Despite the availability of diagnostic tests and treatment options available across public and private sectors, including curative stem cell transplants, only between 5 and 10% of children with thalassaemia receive optimal care in India (Parmar et al. 2018; Verma, Saxena, and Kohli 2011). These outcomes reflect the broader socio-economic inequalities in access to healthcare for the poorer and rural communities (Chattoo 2018; Ghosh, Colah, and Mukherjee 2015; Patra and Kumar 2010).

The ethnographic research with a parent-led Thalassemia organisation, which we call The Society, involved qualitative data collection on a number of fronts: the routes through which clinical and social care across state and private sectors was accessed; the kinds of strategies and tactics that were mobilised and the processes identified to meet the organisation's goals and counter the challenges it faced; the accountability processes within an organisation led by the parents/relatives and thalassaemia patients themselves, and the organisation's broader levels of advocacy and engagement with policies at the all-India, regional and local tiers of the state.

Field research was carried by Pachauli and Unnithan in Rajasthan between August 2017 and May 2019, as part of a larger project on blood disorders in Rajasthan, Gujarat, Maharashtra and Delhi led by Chattoo, Das, Atkin and Unnithan. Pachauli has worked on health issues with NGOs in Rajasthan for over 20 years and Unnithan has conducted ethnographic research with health-based NGOs in Rajasthan since 2010.[4] Their data collection involved informal discussions and semi-structured interviews with key organisational actors (the president of the Society, parents and young people with thalassaemia who attended the day care ward for their monthly transfusions, observing their interactions with doctors and counsellors at the public hospital, nurses and managers and at a private hospital). Key interlocutors included 7 parents of children with Thalassemia (including 3 office bearers of the Society), 5 young adults with Thalassemia, 8 health functionaries at the various hospitals and specialist services and 7 blood camp participants and volunteers. Regular interactions lasted for about 7 months starting from November 2017 to May 2018. However, intermittent communication continued to make sure that the Society was invited to consultative events taking the findings forward.

Pachauli also 'shadowed' The Society, attending activities and events such as a blood donation camp, annual picnic and educational events to promote awareness of thalassaemia in the state. Increasingly recognised as a reflexive, comparative qualitative method of fieldwork in the study of organisations, shadowing provided us with deeper, embodied insights into social networking practices of Society members (Macdonald and Simpson 2014; Ventura and Keinan-Guy 2018). The selection of The Society as an organisation to shadow was the result of an initial scoping exercise carried out amongst the handful of organisations, actors, and key sets of issues involved in thalassemia care across Rajasthan. NGOs working on thalassaemia were based in four major cities spread across the state and were primarily run by the

parents of children affected by the disorder. State and private hospitals provided care in Rajasthan as in other states, supported by the Indian National Blood Transfusion Council, NBTC, which regulated blood banks and the supply of safe blood in the country. In addition, several private and trust-managed blood banks contributed significantly by running voluntary blood donation camps and providing adjuvant free blood and information campaigns for thalassaemia patients in Rajasthan as elsewhere. Initial fieldwork revealed that only two of these four organisations were active. Mr Bhairav (pseudonym), the President of The Society, was very cooperative and seemed keen to participate in our project. Shadowing of the Society was carried out on Saturdays by CP between January and March 2018.

The Society did not have a designated office space and functioned as an operational support group from within the premises of the thalassemia day ward at the hospital where children and young adults came for transfusion and treatment. We were allowed to access the day ward for observation. Unnithan and Pachauli also had the opportunity to interview the managing director (MD) who was the owner of hospital (which we call Trust Hospital or TH). The MD talked about the pioneering thalassemia services they offered in the state, such as the hospital's specialism in care for children including in stem cell transplants, his motivation to invest money towards thalassemia support services and fund related research pioneered by his key doctor, Dr C.

Pachauli and Unnithan had discussions at the Public Hospital (hereafter PH) with Dr D and counsellor H working at the Thalassemia ward there which provided insights into class and rural-urban contrasts in thalassaemia health-seeking practices and the provision of care among non-Society members. Pachauli also attended events of the Society such as an annual picnic and a blood donation camp organised to mark World Thalassemia Day in May 2019. All conversations took place mainly in Hindi. Pachauli's knowledge of Rajasthan's public health care system and policies, given her long-standing work in the area, was key in developing the rapport with our respondents. She was able to provide them with information or contacts which they found useful. Given that her organisation has been involved in advocacy for free medicines and treatment at public health care facilities, office bearers of the Society found it aligning well with their mandate and saw value in collaborating on our project. Ethical clearance for the work by Pachauli and Unnithan was gained from the hospital managing committee at TH while the overall project received ethical clearance from the Research Ethics Committees at the University of York, Sussex and in India from the internal ethics committee of Prayas, where Pachauli was based.

Organising for thalassemia care

During our fieldwork between 2017 and 2019, the Society had 280 registered members from across the state. The membership was limited to parents of children with thalassaemia. As explained by Mr Bhairav, the President:

> Only parents can understand the problems and needs of these children …. Others may want to join it out of sympathy…, but they would never be able to recognize and identify with the problems and the pain that the families with children who have thalassemia really go through.' (20th January 2018).

Formed in 1986 and registered as the Society in 1993 its objectives were to: i) work for the relief of persons with thalassemia, ii) promote and co-ordinate research, iii) educate

people on the problems of thalassemia, iv) offer counselling to patients and carriers; v) bring together patients, families and well-wishers to exchange ideas and information (society charter).

Membership involved a small annual fee of INR 300/- (approximately £3), with the Society being largely dependent on donations from the public and members of commercial corporations. Most registered members lived in Jaipur with few outside the city. Families were likely to lose touch following the death of their child, a bone marrow transplant, or if they moved to another city. The Society's executive committee of 11 members met regularly, at each other's houses.

The Society's main concern was to ensure a continuous supply of safe blood, drugs and filters, procured and distributed at a subsidised rate. The state government provides blood free of charge to all thalassaemia patients registered at a treatment centre along with free oral and injectable chelation agents under the Essential Drugs scheme (unless a drug is in short supply).5 Nonetheless, concerns about the quality and safety of blood and availability of medicines have steered a majority of these member families to seek care in a smaller private/charity hospital.

The Society often procured filters[6] at subsidised rates from Thalassemics India, who get bulk price-orders from reputed companies for distribution to smaller thalassemia organisations across the country at 580 rupees each (approximately £5.80). Members are able to buy filters from the Society at a further reduced cost of 350 rupees (around £3.50). However, due to the financial constraints and to maintain equity, the Society caps the lowest price at a maximum of two filters a month for each member. Any direct procurement of filters is done from reputed companies, without compromising the quality. During one of Pachauli's visits to the ward at TH, she found two representatives from BioR, a manufacturing company, observing the functioning of a fresh batch of filters supplied by them. Mr Bhairav and some parents were concerned that these filters were slower, increasing the transfusion time, compared to the previous ones (discontinued due to a price rise). The discussion continued for several hours and eventually the BioR filters were approved once doubts had been cleared. Interestingly, the technical details about the efficiency of the filters were not deemed to be the responsibility of the clinical team administering the transfusions. Safety of blood and blood products continues to be high on the agenda of local and national thalassemia organisations across India.

Blood donations

Ensuring a regular supply of safe blood meant that the Society worked closely with all registered blood banks and charities involved in blood donation (*rakt dan*) and collection services. It also organised its own blood donation camp although increasingly the practice seemed to be more of symbolic significance, given the responsibility of the Red Cross and the IBTS for maintaining a safe, free blood supply for these patients.

Blood camps were jointly organised by the Society and the Bhatia (caste) Youth Brigade, which is a part of Mr Bhairav's Bhatia *biradari* (extended kinship and caste group), who arranged a free venue. TH provided a team of doctors and paramedics, who carried out the required medical procedures. The camp went on for about five hours, where food was served and donors were presented with gifts as a token of thanks by the society. The attendees were young and old with roughly similar representation of men and women. Nineteen-year-old

Nishita, a student, had come to donate blood for the first time as had Gauri, a thirty-two-year-old housewife with two children. Her husband Anil, who worked in the finance sector, was one of the key persons in the Society who helped mobilise donors. Pooran, in his 50s, was a frequent donor and was donating for the 46th time that day. He had known Mr Bhairav for a long time and was aware of the difficulties that children with thalassemia and their families faced. (Pachauli notes; Blood donation camp, Jaipur May 2018).

In the past, access to blood was a persistent issue facing parents who had to donate blood in exchange or pay a donor. Holding camps, executive members felt, was a way of reinforcing the notion of 'giving something back', reinforcing a culture of blood donation and service (*sewa*) that would not only benefit thalassemia patients but others as well. It is worth noting that such camps are common across India, commemorating secular and religious events in the calendar ranging from the Independence Day, Diwali to birthdays of saints and prominent public figures (see Copeman 2009).

Whilst kinship and caste underpinned the camp activities, the core membership of the Society included parents from different social and religious backgrounds. For instance, Mr SK, the Secretary of the Society was a Muslim. What connected the members at the broadest level was their middle-class affiliation, and similar experiences of accessing care from the relatively expensive private hospitals. They also shared the confidence and skills (social capital) to engage with the medical, pharmaceutical and state authorities compared with other 'grassroot' NGOs we have worked with in Rajasthan. The social capital aspects of successful advocacy are shared in health activism more broadly, as we discuss further below.

Public versus private healthcare

The significance of class in the Society membership and activism was quite evident. The organisation functioned out of TH, which was an urban, private hospital. Most of its members came from middle to upper middle-class families who could afford to pick up some of the costs involved in sourcing blood, filters and medication. None of its members were from rural or poor households. This was in stark contrast to patients in the ward of the public hospital (PH) we visited. At PH, there were long queues in the hospital reception area for the low-cost or free medicines (*nishulk dawai).* As explained to us by counsellor H, another significant factor impeding poor patients was the added cost of transport (Rs. 800–1000 each time) and accommodation which meant that most families spent more than what they earned in a month on one treatment cycle of a family member. The attendance of the rural, labourer families further fluctuated in response to the agricultural cycle, disrupting their treatment schedule.

Despite the free services and medicines provided at the public hospital, the unavailability of NAT (Nucleic Acid amplification Tested) blood at government facilities was a key reason why patients who could afford to shifted from the public hospital to TH. NAT tested blood is considered safer for reducing the risk of transfusion-transmitted viral infections such as HIV, hepatitis B&C, particularly as thalassaemia patients receive multiple transfusions from multiple donors over their lifetime. The members received better facilities at TH, at about Rs. 2000 (including the doctor's fee, Rs. 850 for NAT tested blood and Rs. 350 for the filter). However, given the chronicity and complexity of thalassaemia, the recurring

treatment costs every month, was a source of financial strain even for these better off families.

Compounding the inequity of care, at the private hospital, empathetic and personalised care was ensured by the chief of Paediatrics (Dr C)[7] who supervised the thalassaemia day centre and ward. In fact, Rila, a parent described Dr C as a 'pillar of strength'. In contrast, doctors in overcrowded public hospitals simply do not have the time or resources to provide such individualised care. Mr AC, treasurer of the Society recounted his experience of taking his son, Shankar, for transfusions to the PH:

> The doctors and the staff at PH never empathised with us. I began to lose hope as they would, at times, make me feel as if I was making a futile effort to save my child…. …the staff were not attentive. They were harsh, at times, if we asked them anything…A hospital should fill you with hope, not leave you in despair. [21st January 2018].

A majority of the poorer families were unable to access the quality of care that Rila or Mr AC experienced at TH, despite the fact that treatment is free at PH, where some of the state's best paediatricians work. Doctor G at the public hospital did however say that he referred his patients to a specialist paediatric centre run by a charity, which offered these services as part of the government Bhamashah (insurance) scheme which subsidises the treatment costs of Bone Marrow Transplantation (BMT) for a limited number of families living below the poverty line.[8]

Concerns of accessing quality care at affordable costs for members, framed the Society's long-term vision and engagement with State health policy. At the same time, sustainability of care as a matter of routine depended on diverse forms of networking and kin mobilisation. To what extent was such mobilisation determined by politics within the Society and its responsiveness to younger members as well as shifting state policy? We now turn to this question, examining the opportunities and limits of parental activism.

Kinship and parental activism: solidarity and conflict

We first met Mr Bhairav, in his mid-fifties, at the entrance to the Trust Hospital (TH) in August 2017. His Saturdays are usually spent at the TH where he accompanies his son, Vipul, every alternate week for his transfusion. Mr Bhairav lost his wife about two years ago and has a daughter who is married and lives in another city. Vipul is 29 years old and works in a bank. He is among the oldest thalassemia patients in the TH ward.

As a parent, Mr Bhairav's therapeutic encounter with thalassemia took place when Vipul was three and he started showing signs of severe anaemia. It was a year later, in 1992, when Vipul had this thalassaemia diagnosed at to a tertiary hospital in Delhi. According to Mr Bhairav:

> I had never heard of thalassaemia before and had no idea about the severity of the problem. Later when doctors explained to me what it was and I began to read more about it, I realised what this meant for us as a family. I had a feeling of complete despair. The one thought that repeatedly came to haunt me was, why did this have to happen to me (*ye mere sath hi kyun hua*)? [20th January 2018]

Born into a Hindu family that immigrated from Pakistan to Uttar Pradesh before moving to Rajasthan, Mr Bhairav obtained a BSc honours degree before running a family-based

handicraft business in the city. Despite making modest profits, he believed that his business would have flourished had he not committed his time to the cause of thalassaemia.

Following Vipul's diagnosis, Mr Bhairav initially took his son to the state paediatric hospital in Jaipur (PH). Finding the quality of care to be unsatisfactory, he shifted to a private, multi-speciality hospital (TH), offering subsidised treatment for children with thalassaemia. Vipul was among the first cohort of 35 children who were treated free at the hospital. Mr Bhairav's early relationship with TH and in particular, the paediatrician, Dr. C., marked a critical step in his journey of activism. Ever since, he has advocated for better state health services and support for thalassaemia patients as a parent and, subsequently, President of The Society. He learnt about The Society in 1995 through other parents at the TH hospital and decided to join. He described the early phase of The Society as one of relative dormancy, due to members inactivity. Running his own business, provided him flexibility, unlike other members, a factor contributing to his success at running the Society.

Mr Bhairav was elected Secretary in 1997 and shortly after President of The Society. This entailing a sense of personal responsibility (*zimmedari)*. His advocacy efforts began with ensuring regular supplies of drugs under the government's free medicines scheme; and blood chelation filters from Delhi. He also started representing the Society in regional and national conferences. Since 2000, the Society has organised an annual meeting in collaboration with TH to mark 8th May, International Thalassemia Day. One of the first activities that Mr Bhairav engaged in, when he joined the society in 1995, was to organise a blood donation camp. He proudly described to us how he was able to collect 21 units of blood, using his friendship network as a regional cricket player. This number gradually increased to 72 units, boosting confidence and expanding the Society's portfolio of activities. Throughout, his focus was on caring for his own son but he felt that his contributions would benefit the other children in the Society, linking the health of the individual to that of the wider collective good of the 'family' (Society).

'Like a Family': bonds and tensions of membership

Society members acknowledged a common bond, reciprocal rights and shared interests, created through their common experience of thalassaemia. In a more symbolic kinship sense, the bonds represented a shared vision of striving for the best care while challenging the stigma surrounding thalassemia (similar to HIV support groups described by Reynolds Whyte and her team in Uganda, 2014, Biehl for Brazil 2002 and Nguyen 2005). Members shared a deeply felt stigma in terms of their children's inability to form their own families, hold 'good jobs' and thereby gain social acceptability as independent adults (a shame and secrecy linked to genetic disease in other parts of the world as well). The reciprocal flows between Society members were premised on an identity as a family of shared experiences, stigma, and pain, despair and suffering. According to Mr Bhairav, '*the Society is like a family and most of us have known each other since years now, both children and their parents. We bond with each other and try to help one another whenever in need.*' Observing their everyday greetings, Pachauli noted how the children proudly talked about their academic successes, getting a coveted job or winning a school or college competition. They treated Society members with utmost respect and admiration, touching their feet when they met them (a popular gesture of respect reserved for older kin).

Despite the notion of kinship and a shared bond between members, difference and dissent also occurred. This was noticeable especially in the dominant influence exercised by Mr Bhairav in decisions about treatment choices and the Society's charter. Rila, for example, was keen for her son Yuji to undergo a bone marrow transplant (BMT); their only hope for a potential cure. She did not, however, want to mention this to Mr Bhairav who, she knew, disapproved. Rila nevertheless was keen to pursue the option and quite emotional when she told CP:

> I don't want my son to live a life like this. Is this even a life? I will be ok if the transplant (BMT) doesn't work. But I would definitely try to bring him (Yuji) out of all of this (misery) that he is going through every month (CP, field notes, 2018).

Mr Bhairav believed that the commitment to the Society of those parents who decided to go for BMT was limited, because they would not 'come back' and literally disappear after their child's need for treatment had been met, abrogating their collective responsibility to the Society. Tensions between Mr Bhairav's views on BMT and the aspirations of parents resurfaced when the State propagated the promissory nature of stem cell transplants through provision of subsidised treatment for children who qualify. Hence, after considerable deliberation 11-year-old Shankar's parents decided to have a second child, hoping to have a BMT donor. Again, common to other contexts of living with genetic disorders, this is what Sui and Sleeboom-Faulkner (2010, 2011) describe as the making of 'saviour siblings'.

There seemed a disjunction between the professed values of the Society about sharing and educating others and fighting stigma against thalassaemia, misconstrued as a terminal condition, and the secrecy maintained by parents and young people themselves within their wider social networks. Rila's personal fight as a parent against the stigma faced by her and her child from their wider kin community emerged in her dairy. She revealed how her diary collected hand-written wishes for Yuji from different people, including his doctors and teachers, on his birthday. On some pages, Rila had glued in newspaper cuttings of inspirational articles and quotations about thalassaemia. She was preserving every moment of her struggle, the little victories, hopes and motivation to carry on. The trauma of stigma and 'othering' emerged clearly in the accounts of the older children in the group, as we see below.

Conflicting values, aspirations and inter-generational tensions

Like all community support groups, there were differences between members about visions of the future. We found this to be especially so between parents and their older children. The dissension focussed on a few key issues: one of which was the termination of a foetus following a positive prenatal diagnosis. In Indian public health discourse, there is a predominant assumption of the benefits of termination, reflected in the proclaimed aim of making India a 'thalassaemia free' country (Chattoo 2018). Members of the Society had mixed feelings about this. Most parents supported the mandatory testing of pregnant women. Given their struggles in providing basic care to their own children and having seen their families go through so much pain, they did not wish thalassaemia on anyone else. Some young people who had thalassaemia also supported policy interventions for prevention. Preeti, in her late 20s, believed that, '… *testing before marriage should be made mandatory so as to prevent thalassemia.*'

However, not all the young people agreed. Vipul, for example, was more critical of the notion of prevention and challenged the negative, disablist attitudes toward people with *his* condition. According to Vipul,

> People may die untimely deaths due to cancer or a road accident as well. Sometimes they may become bedridden and may be completely dependent on others for every little activity and may require long term treatment. Thalassemia is not any different from this, then why despise it so much? [17th February 2018].

Despite Vipul's more levelling approach, thalassaemia continues to be associated with premature death, a degree of shameful secrecy, a 'burden on society' in family and public discourse.

A second contested issue amongst Society members concerned marriage. Echoing the wider cultural value placed on marriage across religious/ethnic groups in India, and other parents, Mr Bhairav said:

> These children should be able to get married, have kids and lead a normal life. They shouldn't remain deprived of this happiness just because they have thalassaemia. Parents are not going to be there forever. If they get married and have a family, they would still have somebody to fall back on when they need care and support.

Such thinking pointed to a further, thornier ethical issue of the marriage pool and whether marriage partners should be 'normal' (non-carriers). Diya, a younger member of the Society was in her late 20s and worked in the financial sector. She had married the man she loved who was not a carrier and they had an 18-month-old toddler, challenging the myth that 'normal' marriages were not successful for thalassaemia patients. Despite her success, Diya faced stigma as a child. Reflecting on what needs to change, she said,

> There's a need to create more awareness about thalassemia among people. There's a lot of stigma attached to it, so much so, that my parents never let anyone know that I have thalassemia. Not even my teachers ever knew about this.

Despite initial tensions, her parents, who lived close by, share childcare during the week while Diya and her husband are at work.

Some thalassaemia support groups have added a tab to virtual matchmaking on their webpage. Young members like Diya remind us that the focus of the Society's mobilisation might well be shifting. Given the social and cultural value placed on marriage, support for young adults means enabling them to have a family of their own. Some of the members, such as AC, told us, '*I have taken up the responsibility to find matches for those who are now grown-up and want to get married. There are quite a few of them.*' As is common in wider cultural practice parents/adults within an extended family continue to play an important role in 'arranging' or 'approving' a marriage proposal (Mody 2008).

The gap between the original charter of the Society and the shifting needs and aspirations of the young adult patients highlighted critical issues, which underscored a 'success as failure' transformation now occurring in the organisation. In addition to facilitating marriage, there was a strong emphasis to modernise to offer online support. The decentring of clinical knowledge with the proliferation of online information resources conflicted with the older remit of thalassaemia organisations as the main source of information for parents and patients (Chattoo, personal communication with the Secretary, NTWS, Delhi). Securing

long-term health and assistance from the state was a priority for young people, beyond the agenda of access to blood and medicines. Here the debates around the strategic positioning of thalassemia as a disability were critical.

Strategic mobilisation: claiming disability rights

> … now that thalassemia has been recognised as a disability the Society must advocate to ensure that everybody benefits from it. People are reluctant to give us jobs right now and this is a huge setback. [Vibha, 30 years, Society member]

Vibha and Preeti, both in their early 30s and working in a family-run business (a watch shop and a boutique respectively) emphasised the importance of ensuring that the benefits of the Disabilities Act (RPWD Act) 2018 accrued to those with thalassemia.

Preeti said, '*I wrote letters to the Prime Minister and the Home Minister earlier highlighting the issue that thalassemia was often not being mentioned in the list of disabilities in examination forms despite it being recognised as a disability now*'. Arjun, in his mid-20s, also wanted the Society to lobby for disability 'reservation' (positive discrimination) in employment for people with thalassemia, saying, '*I want to be independent and have a job of my own, but it's very difficult to find one, especially if you have thalassemia*'. He echoed the concerns of a majority of young people that we met during our research, who faced covert and overt disadvantages in the job market due to long-term effects caused by the loss of school/college days and poorer overall educational attainment.

Inclusion within the RPWD Act was critical to ensure the possibility of gainful employment for young people with thalassaemia. Parents could see other long-term merits. As Mr Bhairav said:

> Having a job makes a big difference. It boosts their (the child's) confidence and makes them feel that they can do anything that others can do. This has a huge psychological impact as well. They feel good inside and that's important to help them lead a healthy and long life…. If they have good jobs, especially in government sector, this will at least attract some people to come forward to marry them. [24th February 2018]

However, implementing the RPWD Act to certify the level of disability faced by someone with thalassemia was a major challenge. A person needs to be certified as having a 40 percent disability (based on a physical impairment model) to be included for reservation in education and employment. The poor implementation of the Act at a state level during the time of fieldwork, an issue raised with the Union Ministry of health by the Thalassemia Patient Advocacy Group (a branch of Thalassemics India) compounded these challenges.

The framing of thalassemia within the purview of the Disability Rights can be seen both as a strategy to gain public visibility and a funding commitment from the state but equally one which enhances the notion of thalassaemia as a disability, associated with stigma, which Society members and young adults wished to challenge. The recent shift in Society strategy from localised parental activism toward a discourse of disability rights aimed at the state suggests that kinship concerns and insights have begun to move 'beyond the home' (also suggested by Rapp and Ginsburg 2011). Beyond the transformation of kinship concerns it also signals an advocacy strategy in transition, with an uncertain future.

Concluding discussion: the limits and transformation of parental activism

The activism of the Society represents a micro-mobilisation which is predominantly locally constituted, and, unlike other emergent forms of NGO activism within India as described by Appadurai (2002) and Merry (2006) has little international engagement. In their association with Thalassemics India, however, the Society has forged an indirect link with Thalassemia International Federation and its global agendas. This is reflected, for instance, in their celebration of the World Thalassaemia Day and in the shared mobilisation around the RPWD Act. Whilst not claiming global ties or resources, as Leach and Scoones (2007: 27) observe for other forms of micro-mobilisation, the Society nevertheless 'reflects the emergence of 'responsibilized citizens' who join forces to articulate individualised rights and life-style choices in relation to public goods and regulation proposed by the state (Petryna 2002; Beckmann 2013). Although 'disability' as a category of representation is contested by Society members and 'rights' may not be the most morally appropriate conceptual tool for justice claims, these nevertheless provide the most powerful discursive devices available to activists (Petchesky 2003; Unnithan and Pigg 2014). The political use of such devices, we suggest, can be seen as acts of 'performative intervention that demand changes in exclusionary practices' which Ginsburg and Rapp (2017) term 'cripping' (4, note 5).

Society members demonstrated a keen awareness of the limits to effective mobilisation, for a small, localised group. As Mr Bhairav remarked, the availability of limited resources meant the Society could only undertake small-scale interventions:

> We already have so many issues to deal with that we remain entangled within these (*hamari to apni hi itni samasyayein hain ki hum unmein hi uljhey rehte hain*). Only 2–3 committee members work actively. We are a *sookha-kuan* (literally, dry well) as far as funds are concerned. There's a reason we do not have a designated office or staff.

However much the Society helped raise awareness through its membership networks and meetings, members believed the Government bore ultimate responsibility for creating a wider awareness of the condition (a similar observation was made by grassroots NGOS in Rajasthan around rights mobilisation in the context of reproductive health, 2012, 2014 authors anonymised). This realisation has in recent years been accompanied by growing rights-based claims on the state to carry out its duties of healthcare. The Society's campaign for access to free medicines based on the Act of 2011 *(Mukhya Mantri Nishulk Dawa Yojana)* is a point in case.[5] Mr Bhairav described holding successive meetings with senior health officials and with a previous Chief Minister of the state. Consequently, most essential thalassemia medicines were included on the list of free medicines. For example, the chelation medicine, Desirox, costs about Rs. 1100 in the market but is provided free to thalassemia patients across Rajasthan, making treatment affordable for the poorer families. Mohd SK, the Secretary, saw this inclusion as the Society's biggest achievement, although this advocacy strategy does not chime with the desire of young adult members to connect with disability rights campaigners. Their unanticipated survival could be seen as shifting the Society's activist engagement.

The earlier successes, however small, were an example of how 'accidental' (spontaneous) therapeutic mobilisation, which is parent-led and largely disconnected from the global forms of engagement, can achieve important gains in response to long-term, localised care

needs. One of the Society's challenges as it moves forward will be to address the new pathways that have opened up as a success of its strategy to ensure survival, especially with regards disability consciousness and action. As for any NGO sustaining its activities and maintaining the commitment of its members is a difficult task. For Mr Bhairav, given that thalassaemia is such an intimate, relational chronic condition, '*it's difficult to have people or organisations who would want to work with us for a long term,*'. Nevertheless, because the Society was constituted by parents and children affected by the condition, there would always be a core group of committed and active members. Sustained mobilisation was however, hampered by the differing notions of therapeutic 'risk' held by some parents and the fact that death of a thalassaemic also often entailed death of Society membership.

The unanticipated survival (Block 2020) of some of the younger members, who are likely to be supported through disability rights legislation, challenges the 'success' of the Society, while simultaneously portending new forms of activism. The dynamic tension between parental therapeutic activism which is family oriented – often the starting point for many NGOs – and the need to respond to more rights-based approaches, informed by a collective commitment to social justice, is likely to become more significant as care for chronic conditions become more publicly recognised (in law, medicine, and policy) as well as everyday life in the 'new normal' (Ginsburg and Rapp 2017:12). The original medical focus and the struggle for recognition and basic health care have changed, as the 'choice to survive' is associated with the outcome of social and political struggles; and attention shifts to a more sensitive regard for the 'art of living' (see Rose 2013), in which people can flourish (see Fassin on the value of life).

Note

1. We thank the first reviewer for this insightful point.
2. Mol's social analysis of anaemia suggests a social theory of agency beyond network analysis.
3. Similar to 'service' enacted in blood donation camps organised by reformist religious organisations such as the Hindu Sikh Niranakari groups described by Copeman.
4. Findings from Unnithan's ESRC funded fieldwork on right-based approaches to reproductive health, 2010.
5. The Mukhya Mantri Nishulk Dawa Yojana (MNDY) programme was rolled out by the Rajasthan government in 2011 with the mandate to provide free essential medicines at government health facilities. Currently there are 712 medicines, 181 surgical items and 77 sutures provided under this scheme.
6. Since thalassemia patients only need red cell transfusions, a blood separation machine is required to separate the red cells from the plasma and leucocytes before the blood is transfused. The leuco-filters filter out any residual white blood cells during a transfusion. The clinical efficacy of these filters is contested.
7. The thalassaemia service and research programme at TH started in mid-1990s when Dr. C joined as a young paediatrician. His expertise in foetal haemoglobin measurements enabled TH to establish the first diagnostic and treatment centre for thalassemia in the state (interview with MD and Dr. C, 2/01/2019; Pankaj 2017). TH procured free blood from the blood banks, filters and Desferal infusion pumps for chelation from Thalassemics India and provided filters for sifting white blood cells at subsidised rates for their patients at 350 rupees.
8. Although the costs for BMT were approximately 17–18 lakh INR (up to £20,000), the Bhamashah health insurance scheme was able to provide cover for 8–10 lakh INR (up to £10,000) and other national/state charities or family and friends would have to raise the rest of the money.

Ethical approval

Ethical clearance for the work by Pachauli and Unnithan was gained from the hospital managing committee at TH while the overall project received ethical clearance from the Research Ethics Committees at the University of York, Sussex and in India from the internal ethics committee of Prayas, where Pachauli was based.

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Data availability statement

Supporting data can be accessed on the UKData Share, at pasted below. (https://reshare.ukdataservice.ac.uk/855984/.

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References

Appadurai, Arjun. 2002. 'Deep Democracy: Urban Governmentality and the Horizon of Politics.' *Public Culture* 14 (1): 21–47. doi:10.1215/08992363-14-1-21

Beckmann, N. 2013. "Responding to Medical Crises: AIDS Treatment, Responsibilisation and the Logic of Choice." *Anthropology & Medicine* 20 (2): 160–174. doi:10.1080/13648470.2013.800805.

Biehl, J. 2007. *Will to Live: AIDS Therapies and the Politics of Survival*. Princeton, NJ: Princeton University Press.

Block, P. 2020. "Activism, Anthropology, and Disability Studies in Times of Austerity." *Current Anthropology* 61 (21): S68–S75. doi:10.1086/705762.

Carsten, J. 2011. "Substance and Relationality: Blood in Contexts." *Annual Review of Anthropology* 40: 19–35.
Carsten, J. 2019. *Blood Work: Life and Laboratories in Penang*. Durham, NC: Duke University Press.
Chattoo, S. 2018. "Inherited Blood Disorders, Genetic Risk and Global Public Health Framing 'Birth Defects' as Preventable in India." *Anthropology and Medicine* 25 (1): 30–49.
Copeman, J. 2009. *Veins of Devotion: Blood Donation and Religious Experience in North India*. New Brunswick: Rutgers.
Copeman, J. 2016. "Religion, Risk and Excess in the Indian Blood Donation Encounter." In *Giving Blood: The Institutional Making of Altruism*, edited by J. Charbonneau and A. Smith, 129–144. London/New York: Routledge.
Douglas, M. 1966. *Purity and Danger: An Analysis of the Concepts of Pollution and Taboo*. London: Routledge and Kegan Paul.
Ghosh, K., R. B. Colah, and M. B. Mukherjee. 2015. "Haemoglobinopathies in Tribal Populations of India." *Indian Journal of Medical Research* 141: 505–508.
Ginsburg, F., and R. Rapp. 2017. "Cripping the New Normal: Making Disability Count." *Alter: European Journal of Disability Research* 11: 179–192.
Government of India. 2018. *Prevention and Control of Haemoglobinopathies in India: Thalassemia, Sickle Cell Disease and Variant Haemoglobins in India*. New Delhi: Ministry of Health and Family Welfare.
Leach, M., and I. Scoones. 2007. "Mobilising Citizens: Social Movements and the Politics of Knowledge." IDS Working Paper 276, pp. 1–37. Brighton: Institute of Development Studies.
Macdonald, S., and B. Simpson. 2014. "Shadowing Research in Organsations: The Methodological Debates." *Qualitative Research in Organisations and Management: An International Journal [Online]* 9 (1): 3–20.
Mattingly, C. 2010. *The Paradox of Hope: journeys through a Clinical Borderland*. Berkeley: California University Press.
Merry, S.E. 2006. *Human Rights and Gender Violence: Translating International Law into Local Justice*. Chicago, IL: Chicago University Press.
Mody, P. 2008. *The Intimate State: Love-Marriage and the Law in Delhi*. London: Routledge.
Mol, A. 2002. *The Body Multiple: Ontology in Medical Practice*. Durham, NC: Duke University Press.
Mol, A., and J. Law. 1994. "Regions, Networks and Fluids: Anaemia and Social Topology." *Social Studies of Science* 24 (4): 641–671.
Nguyen, V.-K. 2005. "Antiretroviral Globalism, Biopolitics and Therapeutic Citizenship." In *Global Assemblages: Technology, Politics and Ethics as Anthropological Problems*, edited by A. Ong and S. Collier, Malden: Blackwell Publishing.
Pankaj, Bhavana. 2017. *Thallassemia: The Programme at TH Hospital. In-House Publication*. Jaipur: Designations
Parmar, L., A. Sedai, K. Ankita, R. Dhanya, R. K. Agarwal, et al. 2018. "Can Inequity in Healthcare Be Bridged in LMICs: Multicentre Experience from Thalassemia Day Care Centres in India." *Pediatric Hematology Oncology Journal* 2 (2017): 88–93.
Patra, P. K., and S. Kumar. 2010. "Socio-Ethical Implications of Genetic Screening Programmes: An Anthropological Study of Two Tribal Communities." *Jharkhand Journal of Development and Management* 8 (4): 4135–4147.
Petchesky, R. 2003. *Global Prescriptions: Gendering Health and Human Rights*. London: Zed Books.
Petryna, A. 2002. *Life Exposed: Biological Citizens after Chernobyl*. Princeton, NJ: Princeton University Press.
Rabinow, P. 1999 [1996]. "Artificiality and Enlightenment: From Sociobiology to Biosociality." In *The Science Studies Reader*, edited by Mario Biagioli, pp. 407–416. New York: Routledge.
Rabinow, P. 2005. Midst Anthropology's Problems. In A. Ong and S. Collier eds., Global Assemblages. Oxford: Blackwell Publishing. pp. 40–55.
Rapp, R., and Ginsburg, F. 2011. "Reverberations: Kinship and the New Disability Imaginary." *Anthropological Quarterly* 84 (2): 379–410.
Reynolds Whyte, S. ed. 2014. *Second Chances: Surviving Aids in Uganda*. Durham NC: Duke University Press.

Robins, S., and B. Von Lieres. 2004. "Remaking Citizenship, Unmaking Marginalization: The Treatment Action Campaign in Post-Apartheid South Africa." *Canadian Journal of African Studies*, 575–586.

Rose, N. 2013. "The Human Sciences in a Biological Age." *Theory, Culture and Society* 30 (1): 3–34.

Singh, R. 2018. "Active Parents, Parental Activism: The Adipose Stem Cell Invitro Lab Study." In *Global Perspectives on Stem Cell Technologies*, edited by A. Bharadwaj, 173–183. London: Palgrave Macmillan.

Sleeboom-Faulkner, M. 2011. "Genetic Testing, Governance and the Family in the People's Republic Of China." *Social Science and Medicine* 72: 1804–1809.

Sui, S., and M. Sleeboom-Faulkner. 2010. "Choosing Offspring: prenatal Genetic Testing for Thalassaemia and the Production of a 'Saviour Sibling' in China." *Culture, Health & Sexuality* 12 (2): 167–175. doi:10.1080/13691050902914110.

Unnithan, M. 2019. *Fertility, Health and Reproductive Politics: Re-Imagining Rights in India*. London: Routledge.

Unnithan, M., and C. Heitmeyer. 2012. "Global Rights and State Activism: Reflections on Civil Society-State Partnerships in Health in NW India." *Contributions to Indian Sociology* 46 (3):283–309.

Unnithan, M., and C. Heitmeyer. 2014. "Challenges in 'Translating' Human Rights: Perceptions and Practices of Civil Society Actors in Western India." *Development and Change* 45 (6): 1361–1384.

Unnithan, M., and S. L. Pigg. 2014. "Sexual and Reproductive Health Rights and Justice – Tracking the Relationship." *Culture, Health & Sexuality* 16 (10): 1181–1187.

Ventura, J., and I. Keinan-Guy. 2018. "Shadowing as a Central Research Method in Medical Design Anthropology." In *Sage Research Methods Cases*. London: Sage Publications. doi:10.4135/9781526449344.

Verma, I. C., R. Saxena, and S. Kohli. 2011. "Past, Present & Future Scenario of Thalassaemic Care & Control in India." *Indian Journal of Medical Research* 134 (4): 507–521.