

Health, Democracy and Sickle-cell Anaemia in Kerala

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A study conducted of the sickle-cell anaemia patients among the Chettys in Wayanad district of Kerala exposes the failure of public action in healthcare. It emphasises the need for sustainable care of these patients, which can be made available only if panchayats take an active interest. But the sick get less support from the panchayats and mainstream political parties. This is also a reflection of the present crisis in the public healthcare system of Kerala, which is characterised by poor quality and falling utilisation rates.

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Among the many explanations of social development in Kerala, those that highlight the efficacy of “public action” have been popular. Public action, as Amartya Sen has elaborated, refers to people’s efforts to demand action and make governments accountable. The gains from such activism, for example, were evident in Kerala’s equitable and accessible public healthcare system. However, it may be important to understand how public action undergoes transformation as the fields of politics and development experiences fundamental change. A host of changes have led to significant shifts in the fields of politics and development in Kerala since the 1990s, which includes the realignment of class relations and community power, evident in the economic clout of a new globalised non-resident Malayalee capitalist class, the emergence of the consumer-citizen, and the neoliberalisation of the mainstream left. State welfare is now highly individualised and is focused on minimum entitlements defined from above. In this context, one may ask about contemporary public action in Kerala, specifically about its location and conditions which enable it.

We hope to raise this question here through examining the recent efforts led by members of the Chetty community to organise around sickle-cell anaemia by forming the Sickle-Cell Anaemia Patients’ Association (SCAPA) in 2006, in the northern district of Wayanad in Kerala.

Sickle-cell anaemia in the hilly, forested, and once-malarial Wayanad district is prevalent among two social groups – the tribal peoples, particularly the Paniyas and the Kattunaykans, and the Wayanadan Chettys, a small agricultural caste group, classified among the other backward castes. A fairly recent account of the latter classifies them as landholder-farmers, who engage in cash crop cultivation – of paddy, coffee, ginger and pepper [Ravindranath 2002]. It also mentions that the Chettys,

while not a powerful group, do seek modern education and healthcare, and use public services, especially family planning services, extensively (*ibid*: 1574). A recent study on agrarian distress in Wayanad notes that though members of the Chetty community do hold land ranging from 20 cents to five acres and above, they have not acquired much above their ancestral property [Nair et al 2007].

The ongoing agrarian crisis in Wayanad is indeed the broader context in which sickle-cell anaemia is perceived as a debilitating disease for the individual sufferer, the family and the community. Wayanad has been ravaged by the combined effects of fall in agricultural prices, ecological destruction and crop failure since the early years of this century, leading to an upswing in suicides by indebted farmers. Several studies of recent agrarian distress in Kerala have indicated a general fall in the standards of life in urban farming households, and rise in livelihood risks [Nair et al 2007; Nair and Menon 2007], and this seems to apply well to the Chettys.

We conducted in-depth interviews and focus group discussions with key individuals involved in the formation of the recent SCAPA in Wayanad, between February 2007 and February 2008, and also interacted recently with social activists and healthcare professionals involved in the ongoing effort to strengthen public healthcare facilities for detection and treatment of the disease. This group, of some 20 activists, is better educated and with fairly good exposure to public life, and interacts with a fairly large group of Chetty and tribal people, who frequently approach them for advice and help.

The Wayanadan Chettys

Modern community-formation in early 20th century Kerala shaped new axes of social power, in which powerful communities, which acquired modern education and had economic clout were able to exert considerable pressure on the government to extend social development from the early to mid-20th century [Jeffrey 2003]. Early 20th century accounts of the Chetty indicate that they had sought education but were lax about strengthening their economic power. C Gopalan Nair,



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writing on Wayanad in 1911, writes thus about them:

The majority is illiterate but they are now sending their children to school. They are law-abiding and peaceful citizens living on the produce of their lands but are improvident and always indebted to the clever Moplah moneylender of Sultan's Battery... [Nair 1911/2000].

Unlike Kerala's powerful communities, the Chettys remain divided; subgroups mentioned by authors in the early 20th century continue to exist (ibid: 50-57). Unification efforts, while not absent, remain unsuccessful. Ravindranath (2002) mentions the existence of a Wayanadan Chetty Service Society, and our interviewees have mentioned about their recent efforts to strengthen the community through alliances with powerful castes. In the late 1990s, a group of educated Wayanadan Chettys apparently approached the powerful Shetty community of Mangalore and a large meeting of the Chettys was organised at Panamaram, Wayanad, which was attended by representatives of the latter group. However, that initiative did not prosper. Soon, a Chetty Welfare Society was started with the view of offering small loans to members of the community and encouraging small deposits. This too became defunct. As small farmers, this group seems to have borne the full brunt of the crisis, and the drying up of their incomes led to the closure of the bank.

Early accounts of the Chettys claim that in contrast to their east-coast counterparts, the Wayanadan Chettys enjoyed privileges similar to upper caste Nairs and non-polluting caste-status in pre-British Malabar and under colonial rule [ibid: 55-57; Innes 1908/1997: 123-24]. However, present self-perceptions of the Chettys about their place in the caste hierarchy are different, despite frequent references to "better times" in the past in the interviews. A key activist of the SCAPA even remembered being teased at school for being a Chetty; she claimed that though this is infrequent now,

...we are not a powerful group. I would say that there are no people more simple than us Chettys ... we are not thought of as very important by anyone. There are very few of us who have gained really high education and employment, or made money by going to the Gulf.

This probably explains the "things-fall-apart" scenario that surfaced in our interviews with sickle-cell anaemia patients from the Chettys. They connected their illness to the extraordinarily bleak present in which the community was being reduced to "beggary". The president of SCAPA told us:

... I had 2 acres and 88 cents of land. I have had to sell it, portion by portion, to treat this disease. Now I have just 40 cents ... and debt so big that it cannot be repaid even if I had five acres to sell.

Such sense of doom was absent in the narratives of illness by Paniyas and Kattunaykans, whose recent history has been one of continuous loss. Their accounts of the experience of illness were about how the disease trapped them in a vicious cycle of hunger and inability to labour. The Chetty interviewees interpreted this response as following from their being largely "simple folk".

On the one hand, historically, the Chettys do not seem to have acquired the capabilities to diversify their income sources under economic distress; on the other hand, such strategies are made increasingly difficult now precisely because the higher survivor rates among sickle-cell patients in the community mean that there is high demand for caregiving besides escalating costs of treatment, in a context in which the joint family system has ended. This means that a much higher share of time and energy, for families affected with the sickle-cell disease, will have to be spent on caregiving and not on finding sources of income other than agriculture. Among the leading activists of SCAPA, there are a few who have attained relatively better education and secured better chances of employment, who are severely limited by their illness. Indeed, researchers have found that of all the groups among which the sickle-cell gene has been found in India, the Wayanadan Chettys record the highest frequency [Feroze and Aravindan 2004].

Counter-Public

The SCAPA activists talked about the "community" and, importantly, located their initiative outside the state and politics, though many of them had individual affiliations to political parties. They spoke of the flimsiness of membership in the political public in the face of illness – some of the

office-bearers are communist sympathisers, who, however, remarked that once the disease struck, they were forgotten. This experience of isolation was highlighted when they tried to explain why they did not expect much from political parties. However, rather than retreat into closed communities, the activists seemed interested in transforming themselves into a counter-public. Perhaps, this is why local political parties appeared suspicious of the SCAPA. It is important, however, that the formation of this counter-public does not mean that community affiliations have been fully unhinged. Most importantly, the Chettys and tribals appear to be linked in a persisting moral economy that pre-dates the coming of the settlers.

The history of development in tribal areas like Wayanad and Attappady are stories of tribal deprivation growing with governmental interventions [George and Krishnan 2006]. These have provided the conditions under which other forms of governance – in this instance, represented by Hindu missionaries – began to incorporate the deprived. The Swami Vivekananda Medical Mission at Muttill, in collaboration with the Department of Genetics, All India Institute of Medical Sciences, New Delhi, claims to have screened 60,980 persons and found 1,838 persons affected with anaemia and 8,228 persons with the sickle-cell trait (<http://svmm.org/specialclinics.html>). Both the web site and the annual report of the Medical Mission portray it as a "tribal disease" though public health researchers have been clearly aware of its prevalence among the non-tribal Wayanadan Chetty population [Feroze and Aravindan 2001]. This is despite the well-known fact that the sickle-cell trait is a human genetic adaptation in areas, where malaria has been known to be endemic. The Medical Mission hospital has been the major agency offering care for the disease until recently. Treatment was free for tribals but not so for non-tribals. The Chetty activists expressed their ire at this, and felt that this was part of the Medical Mission's effort to Hinduise tribal people in Wayanad.

But the perception of such denial does not seem to be converting into resentment against the tribal peoples. We seem to be witnessing, partly, the shaping of a biosocial community and counter-public

[Rabinow 1996], one with claims of the capability to transform existing governmental categories and possessing exclusive knowledge of living with the disease, which, however, only blurs, not obliterates, local social boundaries.

Researchers have noted that the Paniya tribal people were once bonded labourers to Chetty landowners. The lack of resentment noted above is probably related to the persisting “moral economy”: Chetty landowners who had abandoned rice-farming in 2000 “reciprocated positively to the plea of the Paniya and Naykan households for sharecropping their land” [Nair et al 2007]. Both groups share deep distrust of settlers – our interviewees persistently constructed a shared history of loss. Feroze and Aravindan (2004) observe that higher the access to social development, the better the chances are for sickle-cell patients to survive. The times indicated in these accounts, three generations back, may have been the pre-health transition period which may have masked the prevalence of sickle-cell anaemia in both Chetty and tribal people. In this case, this shared history of loss seems to work in such a way that those social relations that structure “insider-outsider” relations work against producing stigma. Stigma, especially of disease, has been identified as such relations that lead to the identification of the “outsider” as undesirable or dangerous [Takahashi 1998]. In this account, it is the “outsider” implied who is held guilty – the settler from the plains. No wonder that the sense of “we”, when it appears in the speech of our interviewees, seemed to refer at times to the Chetty, and at other times, to a new community of sickle-cell anaemia patients, taking shape across blurred community boundaries.

Community Demands

Not surprisingly, then, the demands of the SCAPA go well beyond better healthcare facilities into “community demands”. They include reservation in educational institutions for sickle-cell anaemia-affected children and children of such parents, reservation of government jobs and debt relief, besides the expansion of public facilities for detection and treatment. Each of these demands is justified by the activists as necessary to achieve relief from and control of the disease. The secretary of SCAPA argued

that all children who have sickle-cell anaemia deserve reservation in educational institutions since they are more likely to drop out because schools are often far away and hunger is now endemic in Wayanad. This, she pointed out, affects awareness creation. Reservation in government services is demanded as support for those who cannot do exhausting physical labour. The activists argued that debt makes it impossible for families to attend to the health needs of members who are patients.

It is indeed striking that these demands – the weakness induced by the disease on the individual body, and the weaknesses suffered by the community in its failure to transform itself into a unified and economically powerful interest group – immediately refer to each other. Sickle-cell anaemia works here as an elaborate metaphor expressing the contemporary experience of the community: as a SCAPA activist eloquently remarked, what had been a beneficial genetic adaptation became a terrible drain to the Chettys; social development that ensured entry into citizenship to all others had paradoxical results for them. This may resemble the history of sickle-cell anaemia patients’ activism in the US, where the disease was read as a metaphor for the historical experience of the African-American community [Tapper 1995]. But as mentioned earlier, in the activists’ narratives, the “community” referred to keeps shifting between the Chettys and the emergent biosocial community. Also, the biosocial community seems to hold out the prospect of transforming the way in which governmental categories are inhabited. The activists argue that they are for the inclusion of sickle-cell among “disabled persons”, a well-accepted governmental category, which, they feel, may be transformed into a platform to put pressure on the state.

Contrasting Approaches

The contrast between the manner in which the state and public health authorities, and the members of the SCAPA approach the disease is best evident in their observations on the Comprehensive Care for Sickle-Cell Anaemia Patients in Wayanad and Attappady (CCSCWA), an extensive project aimed at improving the facilities for detection and treatment of the disease in district and primary level hospitals in Wayanad and Attappady.

Through the project, now supported by the National Rural Health Mission, facilities for detection are being set up in district hospitals and primary health centres; drugs effective in controlling infections and other manifestations are being distributed; doctors and paramedical personnel are being trained to handle sickle-cell anaemia; screening activities are being conducted and a database is being built at the Calicut Medical College which is supervising its implementation.

Interestingly, both the members of the SCAPA and the doctors involved in planning and implementing the project regard it as the fruit of their labour. The medical researchers from Calicut Medical College consider the project to be an outcome of their efforts; the activists regard it as the government’s response to their agitation for better facilities in the public sector, since 2005. They spoke of the dharna they had organised in front of the secretariat of sickle-cell sufferers – mainly children – to make their plight public in February 2006 (*Indian Express*, Kochi, February 2, 2006) and of their petition to the chief minister of Kerala, who announced financial aid of Rs 20,000 to each affected person.

This was not a solution, though it encouraged many people to undergo screening. An office-bearer of the SCAPA remarked that they had evinced keen interest in this project but they were granted no creative role in it. The complaints raised were not against the project per se, but that the given frame renders the sickle-cell anaemia sufferer passive. Here, the SCAPA’s sociological understanding of the disease stands in sharp contrast with the epidemiological view. Also, public healthcare was valued also because “government doctors” were rated as “patient, concerned, and kind”. However, they insisted that doctors did not have the knowledge they possessed – of the experience of living with the disease, which they consider to be equally important. Women members stressed that for women, sickle-cell anaemia posed a wholly different set of anxieties, which may be alleviated only by women healthcare professionals.

Besides, the SCAPA members also seek to position themselves as active citizens mediating between the state/public health authorities and the masses. A SCAPA member cited a recent instance in which a teenager,

who had been diagnosed with the disease at Manipal Medical College much earlier and was under treatment there, was screened at the local hospital, and the report claimed that he did not have the disease. "The confusion created was entirely avoidable; if we had a role in this, we could have played a creative role in resolving such disputes by taking it up with the higher authorities immediately".

The failure of the project to offer citizenship also points to the utter failure of the new dispensation of political decentralisation to "deepen citizenship" among the most vulnerable. It was hoped that democratic decentralisation and the participation of poor women in self-help groups would rejuvenate public healthcare through local funding, community participation to advance local priorities, but the results are far below expectations [Kutty 2001; Kyobutungi and Nayar 2005]. The experience of the SCAPA indicates that local priorities in healthcare continue to be neglected in panchayats. As a NRHM functionary candidly remarked, the sickle-cell anaemia sufferers go unheard in grama sabhas precisely because they lack in numbers, in skills and political clout. The disease is, indeed, eminently local in nature; however, the remedial initiative and funding came from outside and above. Our interviewees – all people of some education and a fair amount of experience in public politics – did not find the grama sabha to be a useful primary platform to place demands. A village panchayat and a block panchayat which responded to appeals offered the sums of Rs 2,500 and 3,000 to each affected person. Panchayat members attended public meeting they held in the Tirunelly panchayat and the activists were asked to "...report any meeting or programme or activity we were planning to hold well in advance to the panchayat". Clearly, the local body's role seems to be confined to disbursing inadequate and individualised welfare in cash – and maintaining surveillance on civil social activities. Sustainable care, however, can be made available only if the panchayats take an active interest.

Conclusions

From the experience of the SCAPA it appears that public action in contemporary Kerala – in Sen's terms – involves people who have

not gained from the early waves of community formation. But it now derives less support from mainstream politics. Claims about the newly established local self-governments "deepening democracy" seem suspect; in this case, the panchayats' interest in monitoring civil society, combined with their disinterest in the issues raised, may not serve the purpose of deepening democracy. The SCAPA's aspiration to a bio-social community is interesting, even though community boundaries and relations of power between Chetty and tribal communities have not disappeared. In Kerala, historically, public action has been facilitated by either the mainstream left or the community movements until the 1970s; oppositional and critical civil social movements have played this role with varying degrees of success since the 1980s. It seems as though the latter continues to throw up new formations despite the state's and political mainstream's open hostility, all the more evident in recent times.

This also leads us to reflect on the present crisis of Kerala's public healthcare system, characterised by poor quality and falling utilisation rates [Navaneetham and Kabir 2004]. Private healthcare is now acknowledged to be the major provider of healthcare in Kerala and recent studies have pointed out that the poor who now access private healthcare as frequently as the better-off are severely taxed by steeply rising costs [Dilip 2008]. Increasingly, a vicious cycle seems to be at work: "services for the poor are poor services". The users of public healthcare are the most marginalised: women, dalits, illiterate people, the income-poor, and people living in the midland and highland areas [Navaneetham and Kabir 2004] – certainly, the sickle-cell sufferers of Wayanad belong here. The option of moving to private healthcare without crippling financial burdens exist only for those groups which have benefited from the early and mid-20th century socio-political transformation, or the late 20th century Gulf migration.

For such groups as the sickle-cell sufferers, good health is accessible only through public healthcare. If the project of "deepening democracy" is to be seriously pursued, perhaps the political mainstream's hostility towards oppositional and critical civil social mobilisations should be abandoned.

Perhaps, in the efforts of the SCAPA activists' efforts to gain recognition as citizens within public health initiatives lies a clue to rejuvenating public healthcare in Kerala. SCAPA activists view themselves as citizens with well-specified claims upon public resources involved in shaping the public health agenda through critical engagement with state functionaries and public health authorities, and mediating between the patients and the state. Perhaps, it is by recognising and fostering such new forms of public action – and not by limiting the "local democracy" to the devolution of power and resources to lower levels – that the public health sector may be truly democratised and rationalised.

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