

Exploration of barriers to access to health care among the tribal population of Tamil Nadu, India

Research grant proposal

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Abbreviations

AUA	American University of Armenia
CHC	Community Health Center
FGD	Focus Group Discussion
GDP	Gross Domestic Product
IHS	Indian Health Service
IDI	In-depth Interview
ILO	International Labor Organization
INR	Indian Rupees
IRB	Institutional Review Board
PALAVAI	Pedagogy and action for livelihood availing entitlements village leadership and advocacy.
PARAN	Pedagogy and action for rights of Adivasis in north Tamil Nadu
PHC	Primary Health Center
SC	Sub-center
USD	United States Dollar

Abstract

Access to health care is an important prerequisite for achieving positive health outcomes in the population and one of the main targets of health care policy and interventions. Several authors conceptualized access to care as “interface between the ability of the population to perceive, to seek, to reach, to pay and to engage” into care and the five dimensions of accessibility of services: “approachability, acceptability, availability/accommodation, affordability and appropriateness.” According to WHO’s 2017 Global Monitoring Report, about half of the world’s population cannot attain essential health services, while approximately 100 million people are pushed into extreme poverty by health expenses.

The inadequate access to and utilization of health care among indigenous populations is a persistent problem globally. The inequities in access are explained by several factors including personal and interpersonal circumstances, community and organizational influences, and policies at the tribal, state, and national level. The structural barriers like geographical isolation and poverty are often compounded by discrimination, racism and a lack of respect and acceptance of the culture of the indigenous population. While it is assumed that indigenous people around the world face similar challenges that cause health disparities and impede access to health care services, the data on the access to care among indigenous populations living in Asia, Latin America and Africa, constituting over 80% of the world’s indigenous people are limited.

In India, one of the states with the largest number of tribal populations is Tamil Nadu with the total population of 7.94 million and the tribal population of 0.721 million. Tribal populations in India are quite diverse in terms of socio-cultural and environmental characteristics. Each community has a unique perception of health care and might encounter unique challenges while accessing care. The existing programs and policies in health care are often constructed from the perceptions of the government and healthcare providers which do not fully embrace the perspectives of tribal populations and specific contexts in which they access care. The proposed study aims to understand the perceptions and experiences of access to health care among tribal communities in the state of Tamil Nadu, India.

A qualitative research methodology guided by the phenomenology approach will be used for the study. The study population will include members of Irula and Urali tribes in Tamil Nadu, India and health care professionals serving those communities. Focus group discussions (FGDs) will be conducted among male and female adults in the age groups of 18-35 and 36-65, while in-depth interviews (IDIs) will be conducted with health care providers who work in nearby Primary Health Centers (PHC). The student researcher along with trained interviewers from the communities will conduct the FGDs and the IDIs. The study guides were developed based on the theoretical framework and include open-ended questions on the domains of ability to perceive illness, ability to seek care and engage with health services, and its affordability. Both deductive and inductive approaches will be followed for the data analysis. Data collection will be carried on until meaning saturation is achieved. After codes and themes are finalized, the report will be written.

A preliminary approval of the study protocol was received from the Institutional Review Board of the American University of Armenia. Prior to the data collection, the participants will be asked to give their oral consent. The duration of the study will be six months. During the first month, data collectors will be identified and trained. Data collection, management, transcription

and analysis of the interviews will happen simultaneously, in the next three months. The report writing will take place during the last two months. The estimated budget of the study is 12,81,500.00 Indian rupees (15,497.50.00 USD approx.)

1. Background

1.1. Access to care: definition and global magnitude of access-related issues

“Health is a fundamental right of every human being without distinction of race, religion, political belief, and economic or social condition”. It implies that everyone should have access to the health care they need, whenever and wherever they need it.¹

The concept of ‘access’ is a key aspect of health care policy and interventions. Access is traditionally understood as an attribute of health care services and is determined by factors like availability, price, quality of services.² The availability of services is usually measured using indicators like per capita number of medical professionals or hospital beds.³ Access is also often measured by geographical factors like location and distance.⁴

While some researchers perceive access more to be an attribute of health service, some others recognize access as the interface between service providers and users of the service or as a by-product of supply factors and demand factors.⁵ Access is defined as the opportunity to reach and receive suitable health care services when a need for care is perceived by a population; it is the product of the convergence of the traits of individuals, families, social and physical environments, as well as the traits/characteristics of healthcare organizations, systems, and providers⁶. Thus, access is seen as having the ability to recognize one's healthcare needs, seek out healthcare services, access healthcare resources, utilize healthcare services, and actually receive services that are in line with one's healthcare demands/needs.⁶

Accordingly, access can be conceptualized as the interface between the abilities of a population, “to perceive, to seek, to reach, to pay and to engage” into care and five dimensions of accessibility of services, namely, “approachability, acceptability, availability/accommodation,

affordability and appropriateness.”⁶ Under the conceptual framework proposed by Levesque et al, these five competencies of users and five dimensions of accessibility of services are interwoven in the process of utilization of health care services. In this process, these abilities and dimensions can prove as facilitators or barriers to access to health care. This framework can guide the identification of gaps or barriers from the perspective of service users and thus frame policies to strengthen the user’s abilities to augment access.⁶

According to WHO’s 2017 Global Monitoring Report, about 50 % of the world’s population cannot attain basic health services, while approximately 100 million people are being pushed into extreme poverty by health expenses.⁷ More than 8 million excess deaths due to issues with access or quality of healthcare were reported in 2016, most of which occurred in low and middle-income nations.⁸ While the gaps in the availability of services are particularly large in Sub-Saharan Africa and Southern Asia, even most developed nations are struggling to provide all their citizens with the healthcare services they need.⁷ For example, in the US, about 30 million Americans from all age groups were uninsured in 2021.⁹ Also, in 2021, 6.3% of US adults failed to get the necessary medical care due to cost and only 88.1% of the US population had normal source of care.⁹ In 2017, lack of access to transportation resulted in delayed medical care among about 5.8 million Americans (1.8%). According to American Hospital Association 3.6 million Americans cannot receive care because of transportation issue, even when a patient has an appointment and access to health care provider.¹⁰

1.2. Access to health care among the world’s indigenous peoples

According to the United Nations’ estimates, there are approximately 370 million indigenous people in the world living in at least 70 countries.¹¹ The health status of indigenous populations globally

tends to be much poorer than the non-indigenous populations.¹¹ For example, according to the Indian Health Service (IHS) of the US, Native Americans and Alaska Natives have a life expectancy of 72.6 years compared to 77.8 years in the rest of the US population.¹¹ Among the indigenous peoples of Canada, life expectancy rates projected in 2017 were 75.5 for First Nations, 68.5 for Inuit and 77.0 for Métis as compared to 81.0 in the rest of the Canadian population. Infant mortality among indigenous people was 10.7 as compared to 5.7 for 1000 live births for the rest of the Canadian population in 2017.¹²

The indigenous populations frequently have limited access to modern health services. For example, in 2018, nearly 28% of the American Indians and Alaska Natives under the age 65 in the US were uninsured, and they continue to have the highest uninsured rate compared to other populations in the US.¹³ Even when the services are available and affordable for indigenous people, they are often of lower quality compared to the care received by the non-indigenous population. Moreover, the healthcare service can be deemed to be culturally unacceptable/inappropriate by the indigenous population.¹¹ These communities' disparities in access to and use of health care are explained by a variety of factors, such as personal and interpersonal situations, organizational and community influences, and policies at the tribal, state, and national level.¹⁴ The structural barriers like geographical isolation and poverty are often exacerbated by discrimination, racism and a lack of respect and acceptance of the culture of the indigenous population.¹¹

Indigenous people around the world face similar challenges that cause health disparities and impede access to health care services. Over 80% of indigenous peoples in the globe are thought to reside in Asia, Latin America, and Africa, yet information on their health status and access to healthcare is frequently lacking, particularly from African countries, due to challenges in collecting and analyzing data for different subpopulations. The available data show persistent

gaps present in available health infrastructure and the ability of indigenous people to utilize it.¹¹ A key indicator in assessing access to health care in less-developed communities is utilization of health care facility prior, during and after delivery.¹¹ In Congo, while 94% of the total population of Congolese women have access to antenatal care, only 37 per cent of the indigenous women have access to it because of a lack of access to health facilities.¹¹ In the Khagrachhari district of Bangladesh, 30% antenatal, and 6.6% post-natal care visits were recorded among their indigenous communities, which is lower than national averages of 47.6 and 16.1% respectively, among the total population of Bangladesh.¹¹ In Myanmar, mortality rate among the indigenous population is three times higher than in non-indigenous population; more than 30% of these deaths occur due to postpartum hemorrhage, which could be averted with basic health care service.¹¹

1.3. Access to health care among indigenous people in Tamil Nadu, India

The indigenous people in India are termed ‘Scheduled Tribes’ by the Indian Government. India had 104.3 million tribal people in 2011, which was 8.6% of the country's overall population. There are 705 scheduled tribes and sub-tribes and 75 primitive tribal clusters in India.¹⁵ Approximately, 90% of the tribal communities live in rural areas. Nearly 80% of the tribal population is concentrated in the eight states of central India and 11% in the North-Eastern states. Geographically, 11% of the tribal population is spread in the North-Himalayan region; the Central region has a high concentration of 57%; while Western India has 25% of the tribal population and the rest of the 7% live in Southern India.¹⁶

The rural health care system in India includes “sub-centers” (SC) which serve as peripheral contact points between the community and the primary health care system, providing essential

health care and carrying out health communication-related tasks. Six SCs are administrated by one Primary Health Care Center (PHC). The role of the PHC is to give curative and prophylactic health care to the rural population. Community Health Centers (CHC) serve as referral centers for four PHCs and are staffed with medical specialists who are supported by 21 paramedical and other staff.¹⁷

According to Rural Health Statistics 2019-20, there had been 9,378 new SCs, 1,682 new PHCs and 1,837 new CHCs opened in India between 2005 and 2020.¹⁷ Several studies point out that the expansion and modernization of the health care system in India in the last decades made a significant contribution to improvements in life expectancy and decreased morbidity among the population.¹⁸ The World Bank reports that between 2000 and 2020, infant mortality in India decreased from 67 to 27 per 1,000 live births; between 2000 and 2017 life expectancy at birth rose from 63 to 70 years, and the maternal death rate decreased from 103 to 35 per 100,000 live births.¹⁹

Even though the tribal populations also benefited from the improvements to some extent, the Ministry of Tribal Affairs, India, acknowledges that there is still a huge shortfall in the infrastructure, health personnel, the availability of medicines and medical equipment²⁰ for this population. As of 2018, there had been a shortfall of 3,684 SCs, 774 PHCs and 93 CHCs.²⁰ Even after the government-initiated changes in the delivery of health care services, a qualitative survey among the Bodo and Rabha tribes in the state of Assam, India, confirmed that the low quality of healthcare given in governmental facilities in rural areas is still a major concern.²¹

The disparity in health burden between the tribal and non-tribal populations remains considerably high, particularly for communicable diseases. Despite making just 8.6% of the total population, the tribal community accounts for 50% of all malaria-related deaths and 30% of all

malaria-related deaths. A report on tribal health in India estimated that in 2015, only 256 out of 10,000 were diagnosed with tuberculosis in the non-tribal population, compared to 703 out of 10,000 cases in the tribal population.²²

One of the states with the large number of tribal populations is Tamil Nadu in Southern India with the total population of 7.94 million and the tribal population of 0.721 million. Thirty-six tribes are broadly spread in all 38 districts of Tamil Nadu.²² Around 80% of them live in rural areas in 13 districts, namely: Krishnagari, Dharmapuri, Vellore, Tiruvannamalai, Salem, Villupuram, erode, Namakkal, Coimbatore, The Nilgiris, Dindigul, Trichy and Kanyakumari. The remaining 20% of the tribal population lives in urban areas. The overall literacy rate in the tribal population is 54.3% and it varies by gender, reaching 61.8% in males and 46.8% in females.¹⁵

National Health Mission Tamil Nadu has initiated various programs like Birth Waiting Rooms in 17 Tribal PHCs in Tamil Nadu, where pregnant mothers are admitted to the healthcare facility two weeks prior to the expected delivery date, in order to combat maternal mortality, since they find it difficult to reach the health center on time before the delivery²³. There are 396 Mobile Medical Units with a team of health professionals in operation to augment tribal outreach health care services, and 10 Tribal Counselors are placed in Government hospitals in tribal districts to create awareness and build rapport with the tribal communities.²³ However, the services remain poorly utilized.²³ Lack of health care providers, poor existing databases about disease burden and inappropriate utilization of care by tribal population, remoteness of their villages from health facilities, and inadequate monitoring of health outcomes are all factors that the Tamil Nadu Health Systems Project attributes to the underutilization of health care services among tribal population.²⁴

1.4. Study Rationale

Tribal populations in India are quite diverse in terms of socio-cultural and environmental characteristics. Each community has a unique perception of health care and encounters unique challenges while accessing care. The existing programs and policies are constructed from the perceptions of the government and healthcare providers and for the most part do not fully embrace the perspectives of tribal populations and specific contexts in which they access care. Exploring the barriers impeding the access to healthcare from the perspective of the tribal population using qualitative research could help generate rich and valuable data and serve as a basis for improving existing policies and programs.²¹

2. Study aim and research questions

The study aims to understand the perceptions and experience of access to care in the tribal communities belonging to Irula and Urali tribes, in the state of Tamil Nadu, India and explore the barriers that impede access to healthcare. The proposed study will attempt to answer the following questions:

- (1) What are the perceptions of the tribal people about their access to care?
- (2) What are their perceived healthcare needs and how are those served by the current healthcare services?
- (3) What is their experience with the existing healthcare services, policies and programs provided by the state government?

(4) What are the barriers that prevent them from accessing or fully utilizing health care services?

3. Methods

3.1. Study design

A qualitative research methodology guided by the phenomenology approach will be used in this study. “Phenomenology is defined as an approach to research that intends to reveal the essence of a phenomenon based on the perceptions of people who have experienced it”.²⁵ This approach can effectively bring out the perspectives of the population under study and their own understanding of the issues with access to care, which can challenge the existing assumptions and policies.²³ Focus group discussions (FGD) and in-depth interviews (IDIs) will be carried out with the representatives of tribal communities and their healthcare providers to answer the research questions.

3.2. Study setting and participants

The study will focus on the two tribal communities of Irula and Urali in Villupuram and Erode districts of Tamil Nadu, respectively. The Irula community, which has a population of 0.19 million and ranks as Tamil Nadu's second-largest tribal group, is primarily located in a rural area in the Gingee administrative block of the Villupuram district.¹⁷ The Urali community lives in the forest area in Makkampalayam village, Sathyamangalam block in Erode district. Makkampalayam has a total population of 1,800 and among them, 750 are Urali tribals. There is a PHC in Kadambur, which is 20 kilometers away from Makkampalayam, the hamlet where the

Urali tribal community resides. The Irula tribal community living in Sennalur village has a PHC located in Anantapur, which is 15 kilometers away from the village.

The adult population between the age of 18 and 65 will be included in the study. The participants will be segmented into 19 – 35, and 36 - 65 years old adults. Segmenting the participants will facilitate in-depth understanding of healthcare needs of each group and enhance free expression and exchange of opinions during the discussions.²⁷ In particular, the 19 – 35 years old participants may experience specific difficulties regarding maternal health care; people in the 36-65 age group may experience occupational health hazards.²⁷ The study will exclude those adults who have physical and mental handicaps that prevent their participation in the focus group discussions. There will be male and female sub-groups in each age group and a separate focus group discussion will be conducted with each sub-group to collect the data.

3.3. Study sampling

“Pedagogy and action for livelihood availing entitlements village leadership and advocacy” (PALAVAI) and “Pedagogy and action for rights of Adivasis in north Tamil Nadu” (PARAN) are the two non-governmental organizations operated by the Jesuits, working for the social development of the marginalized populations of Tamil Nadu, including Irula and the Urali tribal communities. A purposive sampling strategy will be first conducted with the help of PALAVAI and PARAN. Then, snowball sampling technique will be used to enroll more participants. Two FGDs will be conducted for each gender sub-group in each age group; there will be two male interviewers and two female interviewers, conducting FGD with male and female groups, respectively, besides the student investigator. The discussions will be conducted until saturation

is reached. It is expected that at least 8 focus group discussions will be conducted. The participants will be asked for their oral consent before participating in the study.

The study will also include health care professionals from the healthcare facilities in the vicinity of the tribal communities under study. Four IDIs will be completed with health care professionals, a physician and a nurse in each of the nearest Primary Health Centers in the districts of Villupuram and Erode. Health care professionals for IDI will be selected based on having at least one year of experience in providing health care services for the tribal population in the respective locations.

3.4. Study instruments

FGDs among the target population and the IDIs with healthcare professionals will be conducted using interview guides containing a series of open-ended questions. A focus group discussion guide has been developed based on the conceptual framework by Levesque et al. After assessing the demographic profile of the participants with help of a short questionnaire (Appendix 2), the interviewer will proceed with the domains of the ability to perceive illness, the ability to seek care and engage with the health care professionals and the affordability of health care. The FGD will end by discussing the participants' opinions about ways to improve access to health care. A separate question guide (Appendix 3) will be used for IDIs with health professionals including the domains of the conceptual framework. The interviewers will explore the health care providers' understanding of the issues discussed with the tribal people. The guides will be adjusted and revised as necessary throughout the study. The guides were developed in the English language. They will be translated to the Tamil language, which is the language of Tamil Nadu.

3.5. Data collection

The FGD will be conducted on-site in both of the selected districts. The discussion will take place in community halls or common spaces in the village, depending on which option is more feasible for the community members. The IDIs will be conducted with health professionals, a physician and a nurse working in the health facility closest to the tribal communities. Before the discussion, the participants will give oral consent. The student investigator will take field notes of the behaviors and response styles i.e. body language of the participants for contextual information, which will be useful during data analysis.

There will be a team of four data collectors. In order to make the study more participatory, two male and two female interviewers/data collectors will be identified from the tribal community who will be trained by the student researcher to conduct the FGDs and IDIs. The student researcher will be present in both processes of data collection. Data collectors will use notebooks to record their observations and audio recorders to record the discussions and interviews upon the permission from the participants.

3.6. Data Management and Analysis

The recorded interviews will be transcribed in the Tamil language so as not to lose the original meaning, which might happen during translation. Transcribed interviews will be translated into English by the student investigator. The student investigator will complete the analysis of the data in parallel to data collection. Transcripts will be completed after the end of each focus group discussion or in-depth interview and will be stored in separate folders filed under the name of the

site visited for data collection. The analysis will follow both deductive and inductive approach to come up with codes and themes. The data collection and analysis will be carried on until the meaning saturation is achieved. When codes and themes are finalized, the report will be written.

3.7 Trustworthiness

In order to ensure trustworthiness, several measures will be applied in the study. Triangulation of data sources and researchers, as well as peer debriefing with the researchers will be used to ensure credibility.^{28,29} Peer researchers can serve as sounding boards and may offer valuable perspectives on the data. A thick description of the cultural context of the participants and sampling approach will augment transferability.²⁸ In order to ensure dependability, the processes in the study will be recorded in detail, including information about data collection and analysis by providing adequate contextual information.³⁰

4. Project Timeline

The study will be completed in 6 months (Appendix 4). Preparation for fieldwork and training interviewers will take a month. During this initial month, the student researcher will make preliminary visits to the field to build rapport with the communities through non-governmental organizations and to identify and train the data collectors from the community. Data collection, management, transcription and analysis of the interviews will happen simultaneously, in the next three months. The report writing will take place during the last two months.

5. Logistical Considerations

With assistance of PALAVAI and PARAN, the student researcher will meet the logistical requirements for the study; in particular, the organizations will help with finding the venue for conducting the FGDs and IDIs and transportation for the data collectors and the researcher. In addition, PALAVAI and PARAN will provide a secure physical space for the researcher to do the data analysis in each location and organize the transportation to commute between the two communities. The data collectors will be given audio recorders, stationary items and transportation allowance besides the remuneration from the project funds. Computers, accessories and the software will be provided for data analysis and all the system will be password protected.

6. Study Budget

The estimated budget of the project (Appendix 5) will be 12,81,500.00 Indian rupees (15,497.50 USD approx.) taking into account the transportation cost, and the operational and personnel expenses. Besides remuneration for research personnel, the study will require equipment and accessories for recording the data to be collected. The study will also require transportation (cars, bikes, jeeps) to take those involved in the project to the location of both communities and various interview sites. Further resources will include stationery, other consumables, Wi-Fi modems etc. The request for funds for the project will be sent to Government sources including National Health Mission, Department of Health and Family Welfare and Department of Tribal Welfare, Government of Tamil Nadu; Non-governments organizations like PALAVAI will also be approached for possible funding.

7. Ethical considerations

The Institutional Review Board (IRB) of the American University of Armenia approved the study proposal. Prior to the data collection, the participants will be informed that the discussions will be audio recorded upon their consent and also that they are allowed to end their participation at any point of the study. The participants will be asked to give their oral consent (Appendix 5/Appendix 6). Similarly, through informed consent the participants will be told that the data collected will be shared for research purpose only and data will not be shared with any other persons. The following measures will be followed to ensure anonymity of the information collected: the researcher will apply pseudonyms for participants of the study and alter other identifying details; the researcher will adopt foolproof methods of storing the data by using password-protected file, with passwords that are accessible only to the research team.³¹ The data will be stored for a period of five years.

When the funding for the implementation of this grant proposal is obtained, the IRB boards of Tamil Nadu and the American University of Armenia will further examine this grant request. With updated protocols, the student researcher will submit an application for review.

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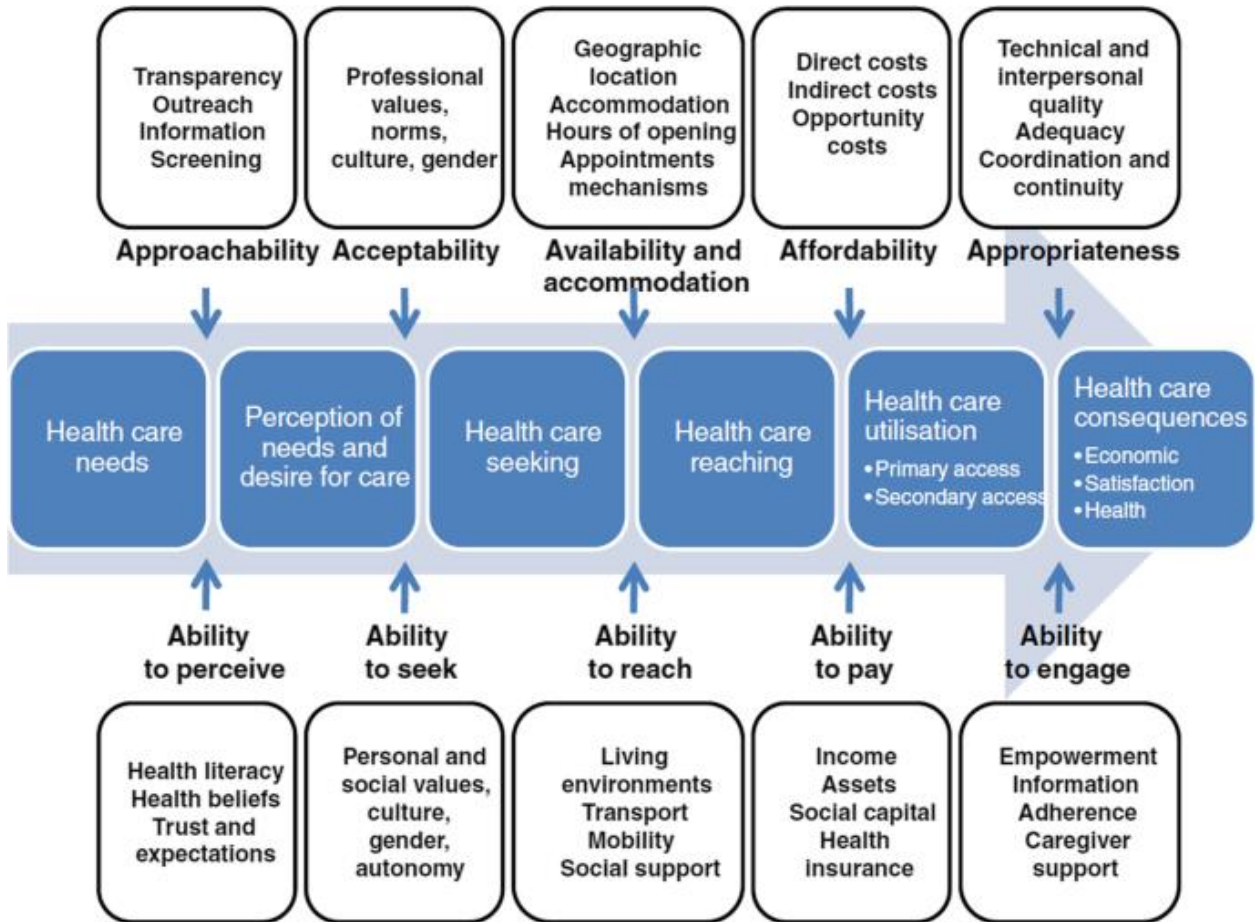
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Appendices

Appendix 1: Lévesque’s conceptual framework:



Appendix 2: Focus group discussion (FGD) guide:

{Interviewer/Facilitator of FGD introduces himself/herself and explains the purpose of the study; reads out the Consent form (Appendix 6) and obtains their oral consent; and also gets their permission to audio record the discussion}.

Date of FGD: ----- Opening Time: -----

Location: ----- Community: -----

Age Group: ----- Gender: -----

1. INTRODUCTION

Tell me more about yourselves:

- 1.1. How long have you been living in this place (name the village)? Do you like it here? Have you migrated from any other place? If so when and for what reasons? Is this place comfortable for living and to find opportunities to work and earn for your sustenance?
- 1.2. What are your occupations? Do you have to travel near/far off to work?
- 1.3. How many families are living in this location?
- 1.4. How big or small is your family? Who are the members? Children/adults? How well you think your earnings cover the needs of your family?
- 1.5. Do all the children attend school?

2. ABILITY TO PERCEIVE NEEDS AND APPROACHABILITY:

- 2.1. Generally, how healthy are your children in your families? What kind of illnesses do your children get?
- 2.2. When do you understand that the child is ill? How do you identify his/her illness? When do you perceive your child needs help? How do you manage when you

find the child is ill? Whom do you turn to for help? What kind of help do you seek?

2.3. How healthy are the adults/young adults/older persons? When do you feel/perceive that an adult is not well? What helps you to perceive any illness? Do you know any symptoms? What help do you require to know/identify your illness?

2.4. How do you manage the illness? When you or someone is ill, what is the immediate action you take? How important is it, in your opinion, to seek health care when someone is ill?

3. ABILITY TO SEEK, REACH AND PAY FOR CARE AND ACCEPTABILITY, AVAILABILITY AND AFFORDABILITY:

3.1. Where do you look for care? Whom do you turn to? How comfortable do you feel when approaching care? Are there instances where you feel reluctant to seek care and could you describe those?

{if they respond 'outside' – find out whether outside means traditional or modern; probe further, as to how long and why}

3.2. Is the (modern) health care service available in your area? Are you able to reach the health care service? How far do you need to travel? How do you travel to the facility?

3.3. In your opinion, what is the government's responsibility in terms of helping you manage your health issues? What is the providers' responsibility?

- 3.4. What kind of health and other benefits do you get from the government? How do they help you to receive the services?
- 3.5. What kind of healthcare services is available in the health center in your area? Are there services which you need, but which are not available currently and if yes, what are those? How do you address your health needs in such cases?
- 3.6. Is there anything that helps you reach the service?
Is there anything that hinders/blocks to access/reach the service?
{Explore the barriers or facilitating factors that connect them with the health care facility}
- 3.7. Do you feel welcome/accepted by the healthcare facility? What are the things that make you feel less welcome/more welcome? Please describe the attitude of the staff towards you.
- 3.8. Do you get medicines from the health center or outside, at a private medical store?
- 3.9. How much does it cost you? How much do you spend on an average, when you visit the health center once? How do you feel about the cost? How expensive is it? Are you able to afford?
{Explore if the cost of treatment is affordable or high; if the cost of treatment, travel to center are reasons that deter them to engage with the health care center}
- 3.10. Have you heard of health insurance? What is health insurance, in your opinion?
If yes: do you have insurance? How has it been used? What do you get out of it?

4. ABILITY TO ENGAGE:

- 4.1. How would you describe the process of communication with the health care professionals about your health issues? How easy or difficult the process is? How well do the providers explain your health issue and the suggested treatment? How well do they answer your questions? Can you give some examples?
- 4.2. How well do you understand what the health care professionals communicate to you? Do you have any difficulty? Do you find any barriers like language or any other?
- 4.3. What do you think about the treatment that your physician prescribes for you? Do you agree with it? Do you continue with the treatment proposed by the health care facility?
- {Explore the reasons for continuing or discontinuing treatment proposed by the facility- the attitudes of health personnel, the environment of the health facility, availability of medicines}*
- 4.4. What has been your experience with the result of your visit to the health facility?
- {Explore what kind of illnesses got ridden or cured after being treated in the health facility, if yes as well as no: What do you think the reasons could be?}*
- 4.5. How would you describe your overall experience with healthcare services in this area?
- 4.6. What would you suggest to improve the results of care at the health facility?

{Explore what steps the group has to take and what the health system has to take?}

5. AGE & GENDER-SPECIFIC HEALTH NEEDS AND ACCESS ISSUES:

5.1. What kind of illnesses do people in your age/gender group generally experience? How do you manage them?

{Explore age-specific, gender-specific health burden, management. Raise such a question at the appropriate time.}

5.2. What are the diseases/conditions that are typically harder to manage? Could you describe how do you manage them? What is the role of healthcare services in helping to manage them?

Concluding questions:

1. Do you have anything else to say about the health of your community/health issues you face?
2. Do you have any suggestions on to improve your health condition? To improve the health facility, about the health care professionals or government's health care programs?

Thank you

End time: -----

Appendix 3: In-depth interview (IDI) question guide:

{Interviewer of IDI introduces himself/herself and explains the purpose of the study; and gives a copy of the consent form to the participant and obtains his/her consent. (Appendix 7)}

Name of location: -----

Interviewee ID: _____ Designation: -----

Interview date: _____

Starting time of the interview: _____

1. Would you please tell me how long you have been working in the health center at (name the village/town)? What is your role at your workplace?
2. Do you live in the same village/town? Are there any barriers to reach to the healthcare center?

{Probe: How long does it take to reach the health center from his/her home?}
3. During your job, how often do you come across the tribal community nearby? What could you say about the demographic characteristics of the representatives of the tribal community that visit the healthcare center? What health problems make them seek professional help?
4. What do you think are the needs of health care for this tribal community in (name the place)?
5. In your opinion, what difficulties do they face while seeking care at this center?
6. What kind of factors helps them seek care with ease? What hinders them from coming here to seek health care?
7. Are you aware of any issues, problems or challenges the tribal families face in accessing and utilizing health care?

If yes: What are the problems they are faced with...?

- 7.1. Could you please identify any difficulties that the community members would face in communicating with you?
- 7.2. What do you think about the cost of the treatment/services to the community?
- 7.3. Would you be having an idea about how far the health seeker has to travel in order to reach the health center?
- 7.4. Do you think the community members feel at ease at the health center?
8. What difficulties do the families talk about in terms of health care when they visit you?
9. Do you visit the communities in their living environment? What are your observations relevant to their health care issue?
10. What do you think about their health needs? In your opinion, what is the common perception of health needs in the tribal community? Do they have the ability to recognize their health needs?

If yes: What are the factors that help them identify their health needs/issues?

If no: What do you think the reasons could be?
11. Do you think that they look for health care in time?

If yes: What motivated them to look for?

If no: What do you think the reasons could be?
12. What would you say about the follow-up visits of the tribal families? How compliant are they to the follow up visits?
13. What do you think, what alternative treatment approaches the tribal communities could be following?

14. Do you think that the current services at the health center are adequate to meet the health needs of the community?

15. What facilities/services according to you are needed to provide better service to the community and to improve the health center?

Thank you for participating in the interview!

Ending time of the interview: _____

Appendix 4: Timeline																								
TIME-FRAME/WEEKS	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
TASK																								
DATA COLLECTION																								
Preliminary visits to communities along with NGOs	█																							
Identifying 4 data collectors from the communities	█	█																						
Meeting stakeholders-Staff at Health Centers		█	█																					
Training Data collectors		█	█																					
Recruiting participants			█	█																				
First Interview, FGD/Reviewing Question guides			█	█																				
Data collection - FGDs and IDI in District 1					█	█	█	█	█															
Transcription, translation-District 1							█	█	█															
Data collection - FGD and IDI in District 2										█	█	█	█	█	█									
Transcription, translation-District 2												█	█	█	█									
ANALYSIS & REPORT																								
Identifying Codes & themes /Data Analysis											█	█	█	█	█	█								
Verification / Cross checking															█	█								
Finalizing the Analysis and Report writing															█	█	█	█	█	█				
Presenting Findings with communities																				█	█			
Final Report																					█	█	█	█

Appendix 5: Study Budget						
N o.	Budget Item	Unit	Number of Units	Cost/Unit	Total (INR)	Approx. in USD
	Personnel					
1	Student Investigator/Project Coordinator	Month	6	60,000.00	3,60,000	
2	Data Collectors (4)	Month	4 persons X 5 months	15,000.00	3,00,000.00	
3	Support staff (Local guide to study sites/to coordinate FGDs, IDIs)	Month	1person X 1 month	30,000.00	30,000,00	
	Accommodation					
4	Project coordinator (Student Investigator)	Month	6	15,000.00	90,000.00	
5	Transportation					
	i) Long travel between Chennai and study sites (to and fro)			30,000.00	30,000.00	
	ii)Preliminary Visits, Data collection visits, Validation - to study sites	Trip	20	3,000.00	60,000.00	
	iii) Travel allowance for 4 data collectors and a support staff	Person	5	6,000.00	30,000.00	
6	Office space rent	Month	6	10,000.00	60,000.00	
7	Devices and accessories					
	i) Laptop – 3	Laptop	3	40,000.00	1,20,000.00	
	ii) Audio recorders (4)	Recorder	4	7,500.00	30,000.00	
8	Stationary supplies				25,000.00	
9	Communication (6 SIM cards for internet service for 6 persons)	1 card per month	36	500	18,000.00	
10	Refreshments during FGD & IDIs	Session	12	1000	12,000.00	
11	Total				11,65,000.00	
12	Contingency			10%	1,16,500.00	
13	Grand total				12,81,500.00	15,497.50

Appendix 6: Consent Form - Focus Group Discussion (FGD)

American University of Armenia

Gerald and Patricia Turpanjian College of Health Sciences

Institutional Review Board #1

Oral consent form

Title of the Research Project: Exploration of barriers to access to health care among the tribal population of Tamil Nadu, India: a qualitative study.

Hello, my name is Vineeth Paul and I am a graduate student of the Master of Public Health program at the American University of Armenia (AUA). We are conducting a study to explore the barriers to access to health care among the tribal population in Tamil Nadu. Many studies have been done in the past about such barriers to access of healthcare for the tribal population. However, we plan to study from the perspective of tribal population and that is the reason you are selected to participate in the study. We will ask questions on how you look at your health issue; how and when you perceive that someone in your family is unwell; how you seek health care and whether you are able to utilize the health services.

Therefore, we would like to invite you to participate in this study. Our discussion will take about 45 to 60 minutes. We have a few questions to which you may share your experience on issues related to accessing health care. We hope that the findings we obtain through our discussions will help healthcare providers to improve and enrich access to healthcare.

Your participation in this study and discussion is purely voluntary; you may also very well stop participating at any time during the study; You can skip any question you feel uncomfortable to answer. The information provided by you and the data obtained are fully confidential; your names or personal details will not be revealed to anyone outside this study team. With your permission we will audio-record our discussion. After the study is complete, the audio recording will be destroyed. If any of you do not consent for audio recording, you may abstain from participating in the discussion.

There are no risks to participation, but we may learn valuable information that can be used to improve access to health services in Tamil Nadu. If you have any questions about this study you can contact the principal investigator of this study Dr.Tsovinar Harutyunyan at tsovinar@aua.am ,(phone no. 060 61250). If you have not been treated well or feel hurt/offended during the course of the interview, you may contact the Human Protections Administrator of the Institutional Review Board of the American University of Armenia Ms. Varduhi Hayrumyan at vhayrumyan@aua.am or (+374)060612561.

Would you agree to participate in this study?

Thank you,

If YES, shall we proceed?

Appendix 7: Consent Form - In-Depth Interview (IDI)

American University of Armenia

Gerald and Patricia Turpanjian College of Health Sciences

Institutional Review Board #1

Oral consent form

Title of the Research Project: Exploration of barriers to access to health care among the tribal population of Tamil Nadu, India: a qualitative study.

Hello, my name is Vineeth Paul and I am a graduate student of the Master of Public Health program at the American University of Armenia (AUA). We are conducting a study to explore the barriers to access to health care among the tribal population in Tamil Nadu. Many studies have been done in the past about such barriers to access for the tribal population. However, we plan to study from the perspective of tribal population, on how they look at their health issue; how they perceive when someone in their family is unwell; illness and how they engage with health care provided by health care professionals. Your information about their perception, health seeking behavior and their engagement with health care professionals and health care facility will be very valuable to the study.

We would like to include you as one of the participants from this (*name of the location*) health center. Our discussion will be through an interview lasting about 45 to 60 minutes. We have a few questions to which you may share your experience on issues related to accessing health care. There are no anticipated benefits or compensation to participation, but we may learn valuable information that can be used to improve the access to health care services in Tamil Nadu.

Your participation in this study and the interview is purely voluntary; you may also very well stop participating at any time during the study; you can also skip any question you feel uncomfortable to answer. With your permission we want to record the interview so as not to miss out any of your valuable information. This audio recording will be destroyed after the study is complete. The information provided by you and the data obtained are fully confidential; your names or personal details will not be revealed to anyone outside this study team. Your name or any other identifying information will not be made available in the final report.

There are no anticipated benefits or compensation to participation, but we may learn valuable information that can be used to improve the access to health services in Tamil Nadu. . If you have any questions about this study you can contact the principal investigator of this study Dr.Tsovinar Harutyunyan at tsovinar@aua.am, (phone no. 060 61250). If you have not been treated well or feel hurt/offended during the course of the interview, you may contact the Human Protections Administrator of the Institutional Review Board of the American University of Armenia Ms. Varduhi Hayrumyan at vhayrumyan@aua.am or (+374)060612561.

Would you agree to participate in this study?

Thank you,

If YES, shall we proceed?