"Everything is provided free, but they are still hesitant to access healthcare services": Why does the Indigenous community in Attapadi, Kerala continue to experience poor access to healthcare?

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Abstract

Background Inequity in access to healthcare services is a constant concern. While advances in healthcare have progressed in the last several decades, thereby significantly improving the prevention and treatment of disease, these benefits have not been shared equally. Excluded communities such as Indigenous communities typically face a lack of access to healthcare services that others do not. This study seeks to understand why the indigenous community in Attapadi continues to experience poor access to healthcare in spite of both financial protection and adequate coverage of health services Methods Ethnographic fieldwork was carried out among the various stakeholders living in Attapadi . A total of 52 in-depth interviews and 5 focus group discussions were conducted amongst the indigenous community, the healthcare providers and key informants. The data was coded utilising a reflexive and inductive approach leading to the development of the key categories and themes Results The health system provided a comprehensive financial protection package in addition to a host of healthcare facilities for the indigenous community to avail services. In spite of this, the community resisted the attempts of the health system to improve their access. The failure to provide culturally respectful care, the discrimination of the community at healthcare facilities, the centralisation of the delivery of services as well as the lack of power among the indigenous community to negotiate with the health system for services that were less disruptive to their lives were barriers to improving healthcare access. Power differentials between the community and the health system stakeholders also ensured that meaningful involvement of the community in the local health system did not occur. Conclusion Improving access to health care for indigenous communities would require UHC interventions to be culturally safe, locally relevant and promote active involvement of the community at all stages of the intervention. Structural power imbalances that affect access to resources and prevent meaningful involvement of indigenous communities also need to be addressed.

Introduction

Advances in healthcare have significantly improved the prevention and treatment of disease globally. However, the benefits of these developments have not been distributed equally across society. In particular, Indigenous populations often have less access to health services than their non-Indigenous contemporaries. Even in high income countries non-Indigenous populations experience better health outcomes compared to Indigenous people(1-6) with the additional barrier of poor access to healthcare compounding the situation further (7, 8). The health of Indigenous communities in India mirrors that of other First Nations' people across the globe, particularly with regard to life expectancy, maternal and child health and access to services (5, 9). Acknowledging ongoing gaps in achieving health for all, the World Health Organisation (WHO) proposed Universal Health Coverage (UHC) as a key policy for enabling equitable access to healthcare (10). Since the 2005 World Health Assembly (WHA), UHC has been adopted globally, with the inclusion of UHC among the Sustainable Development Goals (SDGs) signalling its importance as an international health priority. Despite this nearly half of the world's population still

struggles to access basic healthcare services(11), with Indigenous communities over-represented in this group.

Despite successes in health and development, the South Indian state of Kerala is not immune to the social exclusion and marginalization of Indigenous communities living in the state. Several studies in Kerala point to greater disadvantage for tribals, higher levels of morbidity, and poorer access to healthcare(12-14). On typical indicators of population health and wellbeing such as rates of infant mortality , maternal mortality and under five mortality, the tribal community in Kerala lags significantly behind other Kerala communities (15, 16).

Attapadi is a tribal block[1] located in Mannarghat taluk in the Palakkad district of Kerala, comprising 192 villages inhabited by members of the *muduga*, the *kurumba* and the *irula* Indigenous communities. In 2013, the Kerala Department of Health responded to high levels of infant mortality in Attapadi by implementing reparative measures including upgraded health facilities and the appointment of specialist doctors to improve both the quality of care and the services available. They also introduced a complete financial protection scheme addressing both direct and indirect healthcare costs, and launched a special referral system to provide free super specialist care (17, 18). In addition to these initiatives, the Scheduled Tribes Development Department (STDD) rolled out specific programmes to promote healthcare services among the community including a financial package to incentivise hospital based ante-natal care and delivery. Acknowledging the importance of social determinants, the Government of Kerala also established an active review mechanism to ensure inter-sectoral collaboration and promote convergence among the various departments.

Yet despite these measures, the Indigenous communities in Attapadi continue to experience high levels of infant mortality, and poor physical health. We therefore undertook a qualitative exploration of the socio-cultural factors affecting healthcare access in Attapadi to increase our understanding about why these health disparities are ongoing, so as to be able to identify practical solutions.

[1] The notification of an area as a special tribal block in India ensures that special attention and priority is given to the Indigenous communities living there and special developmental schemes are implemented for their well-being.

Methods

Ethnographic fieldwork was conducted between August 2018 and January 2019 and again between August 2019 and October 2019 in Kerala by the first author (MSG) who is fluent in the native language of the participants (Malayalam/Tamil) and has prior experience working with marginalised Indian communities. Prior to commencing data collection, MSG lived among the Indigenous population for six months adopting their customs and building rapport with the community. This enabled understanding of context and local traditions including protocols for outsider interactions with the community. Two visits

were made to each fieldwork site (villages). The first was to meet the village chief, explain the study, its purpose, and what was required should the community wish to participate. Data collection was carried out in the second visit once permission was granted by the village chief. This approach built trust and rapport between MSG and the participants before data collection, facilitating a frank exploration of issues. Informed consent was also gained from individual participants prior to data collection. Participants were identified through theoretical sampling, with initial interviews providing new topics that were explored in subsequent interviews[19]. Twenty-four in-depth interviews (IDIs) and five focus group discussions (FGDs) were undertaken with three different Indigenous communities living in Attapadi. A further 16 IDIs were conducted with local healthcare providers. Six Key informants including academics, and experts on UHC and tribal health in south India were also interviewed (Table1). Data collection continued until saturation of themes was reached. Participant observation was also conducted at the different health facilities located in Attapadi and detailed field notes were recorded and integrated into the analysis.

With the consent of participants interviews and FGDs were audio-recorded, transcribed, translated into English and cross-checked against the original recordings. The translated transcripts were coded using a reflexive and inductive approach to allow themes to emerge from the data. Once the initial open coding was complete, axial coding was used to express the relationships between the various themes as they arose from the data. A second author (PMU) independently coded a sub-sample of the transcripts and the two sets of analysis were compared. Any discrepancies in coding were reviewed and resolved by in-depth discussion and negotiated consensus. Coding of transcripts was carried out using the software package Atlast.ti 8.4.2. In order to improve the validity and reliability of the findings, the first author carried out member checking[20] with all the stakeholders who participated in the study. Feedback received during the member checking process was integrated into the findings that are presented in this paper. Triangulation of the findings is a well-established method in qualitative research to develop a comprehensive understanding of what is being studied and enhance the quality and credibility of qualitative analysis[21]. Data source triangulation was carried out by comparing the perspectives of different stakeholders on the key findings. An independent report on the functioning of the local health system in Attapadi commissioned by the STDD was also used to confirm and triangulate the key findings presented in this paper[22].

The Human Research Ethics Committees of the University of Canberra (20180074) and the Indian Institute of Public Health Delhi (IIPHD_IEC_03_2018) provided ethical approval. Regulatory permissions were obtained from the Kerala Department of Health (GO(Rt)No2677/2018/H&FWD), as well as the local administration in Attapadi.

Results

We found that whilst the healthcare service provided in Attapadi was technically and clinically sound, its western values and philosophy were at odds to the culture of the local Indigenous community. The themes that emerged from our data suggested that rather than improving access to healthcare, these

services increased feelings of exclusion and marginalisation for the Indigenous community. Overall there was a sense that the gap in knowledge and understanding between the tribal population and service providers was widening rather than diminishing. Moreover, larger determinants of health were not addressed adequately, thereby taking a primarily biomedical approach to health and wellbeing of the community.

Marginalisation of Indigenous healing traditions

The Indigenous community took a holistic approach to life and health which was rooted firmly in cultural tradition. While discussing healing and health, Indigenous participants would often link the environment, the food they ate and their connection to their ancestors as essential for good health.

One key aspect of the Indigenous healing traditions in Attapadi was that everyone was expected to know about the uses of different herbs; healing was not considered a specialised skill practised by a few healers or *shamans*. For example, instead of there being a traditional birth attendant, a husband took responsibility for the delivery of his child, with this knowledge passed to a man by his father when he got married. Only in the case of complications would the husband be required to find someone older to assist him.

However, several participants described how traditional healing had been superseded by the allopathy of the modern health system. Village elders showed MSG various medicinal plants and explained their use. They also described how their younger generation were not interested in learning about, these traditional medicines. This was felt to be an unfortunate and irreversible situation. The community felt that outsiders, in particular the health department staff, not only ridiculed their practices as ineffective superstition, but also strongly discouraged their use.

"What we are talking about, all this used to happen. Even now when you came, I was busy preparing a medicine for someone. But valuing our medicines and using them; all of that has changed. Who wants tribal medicines now?"

Indigenous community FGD, TK12

"Our healers they used to treat so many diseases. In those days our ancestors had to go and hunt in the forest for food, and what do you think they would do if they were bitten by a snake? They had to find ways of healing themselves. There were no hospitals like we have now. Now very few people use any of our herbs. In fact, many of us don't know about it."

Indigenous community IDI, TI 13

Health system participants were generally unaware of local cultural beliefs about healing and did not consider this to be relevant to services they provided. The general understanding was that these practices were superstitious at best and, harmful at worst. No acknowledgement was made of the importance of integrating local beliefs into the health system's practice so as to provide culturally safe and respectful

services. Moreover, most doctors working in Attapadi did not have any meaningful interactions with the community beyond the health centres. Hence, they were unaware of the important role that culture played in the Indigenous communities' management of health and wellbeing.

Lack of community engagement

Several village chiefs pointed out that no one ever asked for their opinion. They felt that given their 'illiterate' status, doctors and other health professionals did not see their views as important. Even when a medical camp visited a village, the chief was not informed about it in advance. Health professionals also failed to use this as an opportunity to actively engage the community. The exclusion of village chiefs and their councils - the traditional decision makers - was common across all programmes. Furthermore, a senior staff member from one of the health facilities noted that while there was a hospital management committee with Indigenous representation, it was more focussed on the development of the hospital than on improving community engagement.

"Even though I am the village chief (*moopan),* nobody has asked me anything so far. Even the doctors who come here on medical camp they don't ask me for my opinion. They do things as they think is best. Our opinion is not taken."

Indigenous community FGD, TK 12

This lack of community engagement lead to initiatives with no value either to the community or the health system. Such initiatives gave the impression to outsiders and higher officials that efforts to promote community engagement existed, but in reality, these were nothing more than symbolic gestures undertaken as tick-box exercises. One example was the feedback system provided at the tribal hospital. None of the participants who had received hospital services knew about its existence. Furthermore, the feedback form was in English and Malayalam two languages that most tribals do not read. One of the doctors interviewed acknowledged that the form was more for the external evaluation team that assessed the hospital, than for community benefit. A key informant who headed a well renowned tribal healthcare initiative in south India pointed out that unless there was strong community ownership interventions carried out among the Indigenous were bound to fail.

Centralisation of healthcare services

A network of healthcare institutions with trained staff and appropriate infrastructure was present in Attapadi (Figure 1). In spite of this, most healthcare services including ANC were provided only at the tribal speciality hospital. The general trend among healthcare professionals at the Primary Health Centres (PHC) and Community Health Centre (CHC) was to refer patients to the tribal speciality hospital. When asked why they did not treat them at their facilities, doctors explained that this was because the tribal hospital had super specialists and better facilities. In contrast community members described being afraid to go to big hospitals away from their homes. Many described feeling disoriented in the tribal hospital, a large building with several rooms and offices. Even more worrisome was the fear that they

would be referred outside Attapadi for treatment to a bigger hospital. Some of the participants shared stories of how they had travelled for several hours to reach the hospital, even though there were other health facilities closer to their villages.

"If someone falls sick in those villages, we are expecting them to come to the hospital which is so difficult to reach."

Healthcare Provider IDI, TP1

"Here in the PHC they won't do anything, for anything we have to go to the tribal hospital at Kottathara only."

Medical Officer FGD, TI 10

A fallout of the trend to centralise healthcare services in Attapadi was how the other facilities such as sub-centres, PHCs and the CHC were being neglected despite possessing excellent infrastructure and adequate healthcare personnel at these centres. Additionally, this also led to overcrowding at the tribal speciality hospital compromising the time available per patient for diagnosis and treatment thereby affecting the quality of care delivered.

Forced compliance

In efforts to improve community access, the local health system tried to enforce compliance with its programmes and initiatives. Pregnant women were required to make monthly visits to the tribal hospital in Kottathara to receive ANC care. This put many pregnant women, especially those who lived far away, into great difficulty. The community did comply with the requirements of the health system, but primarily from fear of the negative consequences of non-compliance. They felt that the health system was unable to appreciate the context of their daily lives, implementing interventions that were disruptive. When probed on this issue, healthcare providers stated that they acted as they did for the community's own good. Forced compliance also had a negative impact on the work of community health workers who explained that such incidents made their work difficult as they lost community trust.

"Now if they know there is any pregnant woman here then they will keep a note of it and before the time comes, they will come and take them away. Even if you go and hide in the forest they will come and take you to the hospital. Even one month before your date they will take you away even if you are not happy with it."

Indigenous community IDI, TI8

Closely linked to this enforced compliance, was the fear expressed by the community about receiving inpatient care at the hospital. Doctors found it difficult to communicate effectively with their patients and the community resisted some of the efforts of well-meaning doctors to provide certain services for them.

The lack of trust among patients was discussed by some of the doctors who felt that their experience in Attapadi clearly exposed a gap between the healthcare providers and the community.

"The sight of the labour room makes them worried; they get very scared; I have seen that"

Medical officer IDI, MO 1

"Now I won't go, I am alone, it is scary to go alone and stay in the hospital."

Indigenous community IDI, TI 8

"They will never cross a certain line and get close. The personal touch and trust that should characterise a doctor patient relationship, I find it is missing here completely."

Medical Officer IDI, MO3

Fear was also expressed by the community about being referred out of Attapadi for specialist treatment. Many of the older participants who were referred out to other super-specialist hospitals outside Attapadi spoke about how in addition to being disoriented in large hospitals, they were scared of being outside Attapadi. One of the participants noted that while the doctors at the referral hospital where she was admitted took good care of her, she wasn't willing to go outside Attapadi again for follow up care. On exploring this further with her, she explained that leaving Attapadi was something that made her very uncomfortable as that was her land and leaving it meant being cut away from her land and ancestors during that time which was a source of distress to her. This issue was further explored in subsequent interviews and found to be true among the Indigenous community. Health system participants were unable to appreciate this or account for these concerns as part of the referral process. They wondered what they were supposed to do if someone needed a particular treatment which was available in another location and made it clear that they did not refer anyone without a strong clinical rationale.

The topic of fear was also brought up by health system participants in the context of working in Attapadi. Doctors in particular pointed out that negative media coverage that followed incidents such as infant or maternal deaths, made them very cautious about treating cases especially related to maternal or child health. Doctors were of the opinion that if something went wrong, they would have to face the consequences and higher officials would not back them up. Hence, they referred complex cases to another centre even if it was located outside Attapadi so that they did not face any trouble in case something went wrong.

Stigma and discrimination

Most participants described feeling discriminated against by the health system. This was reported by community members who had received health services, and also by Indigenous staff members in the health facilities. Community participants described the condescending manner in which non-Indigenous staff engaged with them at the health facilities. Indigenous healthcare workers also noted that they were

treated differently by the non-Indigenous staff. One participant who had resigned from her job because of this, explained that it was distressing to be constantly seen as different. Some participants felt that the image of a tribal as an uncivilised savage still persisted. Even though such attitudes were not stated explicitly, the community was unanimous that they were stigmatised by the dominant community, including the health system. It was significant that not a single Indigenous participant, expressed a sense of belonging and ownership about the health system.

"I left because they used to see us tribal staff differently from the others. I did not like it, so I quit my job."

Indigenous community IDI, TM8

"Never once did I feel this is "our hospital". The reason is because they never see us as part of them. And neither have I felt that. They differentiate."

Indigenous community IDI, TK 4

Addressing the broader determinants of health

One of the key themes that emerged from the community was how the loss of their lands and restricted access to the forests impacted their ability to have a nutritious diet. The loss of lands and the resulting marginalisation of the Indigenous community in Attapadi has been long acknowledge by several governments in Kerala. As a result, many of the Indigenous community members are unable to grow their own food which was the custom in the past. Furthermore, with forest laws that in effect prevented communities from hunting small animals for food- a practise that they were used to for generations or go into the forest to collect roots and other produce freely, access to several sources of food was curtailed. Older community members spoke of the special diets provided in the past to pregnant women. Specific wild root vegetables were eaten to improve the health of the mother and their unborn child. However, access to these nutritious diets has declined over the last four decades. Despite several processes set in motion by various governments, most of the lands have not been restored to the Indigenous community, depriving them of the chance to cultivate their own food as in the past. As noted by one of the doctors, it is unrealistic to leave aside socio-cultural determinants of health and expect clinical solutions alone to address community health issues.

"Whenever people talk of health, I ask them about our land. Unless we eat nutritious food, how can we be healthy, what is the use of these big hospitals?"

Key Informant IDI, KI4

"Let's say for example you are bringing in a 20-year-old girl for delivery and I have seen girls who are second gravida at that age. Even if it is a primigravida the weight of the girl will be like 37 kgs. Now you tell me, how can I in a short time make her deliver a baby that is above 2.5 kgs. from her? For that to happen I should be sitting here and doing some magic. That is what I say you can't just do these things sitting here in the hospital."

Medical officer IDI, MO3

Financial protection alone did not improve access

Key informants described the current approaches and debates around provision of UHC in India as inadequate, having narrowed their focus to the provision of financial protection in the form of insurance packages linked to clinical services, provided through a network of public and private hospitals. This they felt would not be adequate to ensure truly universal healthcare access. Post 2014, all healthcare services including referrals to tertiary institutions outside Attapadi were free for the Indigenous community. In addition to direct costs, indirect costs such as those for transport, food, medicines, loss of wages for an accompanying carer, were all addressed by a special renumeration package. The STDD also implemented schemes to ensure that indirect costs incurred from accessing healthcare services were reimbursed. Additionally, financial incentives were offered in order to promote ANC and hospital deliveries. All participants were aware of the renumeration available, and that they did not have to pay for any care received.

"No, it is not a burden. In fact, we used to pay for the transport and all. For ANC too we are paying. For attenders we pay, we give them free food when they are here. We pay something that is the equivalent of a day's wages."

Medical officer IDI, MO1

"Everything was free of cost we did not pay anything for his treatment. They gave us food there itself and also for the attender they gave 100 rupees per day."

Indigenous community IDI, TM7

It was unanimously agreed by the participants that healthcare has to be culturally appropriate and planned in a decentralised manner, taking into account local gaps and aspirations. However, in the face of a global initiative such as UHC, it was acknowledged that there was a lot of pressure to implement an insurance-based financing mechanism as the way forward. All key informants were unanimous that the planning and delivery of healthcare services needs to move from the present fashion of a single template and emphasized the need for decentralising both the planning and the process of conceptualizing both the barriers to access and the solutions that needed to be implemented to address them. One of the key informants who was a senior public health leader in India pointed out that, one of the errors of global initiatives such as UHC was to universalise an intervention and expect diverse populations to respond to it in the same manner.

"I do think that the present approach to UHC is flawed as it is mostly a focused-on hospital-based care."

Key informant IDI, KI 1

"What we need to do is to universalise access, for this we cannot universalise an intervention as the context in Attapadi differs from the context in a big city. So how can you say that one broad approach will ensure access for all?"

Key informant IDI, KI 2

"You cannot import something from outside and expect it to work with an indigenous community"

Key informant IDI, KI 3

Discussion

Our study indicates that the health services and complete financial protection provided by the government has had limited success in addressing the healthcare needs of the Indigenous community in Attapadi. A key issue to emerge which may explain this finding, was that while the healthcare provided was technically and clinically sound, it did not acknowledge the cultural and religious values of the Indigenous community. The health beliefs of Indigenous communities are rooted in unique cultural values, obligations and ancient traditions (23-25). The provision of culturally safe care which both respects and reflects these values is an important facilitator of better healthcare access, that will ultimately lead to improved health outcomes for Indigenous communities (26, 27). Culturally safe care ensures that traditional healing practices are integrated into the local health system, allowing care that is delivered to engender respect for the customs and culture of the Indigenous community.

Discrimination against ethnic groups and Indigenous communities is a well-documented issue, shown to have serious repercussions for the health of these communities and their ability to engage with non-Indigenous led systems (23, 28-31). We found discrimination by healthcare providers against the Indigenous communities in Attapadi was prevalent, mirroring the wider societal view that these are broken communities that need to be fixed. This discrimination emerged as unconscious bias(30), reflected in the condescending attitudes and language used by healthcare professionals when speaking to or about the community, their dismissal of Indigenous health traditions and the manner in which the health system placed the responsibility for poor health outcomes on Indigenous community beliefs and actions. These entrenched attitudes are an important barrier to meaningful Indigenous engagement with the health system and its representatives.

A key observation of this study was the centralisation of healthcare delivery. This was reported as a significant barrier by the community who not only expressed their discomfort and fear of staying in a large hospital, but also noted the long distances they had to travel to reach the hospital. The centralised approach to delivering healthcare from within a large institution meant that interaction between most of the healthcare providers and the community was carried out within the hierarchical set up of the hospital. This also increased the social distance between the community and the health system personnel who were seen as the others. Decreasing the social distance between providers and users of health services has been shown to have positive benefits(30). While designing UHC interventions, policy makers and

programme managers need to ensure that their services are not just clinically sound, and culturally safe, but also geographically accessible to the community. A decentralised approach to the provision of healthcare services with an emphasis on providing services as close to the community as possible would further help improve access.

Despite an acknowledgement of the importance of social determinants to healthcare access, an understanding of how power or the lack of it shapes access to resources including healthcare is lacking (32-34). As described by the WHO charter for health promotion, reducing equity of access to healthcare requires empowering marginalised communities to negotiate healthcare that is sensitive, safe and acceptable to them(35). The lack of this enablement meant that many of our Indigenous participants choose to resist attempts to force them to comply with the requirements of the health system or choose not to seek care when they needed it.

While UHC as a concept is diverse, most interventions to promote UHC are implemented as financial protection schemes that address costs related to accessing healthcare (36). Indeed, most debates around UHC limit themselves to service provision and financial protection. This study provides evidence that in the context of Indigenous communities, this approach to UHC is ineffective. Hence it is essential for UHC interventions to acknowledge the vital role that local socio-cultural context plays in healthcare access. If interventions to promote UHC are to reach marginalised groups such as Indigenous communities, they must be culturally safe, locally relevant and planned with active involvement of the community.

Abbreviations

SDGs: Sustainable Development Goals

STDD: Scheduled Tribes Development Department

UHC: Universal Health Coverage

Declarations

Competing Interests

The authors declare that they have no competing interests

Consent for publication

Not applicable

Availability if data and materials

The datasets generated and/or analysed during the current study are not publicly available due to the danger of compromising the confidentiality and anonymity of the participants but are available from the

corresponding author on reasonable request.

Ethics approval and consent to participate

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Authors contributions

MSG carried out the data collection and drafted the manuscript with contributions from RD, IM, and PU. MSG and PU were involved in the analysis of the qualitative data. All authors were involved in the design of the larger study from which the data for this manuscript emerged. All authors read and approved the final manuscript.

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Table 1

	Irula	Muduga	Kurumba	Total
Indigenous Community	IDI: 9, FGD:1	IDI: 7, FGD: 1	IDI: 8, FGD: 4	IDIs: 24, FGD: 6
Healthcare Providers	Doctors	CHWs*	Others	
	8	6	3	IDIs: 16
Key Informants	Academia	Indigenous health experts		
	2	4		IDIs: 6

Table 1: Sampling framework

*CHWs involved both Indigenous and non-Indigenous frontline healthcare workers working in the government health system in Attapadi
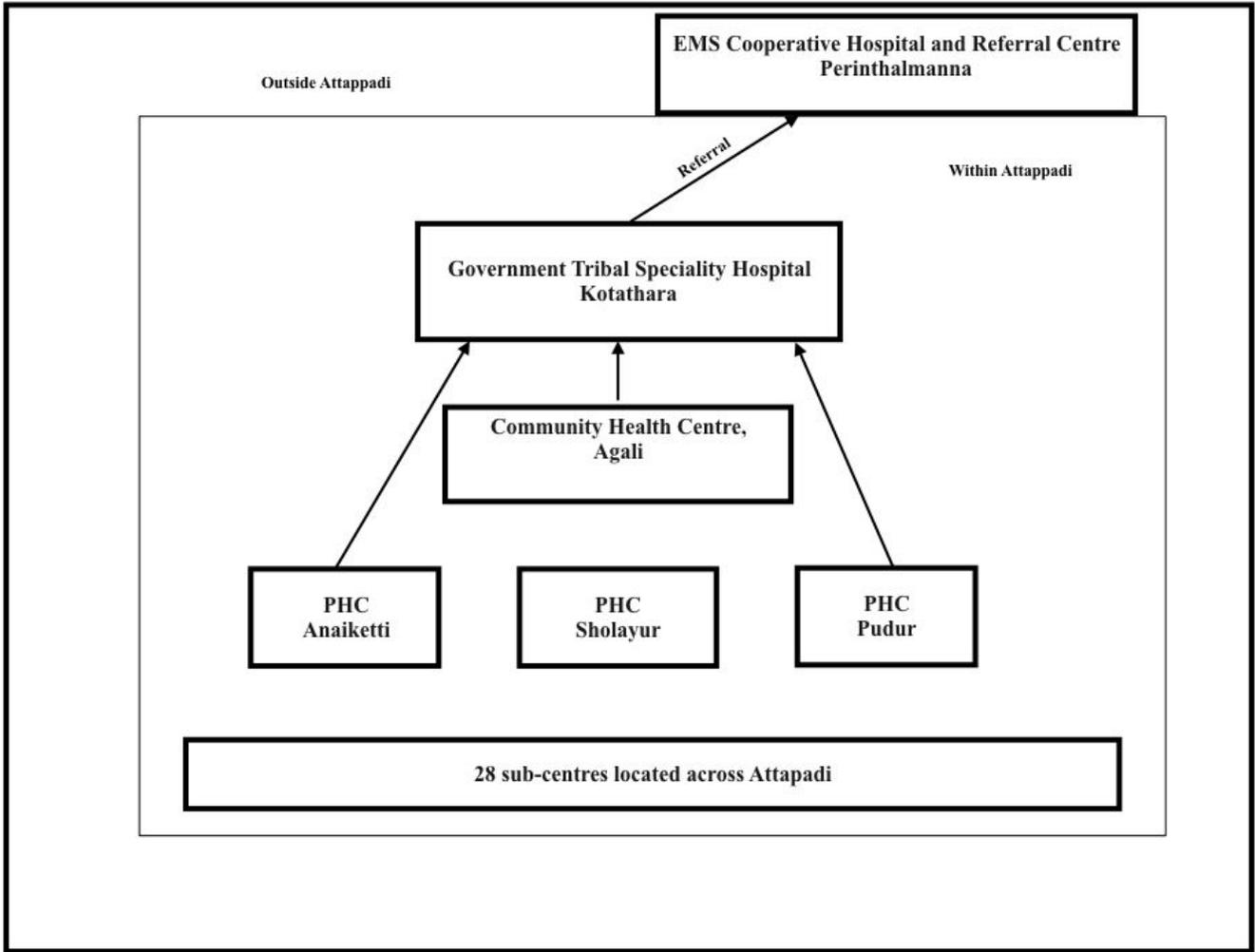
Figures

Figure 1

Health Facility Network