"My story is like a goat tied to a hook." Views from a marginalised tribal group in Kerala (India) on the consequences of falling ill: a participatory poverty and health assessment

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ABSTRACT

Background Indigenous populations tend to have the poorest health outcomes worldwide and they have limited opportunities to present their own perspectives of their situation and shape priorities in research and policy. This study aims to explain low healthcare utilisation rates and opportunities to cope with illness among a deprived indigenous group - based on their own experiences and views.

Methods A participatory poverty and health assessment (PPHA) was conducted among the Paniyas, a previously enslaved tribal population of South India in a Gram Panchayat in Kerala, India in 2008. Purposive sampling was used to select five Paniya colonies, involving 66 households.

Results There were four key findings. First, Paniyas' perception that the quality of the public healthcare system is poor leads them to seek suboptimal care or deters them from using services. Second, there are significant costs of care unrelated to service use or purchase of medicines, such as travel costs, which the Paniyas lack the ability to pay. Third, illness can lead to loss of productive opportunities among those who fall ill and those who provide informal care. Fourth, the Paniyas lack a 'range' of coping strategies as they are wage labourers without diverse sources of income. They rely on a single strategy: borrowing from outside their community, often from landowners and employers, to whom they become indebted with their labour.

Conclusions Improving the capacity of tribal populations to present their own perspectives is likely to lead to more effective tribal development policies and consequently better health.

Although there is a paucity of studies exploring the health of Indigenous populations in low-income regions, especially South Asia and sub-Saharan Africa, there is evidence that they tend to have the poorest health outcomes worldwide.[1–3] Their marginalisation is an underlying cause of poor health limiting their opportunities to present their own perspectives of their situation and shape priorities in research and policy.[1 4]

In India, indigenous populations known as Scheduled Tribes (ST) were historically severely discriminated against. Consequently, as originally outlined in the Indian Constitution, the Government of India has attempted to improve their lives, through a policy of positive discrimination and affirmative action.[5] State governments have adopted further actions to protect tribes and tribal areas.[5] More importantly, institutions of participatory democracy in local self-governing institutions (*Panchayats*), such as village assemblies (*Gram Sabha*) have come into being in India, ostensibly to hear the voices of the disadvantaged. The constitution of special assemblies of tribes (*Oorukootam*) and recruitment of tribal promoters in some states are intended to facilitate the tribal people to access the numerous development schemes. Despite these actions, tribes in India remain the most deprived groups on a number of fronts including health.[6 7]

One particularly deprived tribe is the Paniyas of Kerala state in Southern India.[8] The Paniyas were previously enslaved by upper caste Hindus, working as bonded labourers on their owners' land. Today, they are predominantly landless, agricultural wage labourers living in colonies (clusters of houses in a small geographical area), situated in peripheral areas, with poor transport linkages and being vulnerable to exposure to floods during monsoons. The Paniya tribe face an accumulation of ill health risks[9] and have high health needs (prevalences of underweight, anaemia and goitre among Paniya are 60%, 15% and 11% respectively).[10] Healthcare utilisation rates among the Paniyas are low,[11] despite Kerala's high density of public healthcare facilities.

The aim of this study was to explain the low utilisation rates of healthcare services by Paniyas and to assess their opportunities to cope with illness, specifically, their health-seeking behaviours, barriers to using care, and the social and economic consequences of illness. The study is based on participatory research approaches, which have been advocated as an avenue for improving population health and reducing social disparities in health, while engaging populations in the process.[12] Participatory approaches are also increasingly used in development practice and research to enable local populations to analyse their own conditions and participate in subsequent planning and action.[13] A particular approach entitled 'participatory poverty assessments (PPAs)', explores the processes and often 'hidden' explanations of poverty as defined by the poor themselves, while focusing on results that can be used for collective action.[14 15] PPAs include a range of participatory (eg, mapping, ranking exercises) and qualitative (eg, focus group discussions) methods to enable poor and marginalised groups to define, describe, analyse and express their own perceptions. This approach is especially

relevant for indigenous populations as their cultural worldviews can be integrated into the process when standardised approaches tend to have poor face validity with perceptions. In this study, participatory traditions of public health are built on with the PPA approach to explore health and the interconnections between health and poverty - hereafter known as a 'participatory poverty and health assessment' (PPHA) - in the Indian context.

METHODS

Setting

This study was undertaken as part of a larger action research project in Kerala's Wayanad district in Kottathara, a single Gram Panchayat (the lowest territorial administrative unit) with a population of about 17 000, 30% of whom are tribes. The Paniya tribe constitutes 12% of the population, who are more likely to be poor and have lower social opportunities (table 1).

Kerala is in an advanced stage of health transition with a relatively equitable provision of public resources.[16] Its large public health sector has undergone decentralisation, which brought about a three-tiered structure of local governance to rural areas, namely, district, block/taluk and village.[17] In Kottathara, as elsewhere in Kerala, management of public healthcare facilities are by the local government. There is one primary healthcare centre (PHC) headed by a medical officer providing primary care, four subcentres each staffed by a Junior Public Health Nurse, and an ayurvedic and homeopathic dispensary. The PHC offers preventative as well as curative services to the tribes all through the year. Public hospitals are located in the district headquarters at Kalpetta, 20 km away, and in Mananthavady, 30 km away. There are a large number of private hospitals located in Kalpetta and Mananthavady and, as elsewhere in the state, the population prefers to seek care in these institutions. As private spending is largely out-of-pocket, on a fee-for-service basis, there is a danger of impoverishment. One estimate puts that in Kerala, 17% of households fell into poverty due to hospitalisation of a family member.[16] Two charitable hospitals located within a radius of 10 km provide services exclusively for the tribes. Special government schemes are also available for the tribes. The Tribal Department administers the schemes through the Integrated Tribal Development Project (ITDP). Also, the Gram Panchayat engages Scheduled Tribe promoters to smooth the reach of the schemes to the tribes.

Study design

The design and themes explored by the PPHA were informed by special surveys implemented in 2003 in the Panchayat, including a household census and a survey of tribal colonies. Analysis of the PPHA is ongoing. In this study, analysis is restricted to data related to the study objectives, which come from three participatory mappings of health institutions (where Paniyas rate their preferences for different types of healthcare institutions and the rationale for their choices); 11 focus groups (exploring themes on health-seeking behaviours, utilisation of health services and its consequences); and six semi-structured interviews (seeking individual and household experiences with falling ill and the ensuing social and economic consequences).

Table 1 Selected household characteristics of the Paniya tribe and the general population (non-Paniya), Kottathara Panchayat, India, 2003

Household characteristic	Paniya (393 households)	Non-Paniya (2959 households)
% Below poverty line	84	38
% Not owning land	13	2
% Head engaged in wage labour*	91	42
% Head with no education	71	15
% No adult member participates in a community organisation	80	50
Average household size	5.2	4.8

*Only employed heads below the age of 60 years are considered.
Source: Centre for Development Studies.[8]

Ethical components

Due to the vulnerability of the Paniyas and the large differences in worldviews and socioeconomic circumstances between researchers and the participants, special ethical procedures were followed. A code of research ethics established a set of guiding principles and practices for the research partners in order to conduct the study in a respectful and ethical manner. Also due to the collective nature of Paniya society, community consent (in addition to individual consent) was obtained. These components were based on guidelines and experiences developed in the Canadian context with indigenous populations.[18 19]

Sampling

Selection of colonies for the PPHA was purposive based on their diversity in terms of size, distance to basic services, and living environment. Only five of the 45 colonies were selected as the aim was to conduct quality in-depth analyses (table 2).[20] Each household in the colony was invited to participate in the PPHA. All adult household members (older than 15 years) could participate in activities, although children in the colonies were often present. Visiting Paniyas from other colonies were also invited to participate. The various PPHA activities were undertaken over a period of several months to accommodate the working schedules of the Paniyas. Participants for individual interviews were selected based on their life situations, which became known to the team over the course of their interactions with the colonies. Participants in group interviews were typically convenience samples of colony members who were available to participate on any given day. There were a total of 92 participants in the PPHA activities (table 3).

Data collection and analysis

PPHA data were collected between January and June 2008 by a local non-governmental organisation with expertise in participatory methods, supplemented by additional training by the research team. The research team took detailed handwritten field notes of the process and activities. Data were regularly cross-checked with the participants. The transcripts were translated from the local language into English and reviewed by one author (KM); all names of participants have been changed to protect their anonymity. Data from the PPHA involved thematic analysis. All stages were performed by the first author and subsequently reviewed by the other two authors.

RESULTS

Seeking care/barriers to access

The overwhelming preference of Paniyas was for allopathic care. Allopathic medicine was deemed effective and efficient; a quick recovery from illness enabled an early return to work. The Paniyas used predominantly free public healthcare services. With the exception of one local hospital specialising in tribal healthcare, they described several barriers to access, including lack of health personnel, long waiting periods and inadequate supply of medicines (see box 1). These factors often led to delaying care, in some cases until the illness had become severe (see box 1).

Table 2 Key socioeconomic characteristics, basic amenities, and distance to basic services of participating colonies in Kottathara Panchayat, India, 2008

Colony name*	No. households	Land area	Drinking water	No. households with latrine	No. households electrified	Distance to basic services			
						PHC	Hospital	Primary school	High school
Alathottam	5	35 cents†	Colony well: short supply, poor quality	5	1	>5 km	>5 km	<1 km	<1 km
Olamala	26	1 acre	No safe supply	10‡	3	1–5 km	>5 km	1–5 km	1–5 km
Cheruvayal	6	20 cents	Colony well: poor quality, not used	3	2	1–5 km	>5 km	1–5 km	1–5 km
Vayal	17	45 cents	Two colony wells: steady supply, good quality	7§	2	1–5 km	>5 km	1–5 km	1–5 km
Puthiyamala	16	>1 acre	Two colony wells: steady supply, good quality	15	6	<1 km	1–5 km	<1 km	1–5 km

PHC, primary healthcare centre.
*Colony names have been changed to protect anonymity.
†100 cents equals 1 acre.
‡Sanitation facilities are not used by these households.
§Sanitation facilities are not used by two of these households.

Although the private sector was considered to be of higher quality, the Paniyas are unable to seek their service due to inability to pay.

Alternative systems of medicine were also sought: homeopathic medicine is seen as the best option for children due to the 'sweetness' of the medicine, ayurvedic medicine is viewed as appropriate for older people, whereas traditional medicine, which was previously practiced, is deemed no longer relevant. There was also a strong belief that health improvements require a combination of medicine and prayers - although in cases where there are economic barriers to care; only prayer is undertaken.

Direct costs of care

Typically, the participants did not incur costs of healthcare services or medicine as they predominantly used the public system. There were, however, other financial costs (box 2), such as transportation costs. With the exception of the public health subcentre, households would have to pay for buses and jeeps. Participants reported that travel costs were beyond the ability of most to pay, especially in those cases where patients required specialised care in more distant institutions. Some participants had their travel reimbursed by the Tribal Department. Even in cases where the costs were reimbursed, the Paniyas reported that they were burdened by the incidentals or expenses incurred by the accompanying person, as well as food costs for the patient and persons accompanying the patient, while seeking care and undergoing treatment. Also, special food prescribed for certain health problems (eg, diabetes) led to additional costs, which are generally out of reach for Paniyas who live off a rice-based diet (purchased at the local ration shop). The Paniyas reported that they do not take the prescribed medicine during 'lean periods' (when there is little food available) as it is often prescribed to be taken with food and they do not want to take it on an 'empty stomach'.

Indirect costs of care

Indirect costs of care were also incurred. Loss of time to engage in productive activities by the patient is a key concern, especially as wage employment opportunities are uncertain and there is a need to grab these when they are available. There were also time costs of informal caretakers (box 3). Moreover, family members who need to provide constant care for patients who are chronically ill or disabled may have to give up opportunities to pursue income-generation opportunities or to marry (box 3).

Coping strategies

In order to better understand how Paniyas cope, participants were asked how they managed to meet the costs associated with an illness in the household. The almost universal response provided was to borrow (box 2), more specifically, from individuals outside the Paniya community. Often they would have no other option but to take a loan from a nearby landowner or an employer. This loan would then need to be repaid either in cash or more often in labour (box 2). Borrowing from shopkeepers, either cash loans or food items, was also mentioned. Sometimes repayment would be accomplished by borrowing from another person. In some cases, Paniyas would combine borrowing from outside the community with other strategies, such as receiving benefits from the Tribal Department, support from a gainfully employed colony member, or assistance from local government (ward member). Some form of borrowing was, however, standard, although one colony made efforts to cope without borrowing from outside the community. Generally, there was a strong feeling that indebtedness was integral to their lives (box 2).

DISCUSSION

Lack of capacity to aspire and a sense of resignation are characteristics found among extremely oppressed groups, thereby lowering expectations in an individual's health and other dimensions of well-being.[21 22] As Amartya Sen has pointed out, this can translate into a 'perception bias', including the non-recognition of disadvantage, which in turn can lead to the perpetuation of those disadvantages.[22] The present authors' studies have detected this among the Paniyas who underassessed

Table 3 Key sociodemographic characteristics of participants in the PPHA activities in Kottathara Panchayat, India, 2008

PPHA activity	No. participants		Age group*			Position in household†				
	Male	Female	30	30–59	60+	Head	Spouse of head	Daughter/son of head	Daughter/son-in-law of head	Grandchild of head
Mappings (3)	10	16	18	6	1	3	1	13	0	0
Focus groups (11)	19	41	17	28	8	13	9	19	3	2
Interviews (6)	3	3	2	4	0	3	0	3	0	0

PPHA, participatory poverty and health assessment.
*Numbers do not total 92 due to missing information on certain participants.
†Numbers do not total 92 due to missing information on certain participants.

Box 1 Barriers to access to care reported by Paniya tribe members in Kerala, India, 2008 (names of participants have been changed to protect their anonymity)

Following an institutional mapping exercise, the facilitator asked the participants why in ranking the various institutions that played a role in their lives (15 institutions were identified) the participants ranked hospitals in first place in terms of importance, but ninth in terms of services. The following is an excerpt from discussions held in three of the colonies:

"The hospitals we usually depend upon are…government hospitals. But the service is very poor." (Shantha, 35-year-old female, Vayal colony)

"Why?" (Facilitator)

"The doctor is not regular." (Pokkan, male, Vayal colony)

"When we go to see the doctor, he won't be there." (Shantha)

"Medicine won't be available. We have to buy medicine from outside." (Thamara, 32-year-old female, Vayal colony)

"Even if there are personnel in the public hospital we do not get sufficient services. But in the private it is different." (Karuppan, elderly male, Vayal colony)

"If we go to … [public] hospital we are referred elsewhere…But there won't be ambulance. If there is ambulance there won't be driver." (Kumaran, elderly male, Vayal colony)

…

"Mostly we have to buy medicine from outside. It is because we have financial difficulties that we go to Government hospital. What is the use if we have to buy medicine from outside?" (Balu, 27-year-old male, Cheruvayal colony)

"The disease will worsen and then they will medicate themselves." (Balu)

…

"And where do we get sufficient treatment? My daughter has…pain. Though shown to the doctor, no use: *cheettellam puzhungi thinnan thonnum* (feel like cooking the prescription and eat it)" (Kumaran, 50-year-old male, Puthiyamala colony)

Box 2 Costs and coping with economic burden of illness reported by Paniya tribe members in Kerala, India, 2008 (names of participants have been changed to protect their anonymity)

Focus groups were held in each of the colonies. Participants were asked to discuss their perceptions and experiences with respect to healthcare, in which they revealed their difficulties in paying for travel expenses to seek care (described under 'costs of care'). They were also asked about how they coped with the costs when a household member falls ill (described under 'debt as main coping strategy').

Costs of care

"Treatment is free. But we have to find money for travel and food." (Manikkan, elderly male, Alathottam colony)

"The treatment is going on with gaps in between." (Sumathi, 35-year-old female, Alathottam colony) "Why those gaps?" (Facilitator) "That is because of financial reasons. Last time also the doctor asked us to be admitted in the hospital. But we cannot go right now. We need money to go there. Even though the treatment is free, money is needed for other expenses." (Sumathi)

"But the only problem is the distance to that hospital…We have to pay more than 500 rupees of travel expenditure. How can we afford such a big amount sir?" (Kalyan, 50-year-old man, Vayal colony)

"Also there are travel expenses. Someone accompanies me to the hospital and travel expenses of the two have to be met. The first two times I went to the hospital I went by a private jeep for 200 rupees per trip. Altogether I have gone 12 times now. Where do I have the money to meet all this?" (Kumaran, 45-year-old man, Puthiyamala colony)

Debt as main coping strategy

"Normally none has a single paisa (100 paisa make a rupee) in hand to meet with the crisis situation. What we normally do is…borrow some money from someone." (Manikkan)

"Borrowing money from somewhere is part and parcel of our life." (Sony, 28-year-old male, Alathottam colony)

"We borrow some 10—100 rupees from somewhere else." (Kelan, elderly man, Olamala colony) "From your neighbours or members of other community?" (Facilitator) "Mainly from others, Chettan muthalalimar (Christian land owners)" (Raman, 50-year-old male, Olamala colony) "We mainly work for them." (Kelan)

"…the only way is to borrow money from somewhere." (Veetha, elderly female, Alathottam colony) "From where?" (Facilitator) "Mainly from the land owners who employ us. That is a sort of advance. We have to work in their plots to get released from that indebtedness…This is all an adjustment and rolling! Borrow some money from one person this week and later borrow some money from the other person to pay the debt of the first person. This rolling is going on. We are under indebtedness all the time." (Gopalan, elderly male, Alathottam colony)

their poor health conditions.[23] Although household surveys provide generalisable data,[24] the PPHA approach enables an investigation of the perceptions of marginalised groups that are put into context.

The PPHA approach also provides richer information on poverty and health issues, the 'hidden' aspects that may not appear in standard questionnaires on health and access to care and other health determinants, such as the persistent influence of historical enslavement, signs and symptoms of resignation, or the complex interactions of factors leading to cycles of poverty and ill health. In addition, the PPHA approach is relatively rapid allowing for quick dissemination of information to decision-makers and stakeholders.

Despite relatively good access to public healthcare, the Paniyas of Wayanad have low utilisation rates. Difficulties in geographical access arise due to the remoteness of their colonies, a common problem encountered by indigenous populations.[3 25] The Paniyas also reported several dimensions of poor quality public health services as a deterrent to their utilisation. A decline in public health services in Kerala, which has been documented elsewhere, has precipitated a shift towards the use of private health services among better-off groups and even among the poor.[26–28] However, this option is not open to the Paniyas due to their high levels of deprivation as private services require out of pocket payments. In some cases, their perception of the quality of care to be poor led them to delay care, the consequences of which included untreated morbidity, increased severity of health

Box 3 Case studies on the consequences of falling ill among Paniya tribe members in Kerala, India, 2008 (names of participants have been changed to protect their anonymity)

A number of individual Paniyas suffering from illness or a disability were identified and interviewed, often in the presence of and participation with other family members who care for them. The interviews focused on their condition and the consequences of their illness or disability on their lives and their households more generally. Below are two illustrative case studies.

Sumathi

Sumathi, a 28-year-old Paniya woman from Alathottam colony, suffers from a debilitating condition. She is unable to work and can only manage to sit for a short period of time. Her condition improved slightly following a month of intensive ayurvedic treatment, but despite being advised to return for further treatment she has not been able to afford travel and other costs. Sumathi's husband abandoned her after her illness, she now lives with her parents and two school aged children.

Sumathi was very active before she fell ill - "like a chickpea" (energetic) - now feels happiness and freedom has gone from her life: "My story is like a goat tied to a hook", to which her mother adds (laughing): "Then…not only she, I am also tied…because I am in charge of her! I can't go for work now." Sumathi's mother now cares for her daughter as well as cooking for and looking after her grandchildren. As Sumathi's husband provides no support, there is now only one source of income: the occasional wage labour by Sumathi's ageing father. Money was borrowed earlier to cover the costs of Sumathi's treatment, leaving the household "indebted to many in the world." Sumathi attributes her condition to her "family itself collapsing".

Venu

Venu, a 33-year-old Paniya man from Puthiyamala colony, was diagnosed with a chronic condition several years ago. He has undergone treatment in hospital, but has not completely recovered and is unable to go for work. Venu's wife passed away after the birth of their fourth child; due to a family dispute, his children are currently living with his wife's parents. Venu now lives with his stepsister, Vella. Vella brings in the only income through wage labour or working as a domestic. When asked how they are able to cope with costs, especially as Venu's physician has advised him to reduce his rice consumption, Vella replies: "What to do. At those times I become helpless. One pack wheat powder costs 15 rupees, and I get only 20 rupees for household work. How will I make chapattis for him?". Vella also cares for Venu. When asked if Vella was married, she became silent for a while before replying: "Who will look after Venu if I get married? There is no use of his other brothers and sisters. No one looks after him except me…Even if I have to get married who takes initiative? I am alone though I have brothers and sisters. Venu is the only one I have. And he is ill. I am not sad that I couldn't marry. Who will look after Venu then? No one helps me and Venu."

problems requiring eventual intensive treatment and specialised care, exacerbating the cycle of poverty and ill health.[29]

The preference for charitable health facilities by Paniyas suggests that cultural factors are linked to their health-seeking behaviour. Cultural insensitivity and discrimination have been cited as barriers to access care among indigenous populations in other contexts, such as the Pygmies of Central Africa who had endured humiliating experiences while using public health services.[3] The provision of culturally sensitive health services among indigenous populations requires understanding indigenous views on health and illness, their health needs, and cultural beliefs and practices - and ideally services should be under the control of (or at least in consultation with) indigenous communities.[2 3 25 30]

The Paniyas reported other 'hidden' costs associated with seeking care, which have also been found in other settings where public health services are supposedly free.[31 32] A major expense was travel cost. Paniya colonies tend to be located far from major roads and services. The preferred hospital to seek care (charitable hospital) involved three bus journeys. Even the PHC is not within walking distance for most colonies. As discussed above food costs are also a challenge. These costs, although relatively modest, are sufficient to deter the Paniyas from seeking care or leave a substantial economic burden upon households.

Studies have identified a range of strategies to cope with the burden of illness.[33 34] Various coping strategies have been identified as employed by households in the Panchayat, the most common being: pawning household items, taking a self-help group (a form of microcredit) loan, and borrowing from friends or family.[9 35] Paniya households, however, reported low rates for all these strategies, this is likely to be due to their lack of assets, low participation rates in self-help groups and difficulty in borrowing from within their networks. This is at least partly because their social networks are generally exclusively their own colony members with similar livelihoods. Social networks and intrahousehold relationships generally provide important avenues for borrowing at low interest rates and the provision of labour support.[33] However, for the Paniya, a temporary or permanent loss of a breadwinner in a household due to illness has significant consequences. They are wage labourers. Their work is labour-intensive, unstable, lacking any form of job security or employment benefits, and there are no opportunities for diversifying their activities. Furthermore, the demand for wage labour has been declining due to shifting patterns in agriculture - from paddy to cash crops (eg, banana), reducing the demand for certain types of work typically performed by Paniya women. Loss of a wage labourer in the household, therefore, severely restricts any capacity to overcome productive losses.

The lack of availability of multiple coping strategies to the Paniyas was confirmed by the PPHA. Responses by participants converged on a single strategy: borrow from outside the Paniya community. Although it is generally the case that better-off groups have a wider range of borrowing opportunities, the poorest, marginalised groups are limited to taking loans based on unfavourable terms and conditions.[36 37] This is the situation of the Paniyas who described how living under the shadow of debt is integral to their lives. The Paniyas overwhelmingly borrow from nearby landowners and their employers, thereby becoming indebted in terms of their own labour. This pushes 'the trap' beyond a cycle of illness, debt and impoverishment into the reproduction of historical patterns of Paniya enslavement. It is the recognition of these cumulative effects of 'historical trauma' leading to an intergenerational trap of indigenous peoples[38] that should form the basis for intervention.

CONCLUSION

The present analysis presents evidence of a deprived tribal group's own views and experiences of health in India. Findings emphasise the cyclical nature of the realities of poverty,

indebtedness and illness, rooted in oppression. This is a trap that is comparable to feeling 'like a goat tied to a hook'. Breaking out from this trap requires a two-pronged approach. First, there is a need to overcome barriers to access and increasing culturally appropriate services. Kerala faces a challenge in reducing intra-state inequities in health and access to care, but as it is in an advanced stage of its health transition there are opportunities to focus on tribal groups. Although there are currently some services provided for tribes, there is insufficient attention paid by policymakers to ensure that the marginalised tribes are benefiting. Further research should examine the supply side of the available public programmes and services available for tribes and whether these programmes recognise the diversity of needs and cultural preferences of different tribes.

Second, there is a need to promote voice and aspiration in Paniyas. Richer and more powerful groups aspire to pursue the lives they desire, have the capacity for articulating their demands and take advantage of opportunities. This includes those benefits and special schemes designed for tribal populations - better-off tribes are able to navigate through and consequently convert the opportunities offered to them to achieve health and well-being.[39 40] Marginalised tribes are not. The challenge is: how to create 'real opportunities' among marginalised tribes?

Establishing institutions of local governance with mechanisms for participation, such as village or tribal assemblies, do not in themselves lead to the voices of the oppressed being heard. Such a strategy assumes that these groups have equal capacities to participate. Improving the capacity of tribal populations to aspire and to benefit from public interventions - including allocating resources and the control over how these resources are spent[30] - is likely to lead to more effective tribal development policies and consequently their better health. To help guide policymakers, three avenues of research are suggested. First, there is a need to better understand how marginalised tribes view health and illness in order to develop more culturally appropriate services. Second, breaking the cycle of debt, impoverishment, and poor health will need to be re-examined in the wider setting of the full historical context and intergenerational dynamics among marginalised tribes. Finally, it remains the case that the role of capacity to aspire and resignation among oppressed populations are understudied determinants of health. Further investigations of these determinants may prove to be a missing link in how to improve the health of marginalised groups. Addressing these research questions requires a broad framework integrating health system factors and the social determinants of health, while ensuring the participation of these populations in the process.

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Competing interests None.

Patient consent Obtained.

Ethics approval This study was conducted with the approval of the Comités d'évaluation scientifique et d'éthique de la recherche Équipe Hôpital Notre-Dame du CHUM, Université de Montréal, Montréal, Canada.

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What is already known on this subject

- There is a paucity of studies exploring indigenous health in low-income regions.
- The available evidence indicates that indigenous populations tend to have the poorest health outcomes worldwide.
- The marginalisation of indigenous populations is an underlying cause of their poor health as it limits opportunities to present their perspectives on their situation and shape priorities in research and policy.

What this study adds

- Findings from a participatory poverty and health assessment with a particularly deprived indigenous population (Paniya Tribe of South India) identified various barriers to access public health services (geographical, cultural, economic, and poor quality). The Paniyas lack a range of coping strategies when a household member falls ill, utilising only one strategy: borrowing from the outside community.
- The study demonstrates that the Paniyas are in a trap of poverty, indebtedness and illness, rooted in a history of enslavement. The cumulative effects of this 'historical trauma' have led to an intergenerational trap that affects their capacity to aspire and to benefit from public interventions available to them.

Policy implications

- The Government of India has attempted to improve the lives of tribal populations through a policy of positive discrimination and affirmative action and the implementation of special tribal development schemes. But marginalised tribal populations continue to face high levels of poverty and poor health, while having little voice.
- Improving the capacity of marginalised tribal populations to aspire and to benefit from public interventions is likely to lead to more effective tribal development policies.

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