Estimating Community Prevalence Rate of Sickle Cell Anemia among Tribal Population of Gujarat : A Bio Anthropological Study in Warli Tribe

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This study is an attempt to systematically present the prevalence rate of Sickle cell Anaemia in the Warli tribe. The study is a culmination of effort by all the individuals who have played their role in all earnest.

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Ratnawali

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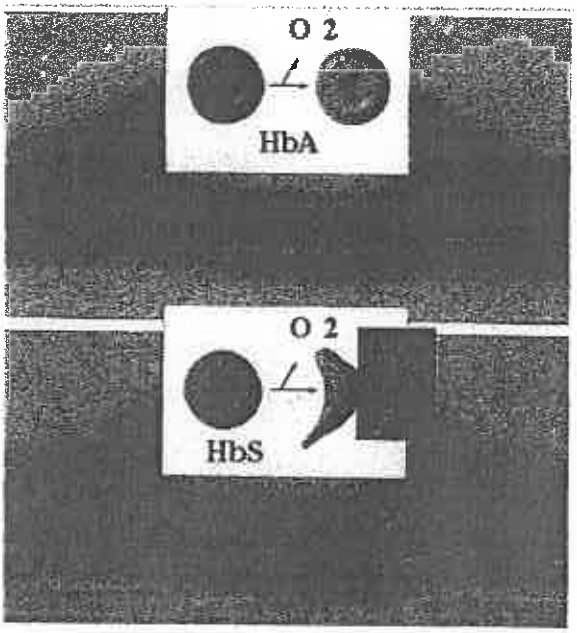
Introduction:

In the evolutionary history of mankind, haemoglobin remains an important genetic marker undergoing various structural changes owing to the selection pressure on human beings. It thus has more than 400 molecular variants caused by a single base change in one or the other of the globin genes resulting in abnormal hemoglobins with adverse consequence on the health. The hemoglobinopathies are one of the commonest, life threatening form of disorder with nearly 7 per cent of world population are carrierers. Some recent estimates suggest that 300,000-400,000 affected children are born every year with these monogenic disorders. Among them a majority of around 250,000 suffers from sickle cell anemia (Roberts and Montalemberts 2007). A substantial proportion among them lives in the tropical region, particularly in the Sub Saharan Africa, India and Middle East. Birth with these disorder imply that at least 1.08 – 2.20 million DALYs or 0.1% of total burden of disease in low and middle income countries. Mortality, out of such disease is reported to be 50-80% between 1-5 years of age.

The disorder is identified with the mutant allele HbS where Glutamic amino acid is substituted by the Valine at the sixth position in b-chain of the hemoglobin. The substitution results in the sickling of red cells under reduced oxygen supply to the blood. These sickle shape blood cells then obstruct the flow of blood through capillaries causing pain and other pathological condition. Figure below show the flow of normal and sickle cell in the blood capillaries and their impact on tissues.

Capillary Flow of Normal and Sickle Red Cells



Normal red cells maintain their shape as they pass through the capillaries and release oxygen to the peripheral tissues (upper panel). Hemoglobin polymers form in the sickle red cells with oxygen release, causing them to deform. The deformed cells block the flow of cells and interrupt the delivery of oxygen to the tissues (lower panel).
Source: http://sickle.bwh.harvard.edu/scd_background.html

Being recessive in nature the problem does not get expressed phenotypicaly in heterozygous condition but in homozygous state the individual shows symptoms of acute anaemia, recurrent infection, acute respiratory problems, intermittent jaundice and severe joint pain. Observations by obstetricians have found higher frequency of hypoxia and deaths among women with sickle cell disease.

Evolutionary significance of the disease

The disease was first detected in a person with African ancestry in 1910 by James B. Harrick when he discovered the sickle shaped cell in the blood smear of the person suffering from anaemia. In 1949, Pauling demonstrated that the sickle cell anaemia is caused by abnormal haemoglobin wherein molecular change in amino acid position results in haemolysis of blood cell in reduced supply of oxygen. The disease was first

detected in India in the Veddoid tribes inhabiting the Nilgiri hills by Lehman and Cutbush in 1952. Since then, sickle cell anaemia has been widely reported from various tribe and caste groups though is predominant in the tribal population. The wide spread of the disease world over lead the scholar to identify the evolutionary significance of this mutation. Looking into the prevalence of sickle cell anaemia in the tropical endemic malarial zone, Haldane (1949) hypothesized an association between the two and observed that the trait confers some advantage to the people in protecting them from the fatal impact of malaria caused by *plasmodiam falciparum*. The hypothesis was corroborated by the Allison (1954) who demonstrated that the geographical distribution of sickle cell mutation in the b-hemoglobin chain, correlated well with the malarial endemicity. While some earlier studies reported inconclusive results about this association (Foy et al 1955, Archibald and Bruce-Chwatt 1954), it was later corroborated by several studies acknowledging the protective advantage of sickle cell carriers against the parasite compared to normal and diseased individuals (May J et al,2007, Williams T N et al 2005, Aidoo M et al 2002). A recent study by Cyrklaff et al (2011), however convincingly reported the advantage conferred by sickle cell gene against the malarial infection by observing the mechanism under electron microscope thereby, validating the malaria hypothesis.

Haplotypes in Sickle Cell Anemia:

The mutation in haemoglobin gene at the sixth position in b-chain, though has a similar structural change in all such variants, the severity of disease varies considerably across the geographical regions of the world. Region wise thus Africa, Arab and South Asia reported disparity in the expression of disease. This has led to the identification of four Haplotypes that have occurred in different geographical region (Adekile etal 1994, Nagel etal 1991, Oner etal 1992, Desai and Dhanani 2004). The nomenclature assigned to them refers to their place of origin and the respective prevalence of these haplotypes in that region. Thus Bantu/CAR (Central African Republic), Benin (Nigeria), Senegal (Senegal) and Arab-Indian haplotypes show remarkable variation in the severity of disease. Among these, the most severe symptoms are reported in the CAR type having two fold increased risk of complications and mortality in early age compared to other haplotypes (Powars

and Hiti 1993). The Arab-Indian type is considered to be more benign with respect to pathological manifestation of disease (Padmos et al, 1991; El-Hazmi et al, 1992; Adekile & Haider, 1996).

Several studies point to the fact that higher proportion of fetal haemoglobin (HbF) and coexistence of alpha-Thalesemia dilutes the severity of disease (Mukherjee et al 1997, Steinberg et al 2006, Odenheimer et al 1987; Ballas, SK, et. al. 1988; Embury, SH, et. al. 1982). Yet correlation between the severity and the variation in proportion of HbF could not be conclusively proved (Dominic Edoh et al 2006, James V.N et al 1951). It is therefore suggested that there could be regulator or modifier gene or some epigenetic factors that influence the variation in disease expression among the four haplotypes (Nagel et al, 1984; Steinberg et al, 1995b).

Morbidity and Mortality:

Apart from protective role of mutated gene against malaria other associated disabilities were extensively studied to understand the morbidity and mortality pattern of the disease. While it compromises on the physical growth of the children by delayed skeletal and muscular development and attainment of puberty (Hisham et al 2007, Elizabeth et al 2002, Atul etal 1994), it also heightens susceptibility to various infectious diseases. A study by the welcome Trust (2010) in Africa found that children with sickle cell anaemia contact more bacterial infections and have highest proportion with streptococcus Pneumonia(44%) and haemophiles influenza type b (12%) or meningitis. Miscarriage and still births are significantly higher in SS mother and they are also prone to high toxemia and haematuria (Balgir et al 1997, Patil and Raut, 1979). The health impact of the sickle cell anaemia when measured by under-five mortality, contributes to 5% of under- five deaths in the African continent, more than 9% of such deaths in west Africa, and up to 16% of under-five deaths in individual west African countries (WHO, 2006).

Socio Cultural Context of the Disease:

Disease and illness can not be seen in isolation of its socio psychological environment within which a physical body interacts with various social and ecological factors. Studies

in this regard provide useful insight to understand the social and cultural factors that recognize the disease and organize its behaviour accordingly. Levingstone (1958) provide a socio-ecological explanation to the evolution and spread of sickle cell gene. According to him cultural adaptation to agriculture appears to be the moving force behind the mutation in gene to combat mortality from malaria. He found a correlation between the clearing of forest for agriculture and consequent spread of malaria in the human habitation. Sickle cell mutation thus comes as a rescue to avoid the lethal impact of malaria. Evidence suggests that sickle cell gene was more prevalent in the agricultural group than among the hunter gatherers.

The debilitating impact of sickle cell anemia was long recognized in certain communities and they have developed various cultural responses to deal with the phenomena. Among the African population, it was noted that the tribal community were not unaware of the disease. Felix Konotey-Ahulu, a Ghanian born medical researcher, recalled that accurate description of the symptomatology is easily provided by the people and there is well established names too, that depict the agonizing pain experienced by the victims of the disorder. Thus the Ga *Chwechweechwe*, the Fante *Nwiiwii*, the Ewe *Nuiduidui*, the Akan *Ahotutuo* all reflect the repetitive gnawing pains, the very characteristics of the sickle cell disorder. Similarly the high mortality of the children in south Nigeria which also has a high prevalence of sickle cell disease is explained by the *Ogbanje* phenomena wherein death of the children is attributed to a cultural belief that such children are spirits that are born to have a taste of life and will then return back to their spirit kins (Asakitikpi Alex. E. 2008). Cultural response to avoid the birth of such child is met with the untidy and unhygienic living of pregnant women to distract the spirit from selecting her womb for birth. It is also believed that children affected with frequent illness are manipulated by spirits hence along with prayer; search and identification of his spiritual paraphernalia are also conducted with the help of medicine man. These are then either destroyed or used as amulets to save the child from manipulation by sprits. Mutilation of the body of deceased child are other means by which the child's soul is expected to be rejected by the spirits due to scars and ugliness of the body and will thus be set free to born again as normal and healthy child (ibid).

In India, no such social/cultural belief or practices are mentioned in the ethnic groups from where the sickle cell has been reported. The ethnographic detail of the disease is while inadequate, lower severity and an array of symptoms associated with the disorder could possibly be the reason that the disease has not been identified in a separate category by the people. However the spiritual intervention and indigenous pharmacopeias in the treatment of various symptoms of the disease can not be ruled out as we shall see later in this report.

The disease inflicts a high burden on the psycho-social environment of the suffering individual. Frequent illness, immobility and excruciating pain lead to poor social integration and low self esteem (Gill etal 1997) Anxiety and depression predominate the affected (Yang et al 1994, Hasan et al 2003) rendering them vulnerable to further social marginalization. Quality of life in people with SCD may therefore be more impaired than that of general population (Kofi etal 2010). Families besides coping with the responsibility of health care giving, live in a perpetual fear of loosing their beloved ones. Examining the scope of impact of financial hardship on sickle cell disease children and their parents, Barbarin et al (1999) found that SCD and hardship contributed independently to impaired child and parental functioning. For parents, illness severity had more negative effects than did financial hardship, but for children, the reverse was true.

The discourse on the disease has been instrumental in raising the issue of equity and identity especially in the contemporary America. The political economy of disease redefined the sociopolitical boundary between the racial groups. It conjured up a pathological body habitus of the black race that was in direct contrast to the superior flawless white body. By conferring an Afroamerican identity, the disease generated an intense political debate vis-à-vis socio cultural locale of the black people in America in the late twentieth century (Wailoo 2001). Medical attention with regard to disease is also not less problematic. The invisibility of pain and suffering of people during early twentieth century gave way to the recognition of disease as first case, defining molecular basis of disease. It thus paved the way for development of new discipline of molecular biology and intense interest in population genetics with growing importance of evolutionary biology. Research and funds were generously flowed to the discipline (ibid).

Nonetheless, the political churning in the late 1970s gave considerable leeway to growing political identity of Negroes which not only highlighted the disadvantageous location of population but also accorded greater negotiating power and support for the better and higher allocation of resources towards the health needs of the hitherto neglected population.

Global Spread and Policy Initiatives to Sickle Cell Disease:

The wide variation observed over the world in the carrier frequency is not only between the countries but also within the regions, sub regions and tribes/castes of individual country. The carrier frequency the world over varies between 10-40% across equatorial Africa, decreasing to 1-2% on the north African Coast and <1% in South Africa. In the eastern Mediterranian countries like Saudi Arabia and Iraq the carrier frequency has been reported as 1.29% and 0.22% respectively. In India it is estimated that carrier frequency ranged between 5- 40 % (Roberts and Montalemberts 2007).

In spite of global spread of the disease, policy initiatives in this regard have been the scanty. Except in America where political mobilization led to enactment of the Sickle Cell Anemia Control Act in 1972 and again the Sickle Cell Anemia Treatment Act 2003, very few other countries have national policy in this regard. The disease though has wide prevalence in Africa, comprehensive attention has not been paid to this issue (Godfrey M. Mubyazi and Kato j. Njunwa 2011, Grosse et al., 2011) except for some recent initiative. NGOs and other private efforts has largely been the main support base of the people affected by the disease.

Looking into the spread and magnitude of the disease, WHO in its 59th health assembly (2006) adopted a resolution on sickle cell anemia and call upon the countries to take appropriate measures to deal with this public health issue. It also took a resolution on the prevention and management of birth defects for Sickle cell disease and Thalessemia at the 63rd world health assembly in May 2010. The resolutions specifically call for

- Increased awareness of the international community of the global burden of these disorders;

- Promoting equitable access to health services;
- Providing technical support to countries for the prevention and management of these disorders; and
- Promote and support research to improve quality of life for those affected.

The adoption of resolution culminated in some efforts at the policy level in a few countries. In India no policy frame work has been spelt out at the national level. The 'Working Group on the Disease Burden' submitted its report for the 12th five year plan incorporating the sickle cell anemia in the hereditary disorder under the programme for prevention and rehabilitation and proposed to be implemented in selected endemic districts (www.planningcommission.nic.in/about us/committee/non_communicable.pds).

Notwithstanding, NGOs in certain states have taken initiatives to screen the population for the mutant allele and work for the management of disease. Gujarat is one of the first states which has launched the Sickle Cell Anemia Control Programme in 2006 based on public private partnership (Annual Development Programme 2012-13). Initially it was started in 4 districts of South Gujarat but was later extended to all 12 tribal dominated districts of the state. The programme envisages improving the quality of life of the sickle cell patients by focusing on the prevention and management of sickle cell disease in the tribal population by identifying the affected persons.

In view of regional and sub-regional variations in the prevalence of disease among various castes and tribes, the state does not have the community level study on various tribes of the state to plan adequate intervention. There has been some prevalence rates for a few tribes but are not based on systematic study. A comprehensive study in this regard is thus lacking.

The present study is thus planned to estimate the prevalence of sickle cell anemia in Warli tribe of the state. Detail of study and methodology is presented in the next chapter.

CHAPTER - I

STUDY AND THE METHOD

It is estimated that nearly 20 million people in India suffer from sickle cell disease (Ghai). In the southern states, Tamilnadu and Andhra Pradesh the frequency is reported as 20 and 17 per cent respectively while in the western state of Gujarat it is 30 per cent. Madhya Pradesh and Orissa show a frequency of 20 and 25 per cent respectively (Roberts and Montalemberts 2007). Apart from the regional variations (Balgir and Sharma, 1998), the frequency of carriers also varies among different population groups of the country. Earlier it was assumed that the disease is confined to the tribal population only, but the recent studies have revealed that the disorder is not uncommon to non tribal population either (Kar et al, 1987). Though highest proportion is reported for the tribal population, other communities have also reported the presence of sickle cell carriers in varying proportions. Among the tribals, the sickle cell gene has been reported in 73 % of studies while it has been reported in 17 % among lower castes, 9 % among middle castes and 1% among higher castes (Rao, 1998).

Tribal and Distribution of Sickle Cell in Gujarat

Gujarat with its 7 million tribal population, is home to 29 tribal communities. They are distributed in twelve districts situated along the eastern belt of the state. A majority of them are located in the Dang, Dohad, Narmada, Tapi, Navsari, Valsad and Surat districts accommodating more than 80 per cent of the total tribal population. Like in other states of the country, tribal are at the lowest rung of development when compared with other social groups of the state.

As a community, tribals are culturally different from other caste/religion groups. They have their own faith and belief system that regulate their social behaviours toward life. For centuries they have been residing in forested regions and their engagements with the other communities had been relatively low in the past. However opening of geographical barriers and implementation of development strategies has resulted in their substantial

visibility in the mainstream population. Yet the socio economic indicator for the population is still the poorest in the state.

Education wise the literacy rate among the population has grown substantially from the early decades. It is 47.7 percent but is way behind the general population (Census 2001) and is poorer for females (36%). 28.5 per cent of the population had lowest wealth index compare to 7.2 per cent for all population (NFHS-3). More than 35 per cent of the tribal population lives below poverty line and nearly two thirds depend upon agriculture for their livelihood with substantial proportion being marginal cultivators. Wage labour is other predominant occupation among the tribal people. Malnutrition and other health indicators need special attention as the population is much below the desired figure when compared with other communities. Three forth of women population and more than 80 per cent children are anemic while mortality in under five age group is unacceptably high (NFHS-3).

As in the other states, Sickle cell anemia is reported more from the various tribal communities. It is expected that nearly 2 million tribal people harbour the mutant gene for sickle cell anemia. Early surveys in 1960s and 1970s, by Vyas (1962) and Negi (1968, 1976) reported the prevalence of the sickle cell trait from the tribal and non tribal communities which varied from 2.2 per cent among the Kolis to more than 15 per cent among the Gamit tribes. However, the recent estimates present the figures from 4.4 per cent to as high as 34 per cent among various tribes of the state. The table below reports the frequency for various tribes.

Proportion of sickle cell carriers among different tribes in some of the studies

Tribes	% of Carrier in recent reportings*	Earlier studies by Negi and others (1962-1978)#	
		% of Carrier	S Gene %
Bhil	29 %	9-15%	10-15%
Gamit	31%	19-31.4%	9-15%
Koli	4.4%	1.2-13%	2-6%
Dhodhia	17.8% and 34%	!3-!7%	6-8%
Vasava	27.9%	26%	13%
Nayaka	31%	16-25%	8-12%
Chaudhari	28.1%	-	-
Dhanka	20.4%	19-30%	10-15%
Rathwa	28%	-	-
Kunkana	33%	8%	4-5%
Warli	-	6.6-13%	3-6%

* Commissionarate of Health and Family Welfare- Sickle cell anaemia control programme 2006
Thalsemia, Haemophilia, Sickle cell anaemia prevention, counselling and blood transfusion Centre

\# Cited by Singh et al 1994

Comparing the recent estimates from the earlier studies it appears that there has been an increase in the carrier frequency over the year, though it is difficult to ascertain as there might have been differences in the methodology (selection of sample) adopted for the study. However, recent estimates for other tribal groups are still lacking.

Warli being one of the major tribe of the state, a considerable population of the tribe is expected to carry the mutant gene as is apparent from the previous studies. The community with a population of two lakhs and a half inhabit the hilly and coastal areas of the state. Thus a substantial proportion of the population is harbouring the mutant allele which has serious implication for the overall well being of the community. In the absence of recent figures for the carrier frequency in the tribe, the state's effort for planning intervention is unlikely to yield desired result. In the above context the present study was undertaken to estimate the prevalence of sickle cell anaemia in the community.

Objectives of the study:

The study envisaged to look into the sickle cell anaemia among the tribal population with the following objectives

1. To ascertain the community prevalence rate of the trait among the Warli tribe.
2. To investigate into the morbidity and mortality among the population identified with the trait.
3. The socio-cultural aspects relating to marriage pattern, social problem related to disease, food pattern and indigenous health practices are to be investigated to get an insight into the societal way of coping with the problem.
4. To obtain a comparative analysis of physical growth using somatometric measurements for normal, carriers and diseased individuals in the community.
5. Availability and Utilisation of medical health services by the affected persons will also be studied to asses the level of awareness and extent of reach of health services in the tribal areas with regard to this disorder.

Sampling and Methodology

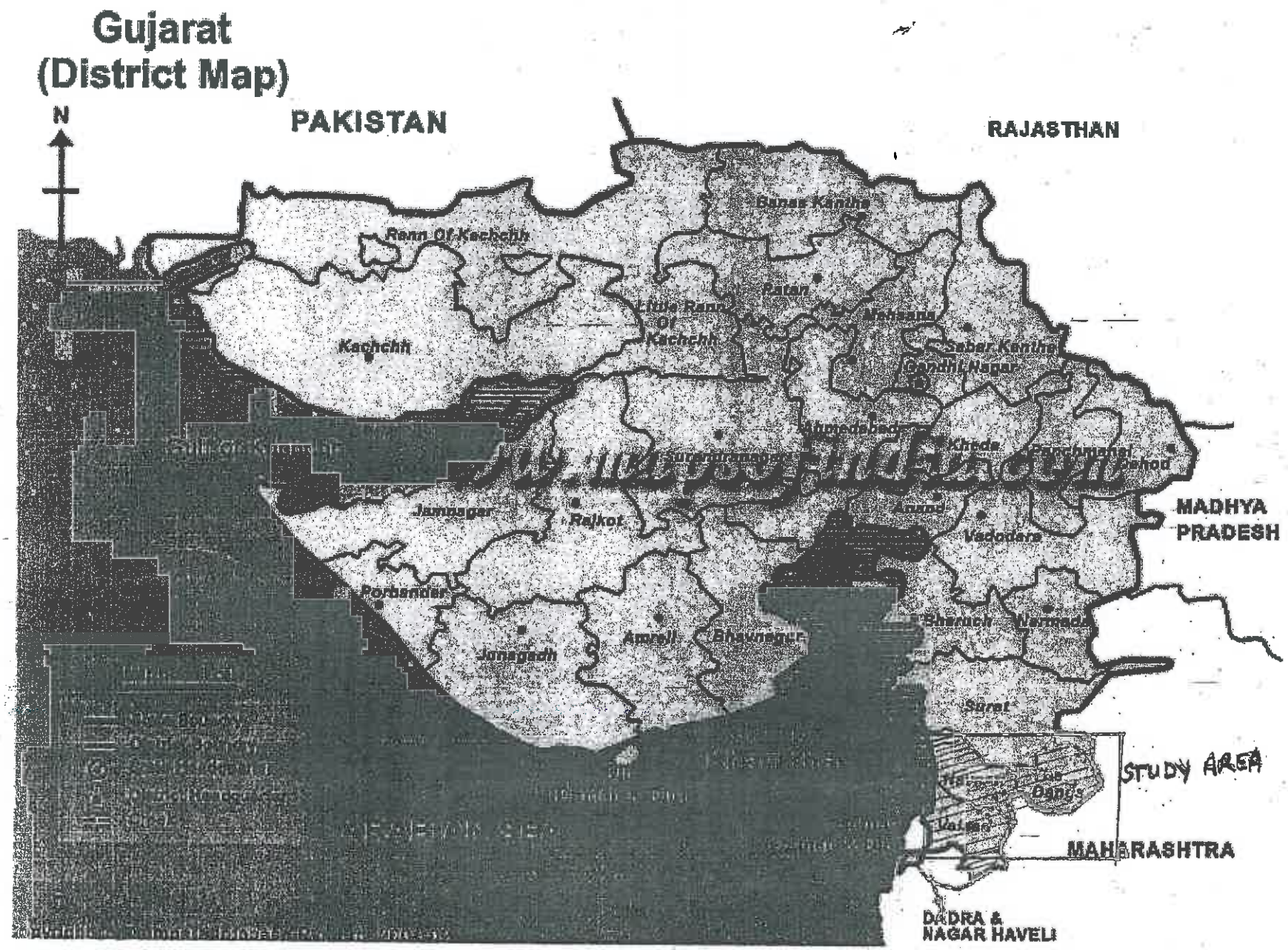
In order to achieve the objectives of the study, a combination of quantitative and qualitative method was adopted. Samples for the study are selected after ascertaining the sample size of population by employing statistical formula relevant to the study. In accordance with the requirement of study, quantitative data were analysed with the help of various statistical tests whereas qualitative investigation was carried out to obtain information about the social and cultural practices of the community with regard to disease.

The sample for the study was selected from the districts with high concentration of Warli tribes to ensure the representation of whole community hence the gene pool[1] of the tribe.

Sample size

The study drew its sample size as per the carrier frequency reported in the previous study by Negi (1968). With 6-13 % reported carrier frequency the sample size at estimated

[1] Sum total of the genes in a given population.


Gujarat
(District Map)
N
PAKISTAN
RAJASTHAN
Banas Kantha
Rann Of Kachchh
Patan
Mehsana
Little Rann Of Kachchh
Kachchh
Saber Kantha
Gandhi Nagar
Ahmedabad
Surendranagar
Kheda
Panchmahal
Dohad
Jamnagar
Rajkot
Vadodara
MADHYA PRADESH
Porbandar
Amreli
Bhavnagar
Junagadh
Bharuch
Narmada
Surat
STUDY AREA
Dangs
Valsad
MAHARASHTRA
DADRA & NAGAR HAVELI

precision of 3 per cent and 95 per cent confidence level is derived as 576 individuals using formula $n= z^2*pq/e^2$ and adding 25% of the estimated sample size to overcome the biasness due to related kindred. Overall 600-610 individuals were the target for the screening but we could manage to conduct the study with 589 individuals.

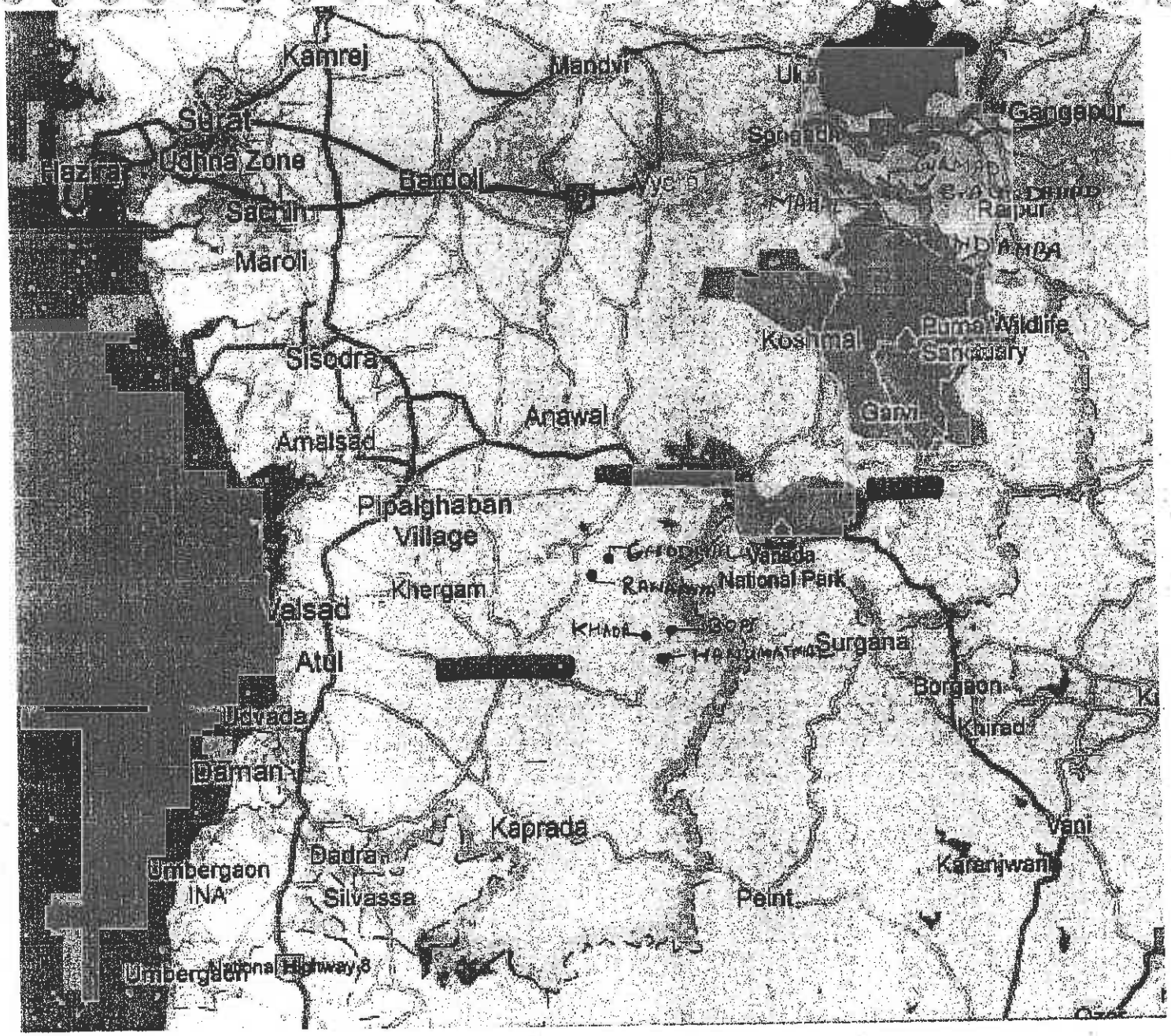
Study Area

Samples were selected from the districts where Warli community has been in high proportion. Thus Dang, Valsad and Navsari were selected for their preponderance of Warli tribe. From each district one taluka was selected. Thus Ahwa in Dangs, Vansda in Navsari and Dharampur in Valsad were selected for the study. Two or three villages from each of these talukas were chosen on the basis of pilot survey for the substantial Warli community therein, to cover the estimated number of samples. Thus four villages from Ahwa, two villages from Navsari and three villages from Dharampur were selected. Altogether three districts, three talukas and nine villages were selected and is presented in the Table below

Districts	*Taluka*	*Villages*
1. Dangs	1. Ahwa	1. Mahal
		2. Dhongiamba
		3. Girmad
		4. Gaundahad
2. Valsad	2. Dharampur	5. Bopi
		6. Hanumatmal
		7. Khanda Bhuwada
3. Navsari	3. Vansada	8. Ghodmad
		9. Rawaniya

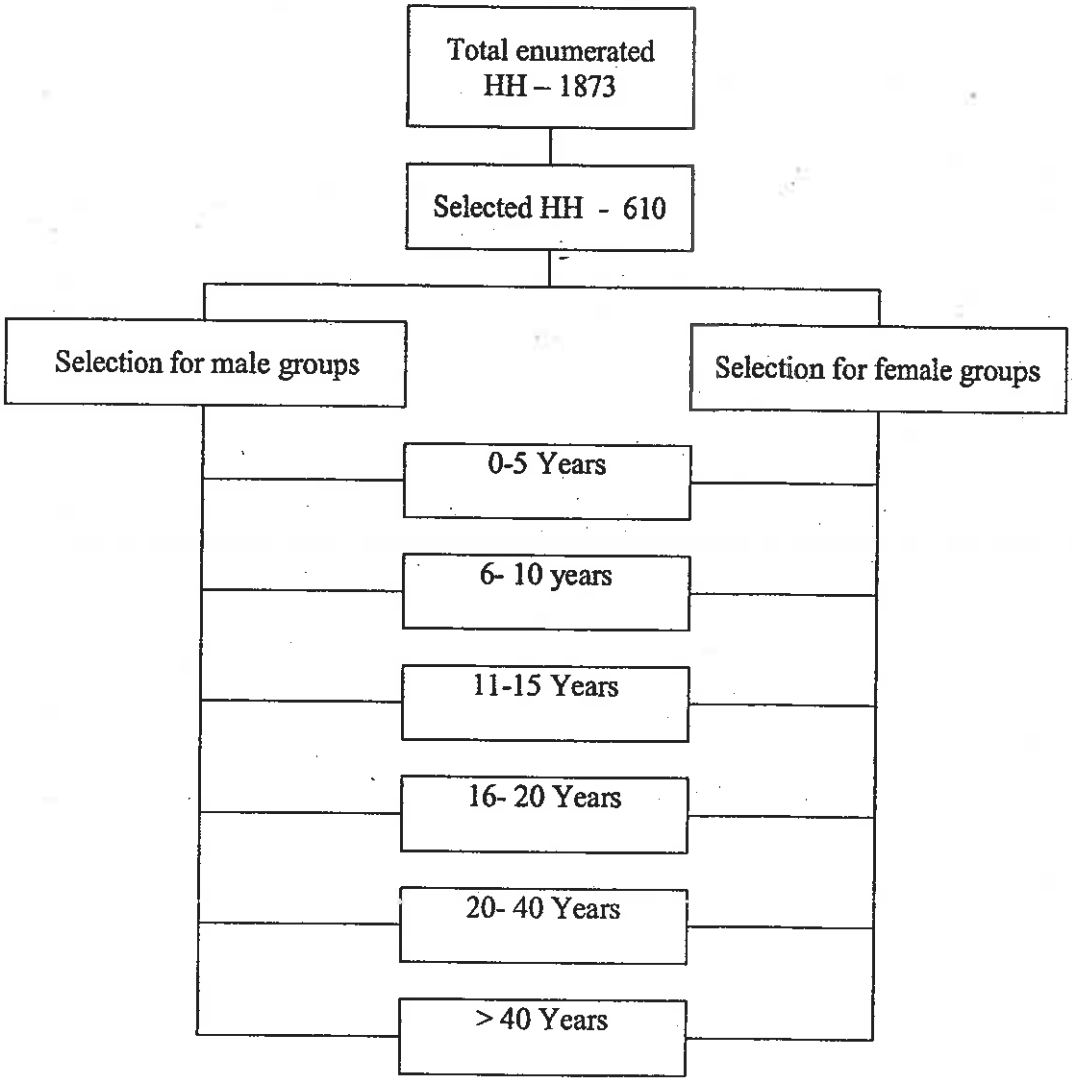
The survey was conducted in two phase:

In the first phase house listing was done in each of the villages to enumerate total population of Warlis in the village. Altogether 1873 Warli households were enumerated from these villages. Random numbers were generated to select 610 HH from the



LOCATION OF VILLAGES (NOT CALIBRATED)

enumerated households. Afterwards all the selected households were divided into two gender groups from which samples were selected alternately for different age groups of 1-5 years, 6-10 years, 11-15 years, 16-20 years, 21-40 years and 40 years and above. Thus a total of 610 individuals were selected. An additional list of 20 HH from each village was also prepared to supplement the sample in case of refusal or non availability/migration of the targeted individual from the place. Figure below give the diagrammatic presentation of samples selected under gender and various age group.



Proportion of enumerated and sampled data with regard to age group is given in Figure-1.

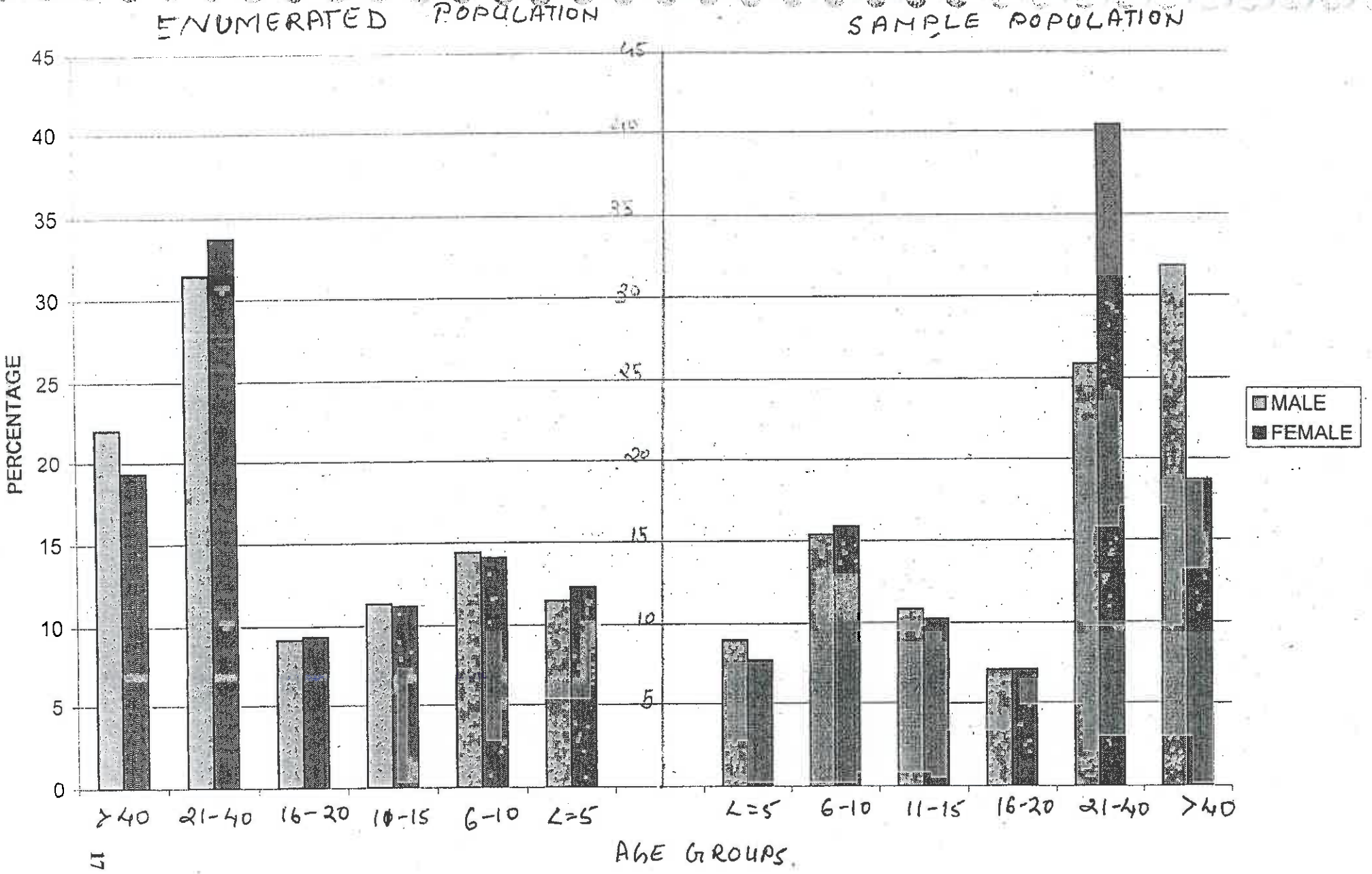

ENUMERATED POPULATION
SAMPLE POPULATION
PERCENTAGE
45
40
35
30
25
20
15
10
5
0
MALE
FEMALE
>40
21-40
16-20
11-15
6-10
<=5
AGE GROUPS

FIG. NO. - 1

Hematological parameters

In order to ascertain the sickle cell status and haematological variation within the normal carrier and disease individuals, blood test was carried out on the selected participants. Since this required a skilled and experienced hand, we entered into a collaboration with Dr. Jyotish Patel (eminent hematologist and expert on sickle cell disease) to collect the blood samples and test them for the sickle cell status and other hematological parameters to capture the association and variation in these parameters within and between the normal, carrier and people with sickle cell disease.

2 ml of blood was collected and was examined at the laboratory first by DTT (Dithionate Tube Turbidity) test to determine the positive/ negative status for normal and sickle cell and then the positive samples were put to electrophoresis test to confirm the Carrier and Sickle cell disease status of the sampled blood.

Values for blood indices like White blood count, Red blood count, Haemoglobin count, Packed Cell volume or Heamocrit, Mean Corpuscular Volume, Mean Corpuscular Haemoglobin, Mean Corpuscular Haemoglobin Concentration, Plateletes and Lymphocytes were ascertained by CBC test (complete blood count) and analysed with respect to their sickle cell status.

Somatometric measurements:

One of the significant casualties of the disorder is the poor physical growth of the affected individuals. The vulnerability of the population was gauged with the help of few linear and circumferential somatometric measurements like Head Length, Head Breadth, Head Circumference, Upper Arm and Calf Circumference, Biceps, Triceps, Supra-iliac and Calf Skin folds, Bicondylar Humerus, Bicondylar Femur, Stature and Weight to obtain the magnitude and differentials of physical growth among the normal, carrier and Disease persons.

Somatometric measurement for Stature was taken with the help of Anthropometer, Head Length and Head Breadth by Spreading Caliper; Head Circumference, Upper Arm and Calf Circumference by Measuring Tape and skin folds were measured by Holtain Skinfold Caliper. Measurements for Bicondylar Humerus and Bicondylar Femur were taken with the help of Sliding Caliper while Weight was taken by Weighing Machine.

A detailed schedule was prepared to capture the socio economic and health status of the population. General morbidity and morbidity specific to sickle cell were inquired and recorded. As the disease is basically hereditary in nature, marriage rules and practices play an important role in the transmission of the trait in the communities. Genealogical table for each participant was prepared to find out consanguinity and mortality in the studied population while personal and group interview were conducted to understand the socio cultural aspects of the studied population.

Doctors, village health workers, traditional health service providers (Bhagat) were also interviewed to understand the medical and social aspect of health behaviour.

Altogether 589 individuals were interviewed. Blood analysis could be done on 584 samples as 5 samples could not be processed and anthropometric measurements could be taken on 572 individuals only.

Compliance to Ethical Guidelines:

In pursuance to ethical considerations, proposal for the study was put before the ethical committee as it involves collecting bio sample from the individual as well as seeking intimate and personal information from the participants. The committee had social scientists, medical practitioner, law practitioner, NGO, government representative and other academicians as members. All issues regarding the design and conduct of the study were thoroughly discussed considering the objectives of informed consent, confidentiality, beneficence and risk assessment. Accordingly, a consent form stating the objective and commitment to confidentiality was drafted and is translated into local language to be understandable to the population. It was also decided to read out the

content of the form before taking the signature of the participants (Attached in Appendix). For the children and those below the age of 18 years consent was also sought from their guardians.

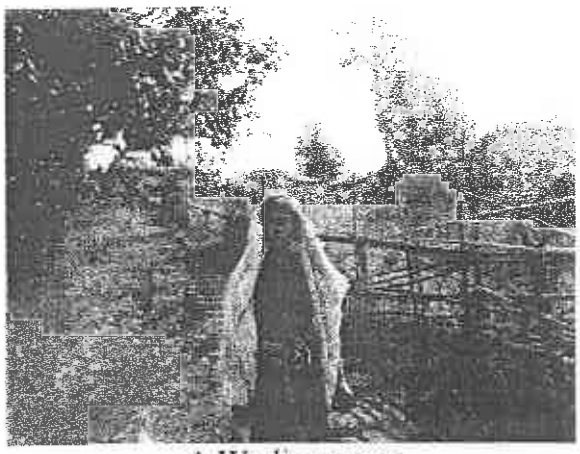
After getting clearance from the ethical committee, investigators were trained as per the sensitivity required to conduct the study complying with the ethical guidelines. Before undertaking research all the villages were visited along with the team to appraise the village head and other panchayat members about our research and to introduce them with our investigators. The rapport thus built was very helpful in getting the support and participation of the individuals. As per the confidentiality measures and part of our social responsibility we provided the blood report to every participant and those identified with trait and disease were additionally made aware of their sickle cell status and requested to inform their doctor about it whenever they are sick.

On the request of District Epidemiological Officer (EMO) of Dang, we shared our blood test report of people from the respective villages of Dang, after discussing this issue with the Director of TRTI (The funding agency).

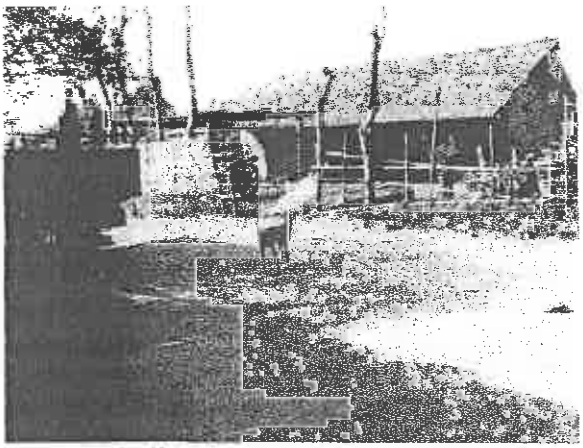
Organising and Conducting the Blood Camp.

At each sampled village all the participant were contacted and informed about the research and its objective. Their consent was also taken in writing or thumb impression on a consent form. Consent for the children was taken from their guardians as well. Village elders and other influential people like village headman, panchayat members and traditional village panch and Asha worker were also informed about our objective and their support was sought for mobilizing the participants to attend the camp for collection of blood samples. On fixed date (intimation for which had already been conveyed) the participants came at the designated site to allow the skilled personnel to collect their blood. It was heartening that attendance at each site were always more than eighty per cent and those who could not turned up either had migrated or reported ill or simply had left for their wage work. In some cases children feared the needle and did not allow the blood drawl despite parent's best attempt to calm them. In such situation we convinced

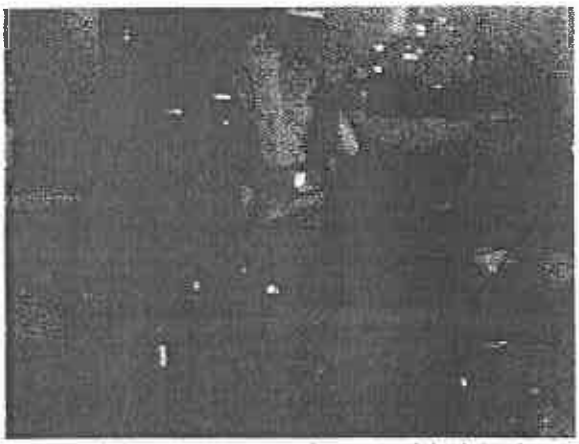
parents not to pressurize their children and let them go. As a gratifying gesture, we provided participants with glucose biscuits and were ready with all possible medical help. Somatometric measurements were also taken at the same site in another room to avoid inconvenience to people by submitting themselves to measurements at another time. As we anticipated some withdrawal, we were prepared with another list to supplement the absentees. Yet we remained short of 20 individuals to reach the target sample size calculated for the purpose.



A Warli woman

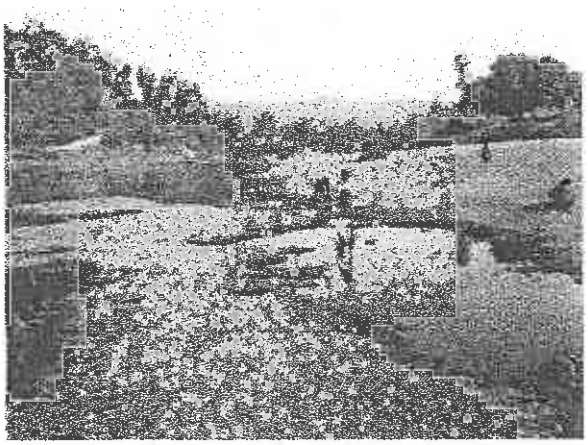


Warli Habitation site at Mahal



An elaborate setting for propitiating the Mawli Dev

Shrine of Vagh Dev at village Khanda – Bhuvada



Chidren playing and washing utensils near the river

Religious place at village Bopi

CHAPTER - II

ETHNOGRAPHIC AND DEMOGRAPHIC PROFILE OF THE WARLI TRIBE

Warlis are located on the southern most part of the state along hilly range of Satpura and Sahyadri range of Vindhyas close to the border of Maharastra. In Gujarat they are mostly found in the district of Dang, Valsad, Navsari with the concentration in the Ahwa, Dharampur, Umargaon and Vansda taluka of the state.

Origin of Warlis is difficult to ascertain as many theories have been propounded in this regard. Ethnologically the word Warli has originated from 'Warud' means uplanders or those who inhabit the hilly and forested area (Wilson,1876). Warlis are also identified as abroginal tribes, proficient in digging out roots and transplanting the new trees in the forest and are also involved in agriculture (Bhawato-Mandal Dictionary). With regard to original habitation of the tribe, it is hypothesized that they have migrated from the Konkan region in Maharastra because of imperialistic movement of Marathas, harassment by Britishers or due to some natural calamities encountered in their original habitats. K.J.Save (1945) has opined that Warlis belonged to Nagarhaveli in the territory of Daman. As he mentioned "many warlis claim that their original home was in Namnagar or nagarhaveli in the Daman territory. Almost invariably they say that they have come from the north either from Dharampur or Daman territory" (The Warlis, 1945).

Elderly and old people in Warlis still could not say with certainty about their origin but some of the elders in Dang mentioned that their ancestors fled from Dharampur because of coercion and atrocities unleashed by the raja of Dharampur and had to take shelter in the upper reaches of hills and in the forest areas. According to Enthoven, Warli belongs to the subtribes of Bhils. In Ethnology of India (1859), Latham has identified Warlis as Kol tribe that belonged to Dravidian group.

Ethnographic Profile of Warlis

Warlis coexists with many other tribes at their habitation sites. They live in close association of Kunkanas, Dhodias, Gamits and Kolghas. Some hierarchial relationship does exist between the tribes where Dhodias and Kunkanas are considered superior in the hierarchy whereas Kolghas are kept at distance and are lowest in hierarchy. They are almost treated as untouchables.

Warlis are well knit community organised along a number of clans. It is difficult to say how clan organization came into being in the tribe as they have a number of *gotra* (clan) which are exogamous. Men and women belonging to same gotra are considered as brother and sisters and marriages between them are prohibited. Marriage within the community but outside gotra is a rule and is socially enforced. With the increasing mobility of the tribe in search of work outside their habitation, there has been some relaxation with regard to marriage outside the tribe. Marriage with Konkana is no more a taboo. Earlier Konkanas were reluctant to take wife from Warli or give their daughter in marriage to them but nowadays such unions are not uncommon. Gotra exogamy is still socially upheld and marriage within the gotra is not permissible. During our field work we have identified more than 100 gotra by the genealogy of the families but it has been reported to be 144 as well (Pandya 1992). Going by the names of gotras, many of them appear to have been named after animal, fruits, tree and birds and therefore it seems that the gotra were totemic in nature which have lost their totemic relevance in the recent past. Apart from these, gotra have also been based on the occupational categories and on the name of other tribes. Thus chauhan, nayaka, chaudharie etc reflect either their settlements near these social groups or they have adopted these surnames because of some matrimonial alliances with these groups.

Despite strict following of gotra exogamy, we came across some marriages that have taken place within gotra, but generally these were referred as exception and are seen with some contempt. Marriages are mostly preferred in nearby locations. It came out from our genealogical data that nearly 62 per cent marriages took place within a distance of 10 kms (26.9% for within 5 kms and 35.6% between 5-10 kms). Marriage distance between

11-30 km accounted for one third of marriages while a miniscule proportion (5.8%) goes beyond. Warlis are patriarchal societies and inheritance run through the male line. They are also partilocal as girls have to settle at their husband's place. Yet mostly newly married couples settle in their separate household near to the boy's parent's house. But joint households are also in practice. Bride price is much prevalent and some of the older people expressed their concern about rising bride price. It was stated that among reasonably placed families the bride price veers around Rs.10000/- to 40000/- and at times it really becomes difficult to get good brides for their son (interview with the women in Gaundaghad and Girmad). But in the Rawaniya and Ghodmal village many among them said that bride price is now a ritual and amounts are not much. It is to be mentioned that these villages are more influenced by the Hindu religion and many families are associated with various sects also. Thus a cultural transition appears to be in offing and process of Hinduasisation could be a reason that bride price is gradually taking a backseat.

Though Warlis are patriarchal society and male dominance is clear in their family and community life, marriages is generally conducted by priestess called *dhalveri.* Officiating such an important ritual reflects that probably the community was earlier matriarchal which has undergone changes over the years (Dalmiya 1988). Premarital relations are not supported but they are not frowned upon either. However in case of pregnancy, boy is either forced to marry or appropriate fine is charged on his family. Widow remarriage or marriage of divorcee is permissible. Monogamous marriage is a norm but polygynous unions are also accepted. In the villages of Dang our interview reveal that nearly 8-10 per cent households belonged to this category.

Marriage between cross cousins is preferred. However, now a day a number of them do not prefer such unions. Importance of such marriage (cross cousin) is still considered good as many elders believe that bringing a girl from a known family helps in proper adjustment of the girl with the family and it also gives a kind of social security to elders as girl is more responsible and accountable to the family than those brought from the outside kin groups. A sense of loss is clearly discernable as younger generation does not

give much importance to such liaisons. The decline of this marriage form can be gauged by glancing over the Genealogical Tables as we did not come across such marriage within two-three generations. Nevertheless, some people reported these marriages in their families. Levirate and sorrorate marriages are other preferred form of marriage.

Economic life of the tribe revolves around agriculture where more than 90 per cent own small patch of land. Since irrigation facilities are wanting, generally one crop during monsoon is raised. However it varies with the village. While irrigation is nearly non existent in the Dang, villages in Vansda and Dharampur have some what better irrigation facilities. Vegetable and other cash crops are also produced. In general, *nagli, tuwer, urad* and *jowar* are main crops cultivated by the people. Occupation wise majority among them are cultivators but engagement in other occupation like wage labour, agriculture labourer, carpentry, masonry as also in other service sectors are not uncommon. Since livelihood options are limited at villages, most of the families migrate out after monsoon in search of work. During our survey nearly 30 per cent of the families in Dang had migrated out in search of livelihood. In other district the rate of migration was a little less.

Religious life of the tribe is dominated by a number of deities associated with various spheres of their lives. *Vagh Dev, Naran Dev, Hirva, Kansari Mata, Kothar Dev and Mawli Dev* are some of the predominant deities who are regularly worshipped and propitiated on specific days. Among them *Vagh Dev, Kansari and Mawli* are given more importance as they influence their vital and daily activities. Beside their grand puja annually and collectively, they are also propitiated and worshipped individually when some calamity is descended upon the family. Poor yield, loss of wealth, death of cattle or family members are taken as anger of the deity and are accordingly propitiated. In case of frequent illness or suffering with long lasting disease *Mawli Dev* is also invoked to take away all misfortunes. Similarly before sowing, plantation and harvesting, *Kansari mata* is worshipped to pray for good yield and to thank her for bountiful harvest.

Birth of girl is taken with equal pleasure as with the birth of boys. Traditionally birth is attended by *dian* but now a day with the facility of emergency service most women prefer

to go for institutional delivery. Women till 5 days are considered polluted and is not allowed to cook or go out of the house for fear of attracting evil eyes. After five days mother and child are given a bath and a ceremony is observed called *Panchora*. After the ceremony child is taken out and is blessed by all the elders of the family followed by a feast.

During death, body of the deceased person is kept in the house for whole night and death songs are sung by a different category of *Bhagat* specialized in these rituals. Next day the body is bathed and *haldi* is applied. Body is then adorned with new clothes and is carried over to the crematorium accompanied by whole village including women. At the boundary of the village women stay back whereas males go along with the body and put it on pyre. After offering rice, liquor and some money the pyre is lit. People return back after taking a bath in the nearby river. For eleven consecutive days rice is offered to the dead. It is followed by *Karaj* on twelvth day where some ritual is observed and community feast is organised.

Demographic Profile of Warli

Warlis constitute 3.4 % of total tribal population (Census 2001). In absolute terms their total population is 2,55,271. Sex ratio in the community is favourable and is more than 1000 women per 1000 men while it is 974 for all ST population. Table-1 below presents the population structure of the tribe.

Table-1 Distribution of Warli Population by Age group

	All	*M*	*F*	*Total married*	*Male*	*Female*
All ages	255,271	126,819	128,452	116,440	56,577	59,863
0-9	77,895	39,530	38,365	0	0	0
10-14	31,102	16,127	14,975	188	43	145
15-19	19,642	9,803	9,839	3,411	650	2,761
20-24	19,277	8,484	10,793	15,197	5,808	9,389
25-29	20,884	9,837	11,047	19,776	9,245	10,531

	All	*M*	*F*	*Total married*	*Male*	*Female*
30-34	19,205	9,238	9,967	18,631	9,005	9,626
35-39	17,043	8,864	8,179	16,523	8,726	7,797
40-44	13,180	6,614	6,566	12,589	6,429	6,160
45-49	11,196	5,877	5,319	10,489	5,678	4,811
50-54	7,750	4,063	3,687	6,874	3,861	3,013
55-59	5,948	2,830	3,118	5,043	2,610	2,433
60-64	5,143	2,465	2,678	3,697	2,139	1,558
65-69	3,281	1,415	1,866	2,110	1,178	932
70-74	2,093	960	1,133	1,116	741	375
75-79	680	283	397	380	214	166
80+	776	342	434	382	232	150
Age not stated	176	87	89	34	18	16
Less than 18	**121,340**	**62,134**	**59,206**	**926**	**181**	**745**
Less than 21	**133,956**	**67,792**	**66,164**	**6,811**	**1,676**	**5,135**

Source: Census 2001

Nearly 30 per cent of the population is below 10 years of age while 27 per cent of the population lies in the prime age of 15-24 years. It can be seen that 145 girls or less than one per cent of girls get married at the tender age of 10-14 years which is three times to that of married males in this age group. The proportion of marriages increases to 17.36 per cent in the 15-19 years age where 2.6 per cent of male in this age group are married before attaining the legal age of marriage. Nearly one third (28%) of all women in this age group get married.

House hold enumeration data from the selected village are presented below

Table-2 Distribution of population by village

		Gender		Total	Sex Ratio
		Male	Female		
Village	Bopi	508	1000	492	968
	Ghodman	747	1442	695	930
	Dhongiamba	454	929	475	1046
	Ganvdahad	232	499	267	1150
	Girmand	308	631	323	1048
	Hanmatman	1011	2011	1000	989
	Khanda-Bhavada	893	1777	884	989
	Mahal	221	446	225	1018
	Rawaniya	773	1514	741	958
Total		**5147**	**5102**	**10249**	**991**

Figures reveal that overall 991 females per thousand males which is far better than the state's average. But the disaggregated data by village show that sex ratio is more favourable in all villages of Dang (Mahal, Dhongiamba,Gaundahad, Girmand) whereas those in the Navsari district (Rawania and Ghodman) show a declining trend. Village wise age group distribution of the population is as under

Table-3 Age group Distribution of Enumerated HH by Village and Gender

Village	Gender		Age-group						Total
			<=5	6-10	11-15	16-20	21-40	>40	
Bopi	Gender	Male	60	79	64	49	153	103	508
		Female	61	76	56	49	159	91	492
	Total		121	155	120	98	312	194	1000
Dhodman	Gender	Male	61	65	101	87	241	191	746
		Female	48	71	92	69	252	163	695
	Total		109	136	193	156	493	354	1441

Village	Gender		Age-group						Total
			<=5	6-10	11-15	16-20	21-40	>40	
Dhongiamba	Gender	Male	79	99	52	27	117	80	454
		Female	83	100	52	36	140	64	475
	Total		162	199	104	63	257	144	929
Ganvdahad	Gender	Male	14	34	21	21	88	54	232
		Female	28	45	28	18	94	53	266
	Total		42	79	49	39	182	107	498
Girman	Gender	Male	49	62	33	17	89	58	308
		Female	52	69	33	20	99	50	323
	Total		101	131	66	37	188	108	631
Hanmatman	Gender	Male	127	154	120	80	317	213	1011
		Female	140	146	106	93	319	196	1000
	Total		267	300	226	173	636	409	2011
Khanda-Bhavada	Gender	Male	95	108	102	94	287	204	890
		Female	111	98	102	86	305	180	882
	Total		206	206	204	180	592	384	1772
Mahal	Gender	Male	30	39	25	20	68	39	221
		Female	41	31	23	23	72	35	225
	Total		71	70	48	43	140	74	446
Rawaniya	Gender	Male	76	101	66	76	259	193	771
		Female	64	83	79	82	280	151	739
	Total		140	184	145	158	539	344	1510

Literacy among the Warlis is poor and is even lower than the tribal population of the state. According to Census 2001, total literacy among Warli is 32.1 per cent with male literacy at 42.1 per cent and female literacy at 22.2 per cent. Literacy rate among the ST population of the state is 47.7% with male literacy at 59.6% while that of female at 36.0 per cent. Village wise literacy rate in the sampled population show that nearly 43.8 per cent are illiterates. 6.1 per cent are children below 6 years of age who have not started

formal education. Level of education reveals that around 62 per cent among literates have attained only primary education (Table 4).

Table-4. Literacy in the Sampled Population

Village Name	Education					Total
	Illiterate	std: 1-5	std :6-10	std : above 10	not enrolled (less than 6 year of age)	
Mahal	8	12	2	0	1	23
Dhongi amba	13	15	3	0	3	34
Ganvdahad	10	17	7	1	2	37
Girmal	21	24	3	1	3	52
Ravaniya	31	27	17	23	1	99
Ghodmal	30	31	17	8	2	88
Khanda Bhavada	33	32	14	7	16	102
Bopi	30	15	4	0	3	52
Hanumatmal	82	10	3	2	5	102
Total	**258**	**183**	**70**	**42**	**36**	**589**

Nearly 40 per cent of the people are engaged in some kind of occupation. A majority (65%) of them are cultivators while a quarter (26.1) among the workers are wage labourers engaged either in farm or in other labour work.

More than 60 per cent (66.2) posses BPL card and are thus categorized as poor. Rashtriya Swastha Bima Card (RSBY) is reported from 18 per cent of households, thus nearly four fifth of the households have to meet health expenses on their own.

A substantial proportion or 66.2 per cent of sampled HH get drinking water from hand pumps while 19.5 per cent use well for the purpose. Thirteen per cent reported tap as a source of drinking water. Less than 1 per cent or just 7 HH reported having reliance on river for the said purpose. A large proportion of population in the village does not have toilet facility. More than three fourth or 76.7 per cent of the HH are devoid of this facility.

CHAPTER III

PREVALENCE AND DISTRIBUTION OF SICKLE CELL IN THE WARLI TRIBE

We have mentioned that prevalence of sickle cell carriers in the Warli population was 6.6-13 per cent in early 70, as reported by Negi et al. But the sample size in this study was too small to allow for the representative of the Warli community. The present study therefore aimed to collect data from the wider spread of the community. Since the tribe is endogamous the whole of the population can be treated as Mendelian population with gene being exchanged within the community. Therefore in order to get a representative sample, data was collected from various locations (Nine villages) where the tribe had been in substantial number to asses the prevalence of mutant gene in the Warli community. In this chapter the spread of the sickle cell gene and the proportion of carrier and affected individual are discussed.

Genetics of Sickle cell anaemia

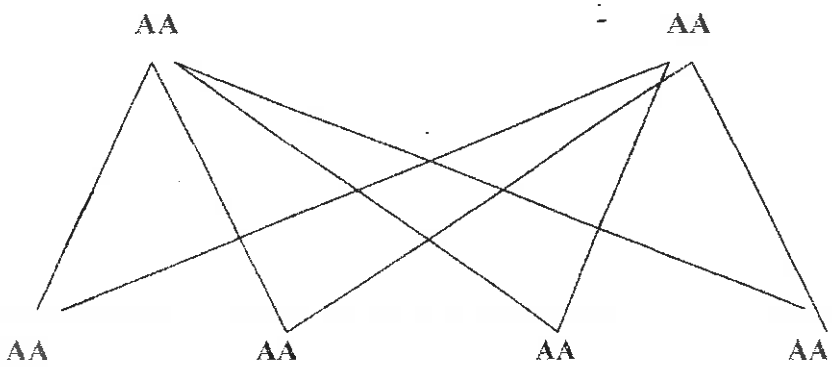
The sickle cell anaemia is caused by the mutation in chromosome no.11 at a locus where Glutamic acid is substituted by the Valine, resulting in a mutant allele normally denoted as S. The locus presents three manifestations in terms of the genotype of the individual. These are normal individuals with genotype AA (homozygous), carrier individuals with genotype AS (heterozygous) and individuals with genotype SS (homozygous). Phenotypicaly or in the physical appearance there is no discernable difference between the normal and carrier but the homozygous with SS constituent differs significantly in terms of physical growth and manifestation of pathological features like excruciating pain in joints, severe anaemia, enlarge spleen, and other related problems. Since the mutant allele S is recessive in nature i.e. it will express the problem only in the homozygous state or when the allele is in double dose. The heterozygotes or carriers, though are physically normal, carry the mutant allele which can be passed on to the offspring.

Mating and Inheritance Pattern of Sickle Cell Anaemia

Based on the above facts, the mating pattern and probability of offspring inheriting the disease is presented as below.

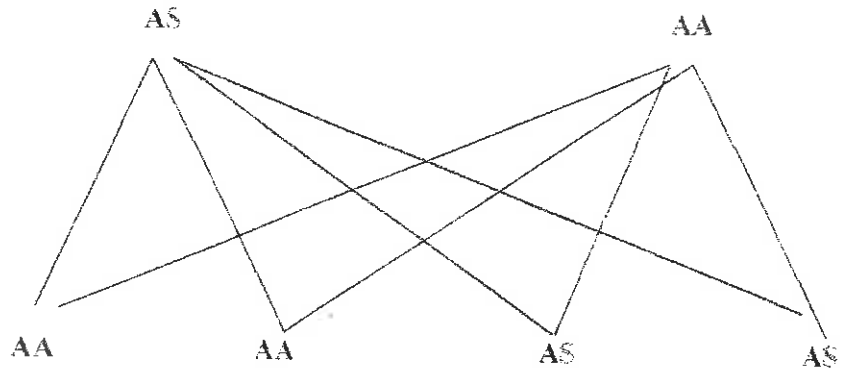
There may be six possible marriages/mating among the three genotypes. It may be between AA and AA individuals, AA and AS individuals, AA and SS individuals, AS and AS individuals, AS and SS and SS and SS individuals. As the offspring receive one gene each from both parents a diagrammatic presentation of these mating and the possible genotype of the offspring are as follows

1. **Both the parents are Normal individuals (AA and AA)**



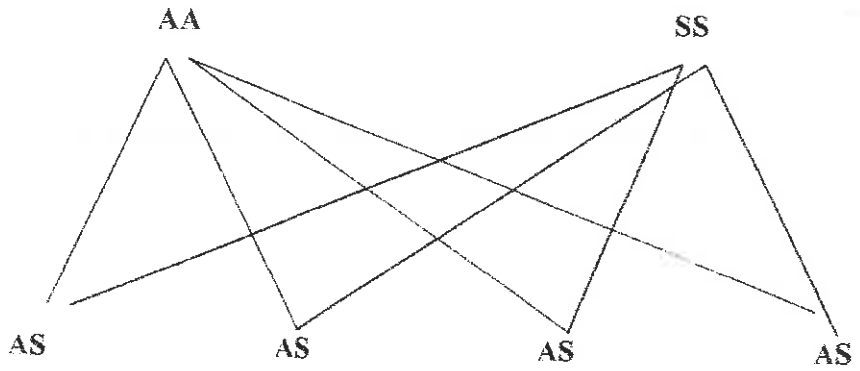
With normal (non sickle gene) parents all the offspring will receive the normal gene hence will be a normal individual in all probabilities.

2. One of the parents is Normal and the other is Carrier (AA and AS)



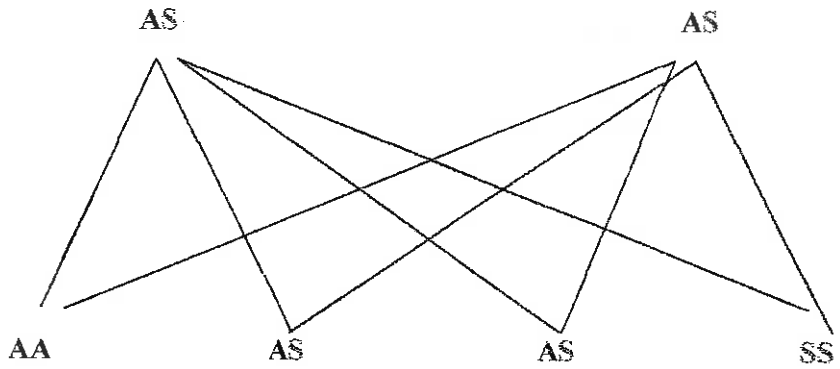
In this mating there is fifty per cent likelihood of conceiving either a normal or carrier baby. Thus the chances of having a carrier or a normal offspring are equal.

3. One of the parents is normal and the other is having Sickle cell anaemia/ diseased (AA and SS)



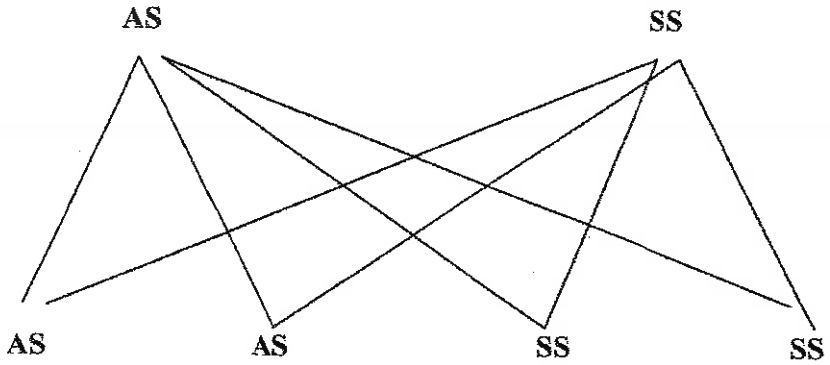
As we see, all the children conceived by the parent will be a carrier and will have a normal phenotype.

4. Both the parents are Carriers (AS and AS)



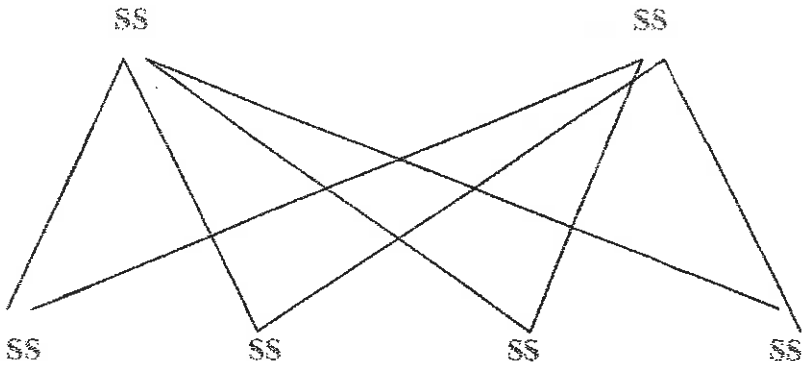
When both the parents are carrier the likelihood of conceiving normal baby is one in four, for having carrier baby it is two out of four and for a diseased baby it is one out of four. Thus the chances for normal, carrier and diseased exists in the ratio of 1:2:1

5. One of the parent is carrier and the other is sickle cell anaemia (AS and SS)



In the above case it can be said that having a carrier or diseased baby stands equal chance. The ratio is 2:2

6. **Both the parents are having sickle cell anaemia (SS and SS)**



There is a 100 per cent chance of having a sickle cell disease offspring. Every conception is likely to result in SS individual.

Prevalence of Normal, Carrier and Sickle cell in the population

As mentioned in the methodology, 2 ml of blood was drawn from the research participants by the skilled professionals. Blood samples of all the selected individuals were put to turbidity test (Dithionate turbidity test or DTT) to ascertain the positive samples for mutant allele. These samples were then subjected to electrophoresis test to determine the confirmed status of sickle cell carrier and homozygous individual for the sickle cell gene.

Village wise prevalence of sickle cell trait and disease is presented in the figures below

Table-5

Prevalence of sickle cell anaemia by village

Village	Gender	Sickle Cell Status			Total
		Normal	Carrier	Sickle cell disease	
Mahal	Female	9	3(25.0)	-	12
	Male	9	1(9.0)	1(9.0)	11
	Person				
Dhongi amba	Female	19	2(9.5)	-	21
	Male	13	-	-	13

Village	Gender	Sickle Cell Status			Total
		Normal	Carrier	Sickle cell disease	
Gaundahad	Female	20	2(9.09)	-	22
	Male	15	-	-	15
Girmad	Female	20	4(16.6)	-	24
	Male	24	4(14.3)	-	28
Ghodmad	Female	43	8(15.6)	-	51
	Male	31	5(13.5)	1(2.7)	37
Rawaniya	Female	44	6(12.0)	-	50
	Male	37	11(22.4)	1(2.04)	49
Khanda Bhuvada	Female	47	11(18.9)	-	58
	Male	36	4(10.0)	-	40
Bopi	Female	24	3(10.7)	1(3.5)	28
	Male	20	3(13.0)	-	23
Hanumatmal	Female	42	9(17.6)	-	51
	Male	41	10(19.6)	-	51
All Villages		494	86	4	584

The variation observed in the carrier and disease frequency between the village was statistically non significant. Prevalence of the disease by gender is given in table 6

Table-6

Sickle cell status in the population by Gender

Gender	Sickle cell status			Total
	Normal	Carrier	Sickle cell disease	
Male	226	38	3	267
	(84.6)	(14.2)	(1.1)	(45.7)
Female	268	48	1	317
	(84.5)	(15.1)	(0.3)	(54.2)
All	494	86	4	584
	(84.6)	(14.7)	(0.7)	(100)

Figures in the parentheses are percentage

Though carrier frequency appears little higher in the females and lower in disease status, the difference between the sexes with respect to their sickle cell status was not significant statistically (p=0.788 at 1df). The result is in consonance with the inheritance being autosomal, i.e. genes are not present on the sex chromosomes hence the inheritance is not sex specific. Genes get assorted irrespective to the gender of the offspring or are independent of gender. Distribution of the mutant gene by age group is given below

Table-7 Distribution of Haemoglobin Variants by Age Group

Age Groups	Sickle Cell Status			Total
	Normal	Carrier	Disease	
<=5 Years	37	9 (19.1)	1 (2.1)	47
6-10 Years	78	11 (12.2)	1 (1.1)	90
11-15 Years	53	9 (14.5)	0	62
16- 20 Years	35	7 (16.2)	1 (2.3)	43
21-40 Years	166	30 (15.2)	1 (0.5)	197
> 40 Years	125	20 (13.7)	0	145
All Age Groups	494	86	4	584

Figures in the parentheses are percentage

It is therefore seen that the proportion of carrier is more in the age group below or equal to 5 years of age where nineteen per cent children harbour mutant allele. Of the total carriers nearly 42 per cent (41.8) are in their prime age of less than or equal to 20 years.

Frequency of sickle cell gene in the population:

Sickle cell allele is a variant of normal allele. Estimating the allele frequency at the population level, we would apply Hardy-Wienberg law to calculate the same. According to it, the allele frequency of two gene in the population must add to one, thus p (normal) and q (sickle or s) or

$p+q=1$ or $(p+q)^2 = 1$

or $p^2+2pq+q^2 = 1$

where p^2 = normal (homozygous)

q^2 = mutant or sickle cell disease (s or sickle cell gene, homozygous)

2pq = carrier (heterozygous)

Total allele in the population = 584 x 2 = 1168

Frequency of **normal allele** would be $p = (494 \times 2 + 86)/ 1168 = 0.92$

$p^2 = 0.8445$

Frequency of **sickle cell allele** would be $q = 1- p = 1 - 0.92 = 0.08$ or approx 0.1

$q^2 = 0.0065$

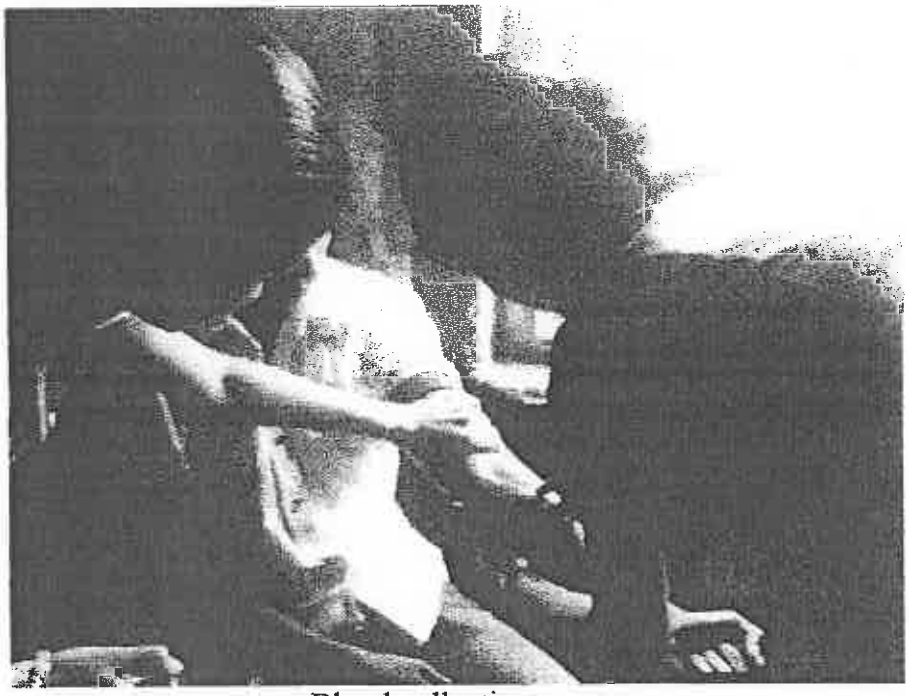
Frequency of **carrier or heterozygous** would be $2pq = 2 \times 0.92 \times 0.08 = 0.147$

From the above it can be deduced that out of every 1000 individual, 6 or 7 will be sickle cell disease person or 1 in every 143 individual will be a sickle cell disease person. There will be 15 carriers per 100 persons or 1 in 7 persons carry the trait.

Projecting this figure to the total population of Warli (Census 2001), it can be estimated that Number of person carrying the trait will be 0.147 x 2,55,296 = 37,528 individuals approximately.

Likewise, number of diseased persons could be 0.0065 x 2,55,296 = 1,659 approximately.

Thus a substantial number of people are expected to be suffering from the disease.



Blood collection camp

Anthropometric measurement taken on the participant

CHAPTER – IV

ANTHROPOMETRIC MEASUREMENTS AND HAEMATOLOGICAL VARIATION AMONG THE WARLI

This chapter deals with the physical growth and development among the Warli tribe with the anthropometric measurements and haematological tests taken upon the sampled individuals. Anthropometric measurements are useful in assessing the overall physical growth and are also helpful in identifying the age at which growth faltering is taking place. The parameters are also valuable in comparing the growth with the reference population to assess the deficit or improvement in the progression of growth in the population understudy. The analysis in this chapter have been based on the cohort groups to get a better understanding of the growth pattern in all the three groups of normal, carrier and disease genotype. However one of the most limiting factors in such comparison is insufficient number of individuals representing the cohort of each group. Hence the effort can best be seen as pointers to the said differences.

Altogether 572 individuals were measured. In 17 individuals (altogether 589 respondents), partial or no measurements could be taken. Of them 10 were children below the age of ten who started crying on seeing the instruments. They were consoled and let to leave while rest seven in the higher age group wished to go as they could not wait till their turn to measurement.

The analysis is based on cohort of small age groups to avoid large variations within with respect to growth and body dimensions. Following are the cohort groups

1. Less than or equal to 5 years age
2. Six to ten years of age group
3. Eleven to fifteen years of age group
4. Sixteen to twenty years of age group
5. Twenty one to forty years age and
6. More than forty years age group.

Anthropometric measurements were taken for linear measurements like stature, head length, head breadth, bicondylar humerus and bicondylar femur. Girth measurements included head circumference, mid arm circumference and calf circumference. Skin folds were measured at biceps, triceps, subscapular, supra iliac and calf sites. Along with these measurements weight of all individuals were also recorded to understand the growth pattern of the tribe with respect to their sickle cell status.

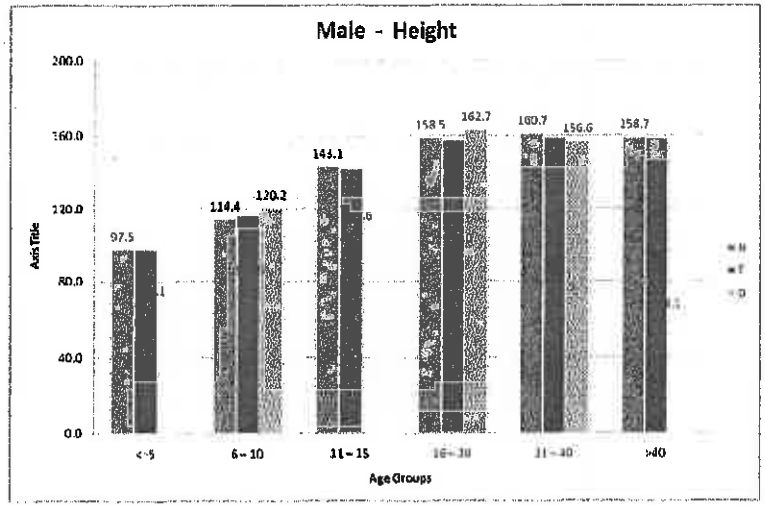
Anthropometric measurements of all the parameters with Mean, Std Deviation and Std Error are given in the Appendix 1.

Height:

It is to be seen that height registers a secular growth throughout the age groups in both the genders (Fig 2). Females are shorter in height at all age group except in the 6 to 10 years. Gain in height in both the gender group is the highest (female-43.4 cm and male 45.47 cm) between 6-15 years which nearly stabilizes after 20 years as marginal gain(female 2.36, male 1.92 cm) is recorded in 21-40 years from the preceding cohort group. While in males the growth is accelerated or is maximum at 11-15 years gaining 28 cm, in females it was little more (23.2cm) in 6-10 years compared with 11-15 years (20.2cm). The higher pre-pubertal spurt in height of girls took over the boys in 6-10 years whereas boys show an accelerated spurt during adolescent which overtake girl's height in the subsequent cohort group. Gain in boy's height continued to be greater in the 16-20 years age group making boys taller by 12 cm at 21-40 age cohort.

Comparing the height of Warli tribe with Indian population (ICMR, 1989), it is observed that Warli males are 3.8 cm shorter to general Indian males in 16-20 age group but females are 5.03cm shorter to general Indian females. Deficit in height continued from 6 years onwards in males but in females it sets in the 11-15 years and continues thereafter. However the present study compare well with the data for Gujarat tribe (NNMB 2000). The males continued to record higher values at all ages except at 6-10 years age group but females have consistently shown lower values at all ages, though it attain equal value

Figure-2



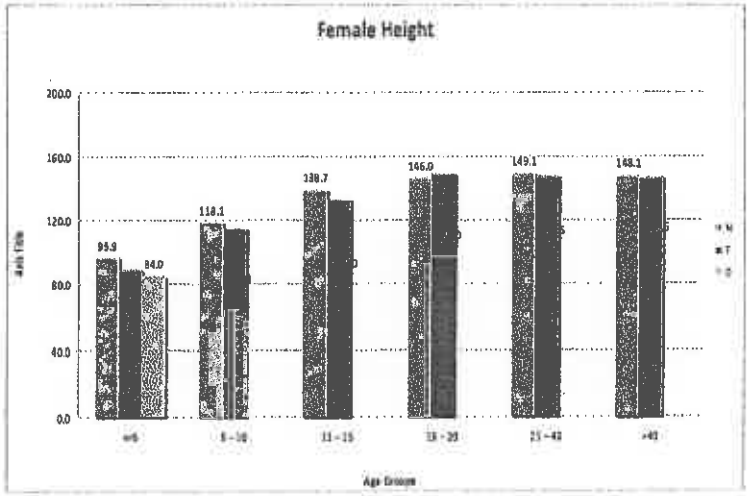
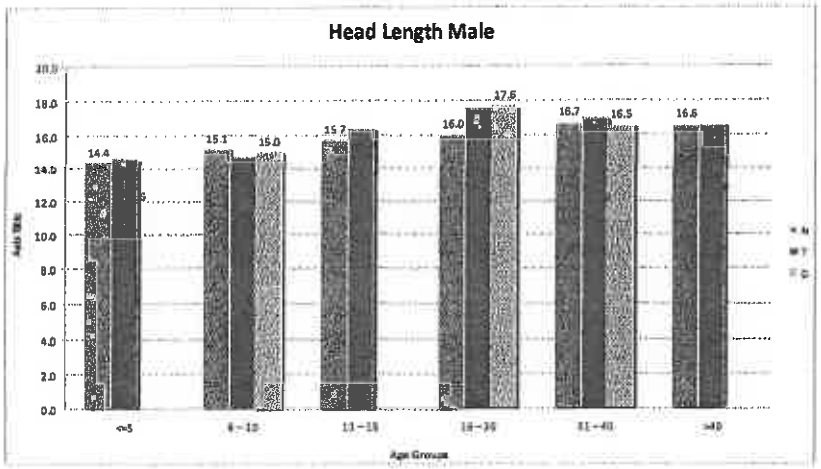
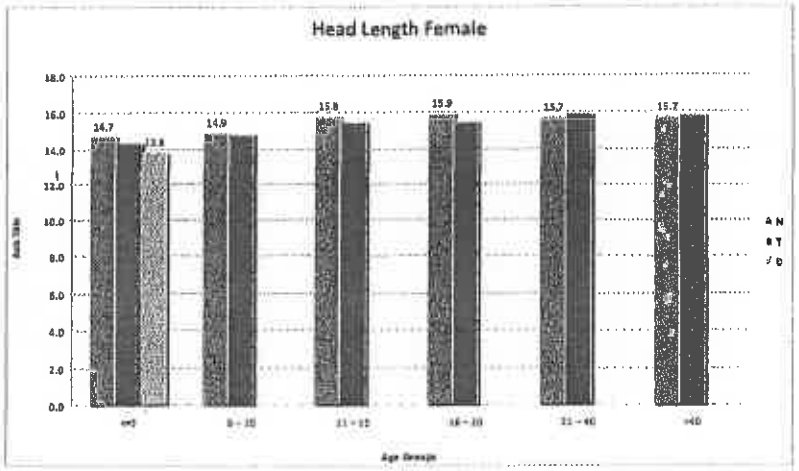


Figure-3





at 21 years onwards. A decline in height is register in the cohort with more than 40 years of age among the studied population which is also evident in NNMB report(Tech Report 19) and is probably because of curvature in the spine that sets in as people grow old.

There is a marked difference in height in females under the age of five between normal, carrier and disease individuals. Values are higher for normal females till the age of 15 years. Among males also little higher values are observed for normal person at all age groups. However the difference between the normal and carriers are not significant statistically (p value 0.059 for female and 0.100 for males).

Head dimensions:

Head dimensions (head length, head breadth and head circumference) attain nearly 90 per cent of their growth in the first age cohort except for the head length in boys (86.4%). Thus by the age of 5 years 90 per cent maturity is attained by the individual because of faster growth of brain during first few years of life. In the later years though growth is still recorded in various age groups, its velocity is higher between 6-15 years age cohort in both the genders (Fig 3,4,5). Gender differentials in head length and head circumference become apparent in the cohort group 16-20 years and beyond where boy's values exceed the girl's. But the Head breadth measurements show the difference from the preceding cohort group.

With the Warli children of Maharastra (Singh, N. 2006), data for which is available for 6-10 years age it was observed that Warli children of the same cohort in the present study have lower values for head dimensions which is more glaring for head breadth measurements. Comparing head circumference values available for Indian population, Warli boys and girls show a lower value by one cm. at all age groups.

Little variation is observed in head dimensions among the haemoglobin variants but these are not significant.

Skin Fold Measurements:

Skin fold measurements are taken at different body sites by Holtain skinfold caliper (with the accuracy of .2 mm.) to record the body fat distribution with respect to growth. As seen in the data biceps values are consistently smaller at all ages across the gender groups (Fig 6). Marginal gain (.35 mm approx.) is observed in the 11 to 20 years age group and is poorer when compared with available data from urban India (Khalid et al, 2008). While female and male show gender differential with higher value consistently for female in the comparable age cohorts, no such differentials were found in the present study and was much below the study mentioned above.

Triceps skin fold gives a good measurement of underlying adipose tissue. In the present study though the values are higher for females across the age group, it is 2-3 mm. lower to the observed value for the tribes of Gujarat. The same is true for the Warli males of this study. Substantial gain is seen only in the age group 16-20 years in both the gender and is higher for females but is still smaller in absolute value compared to study mentioned above (Fig 7).

The Sub scapular and Supra iliac skin fold show the same trend as they compared poorly with the urban population of the country (ibid). There is a huge deficit in the thickness of the skin folds as population moved from 15-20 years age group for sub scapular whereas it remain short of 5-8mm in supra iliac skin folds (Fig 8,9). Calf skin fold is also no exception to this phenomena and it cam be surmised that population is much leaner than is expected and is therefore deficient in terms of adequate fat and muscle cell (Fig 10). Another interesting feature is the negative gain or lower value in all parameters at 6-10 years age group.

However no significant difference was observed between the normal and carrier population with respect to growth of skin fold variables.

Figure-6

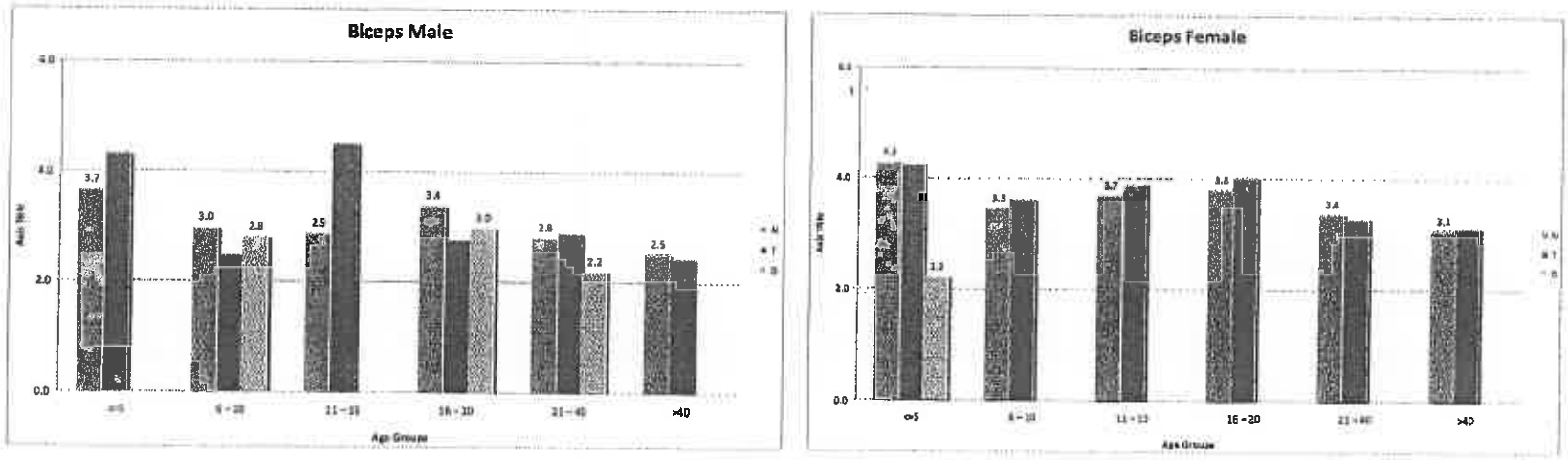


Figure-7

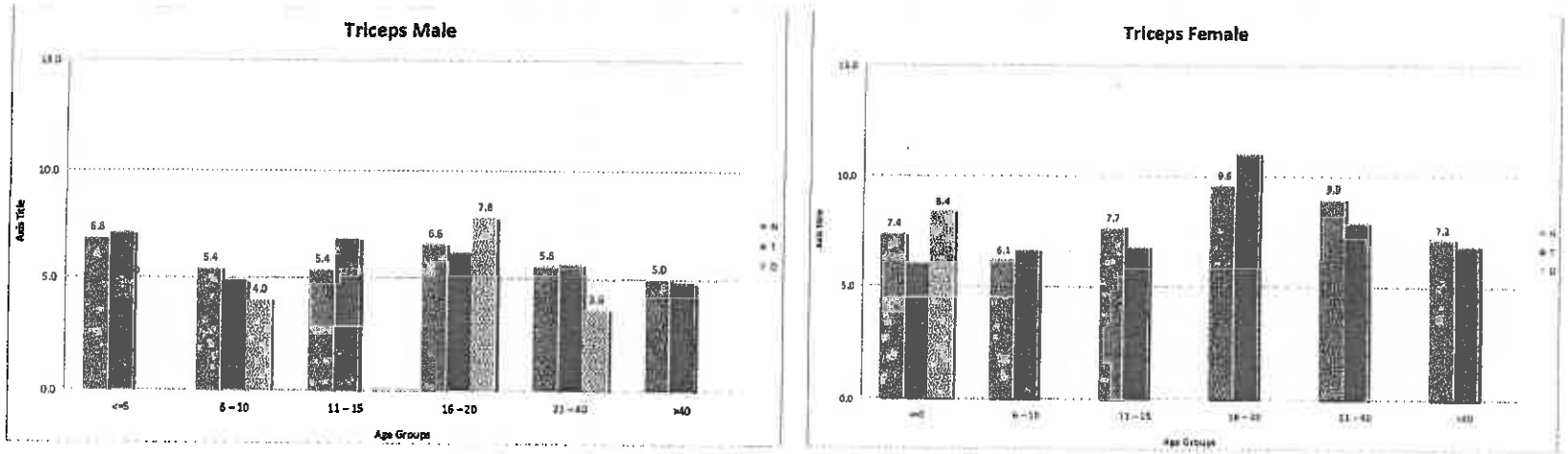


Figure-8

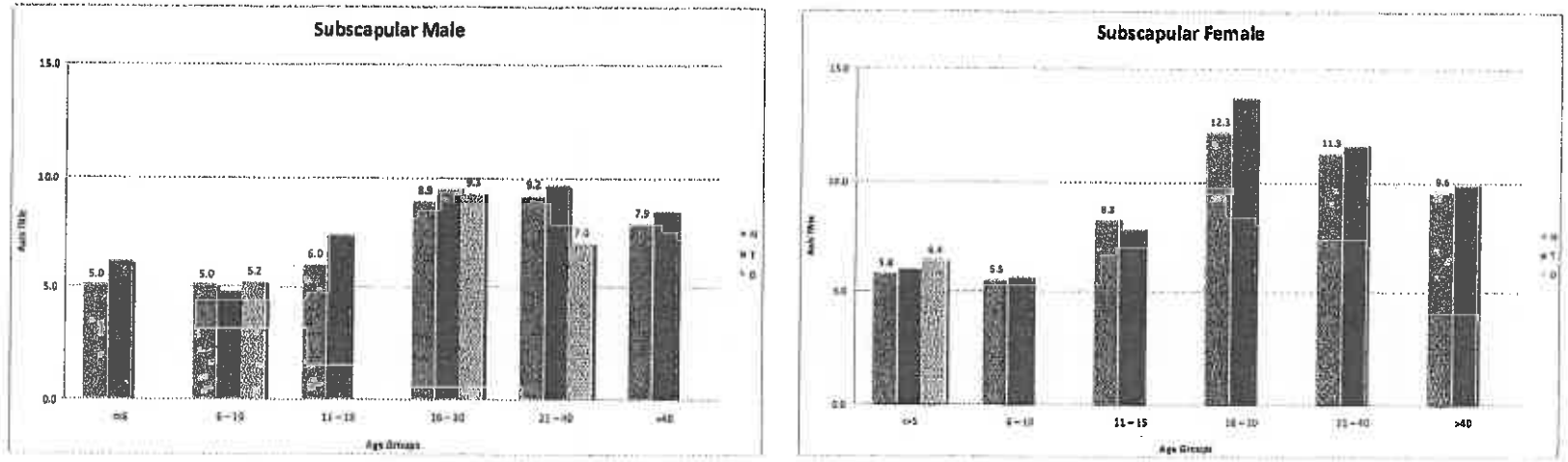


Figure-9

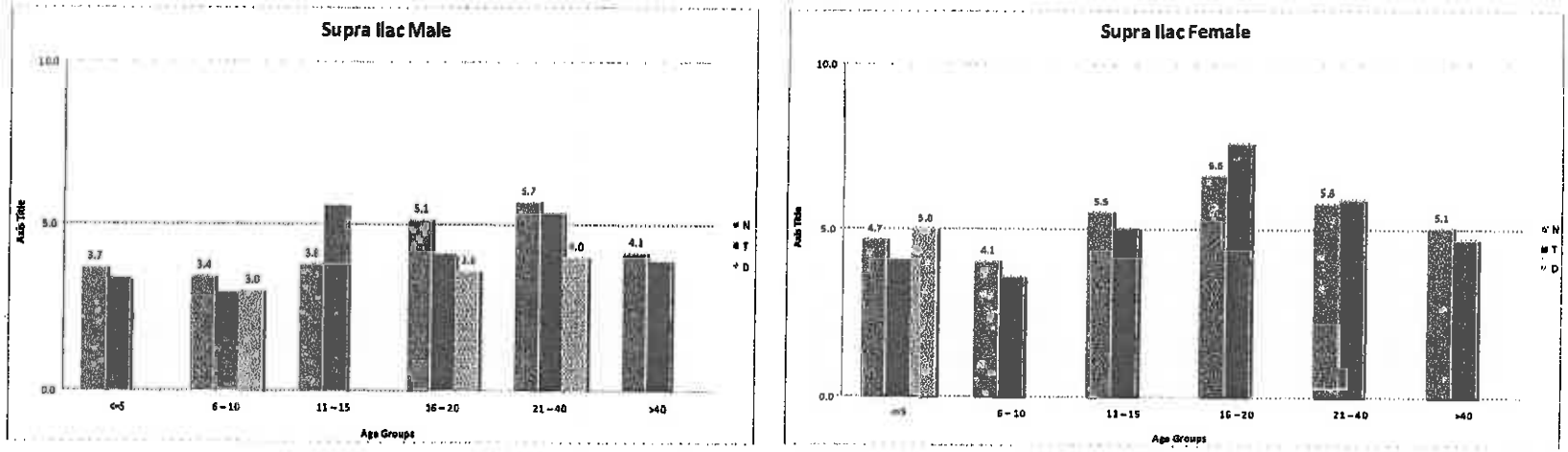
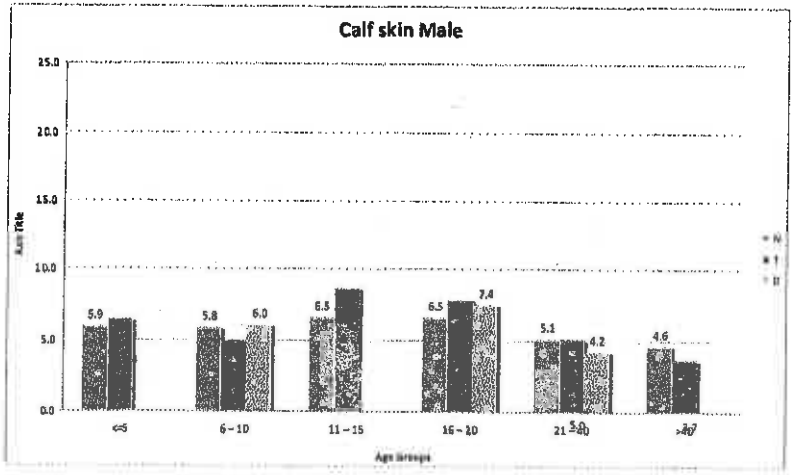


Figure-10



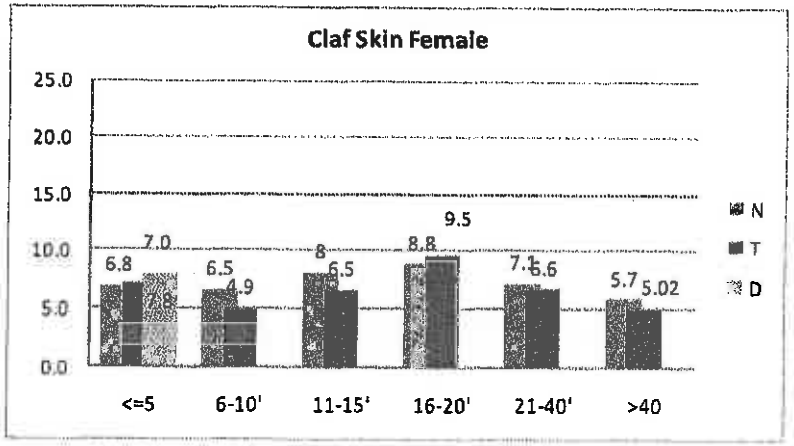
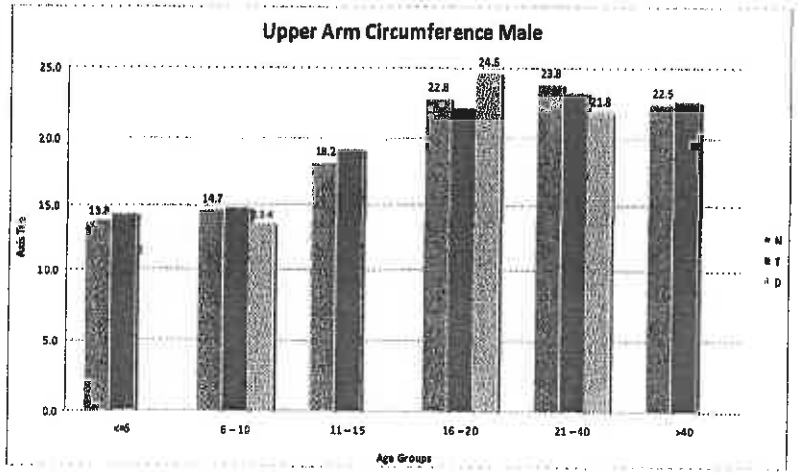
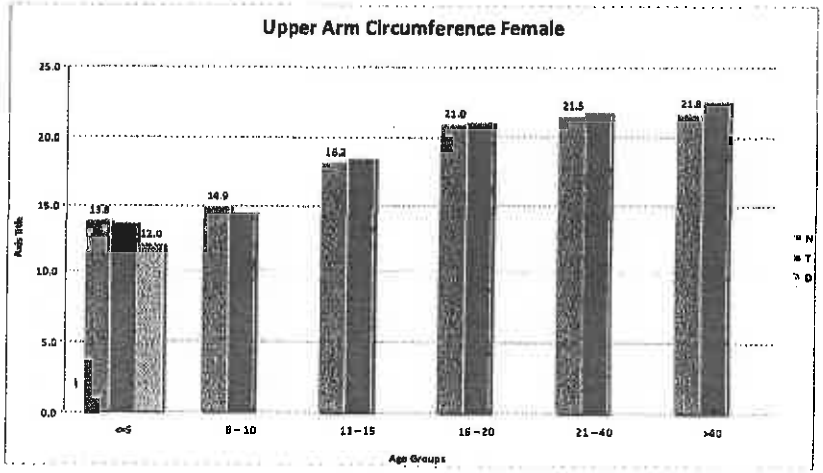


Figure-11





Girth measurements:

For the girth measurements, mid upper arm circumference and calf circumference were measured to figure out the overall muscle and fat deposition with respect to age advancement. While upper arm circumference gives a good measurement of nutritional status among the children less than five years of age, it also gives somewhat reasonable standard to monitor growth of the population.

Overall gain in female for mid upper arm circumference is 57.7 per cent while that of males is 70.74 per cent over the years. Growth velocity has been fastest between the age groups 11-20 years. Females have recorded 76.4 per cent growth while males have attained 82.5 per cent of total gain (Fig 11). Though, with the tribes of Gujarat the mean values remain low for both the gender at all age groups. Deficit appears to set in early (less than 5 years) as females in general tribes attained 64% and males register 40 per cent of total measurement at this age while in the present study the figures are 43.7% and 29.26per cent respectively i.e. 20 per cent less in girls and 11 per cent in boys.

Calf circumference show highest growth velocity during 11-15 years in both the sexes as part of adolescent spurt. Girls attain 48.8 per cent of total gain (52.7%) while boys register 46.5 per cent of the total gain (66.9%). In absolute value boys excel girls at all age groups except 6-10 years where the measurement is equal for both. Like all measurements growth velocity tapers off after 20 years and is negative after 40 years because of loss of muscle and underlying fat tissues. Figure 12 illustrates the growth pattern

The little difference observed between the haemoglobin variants were non significant statisticaly.

Bicondylar Humerus and Bicondylar femur:

Both these variables measure the diagonal width of the bone to understand the skeletal frame of the body taken at elbow and knee respectively.

Figure-12

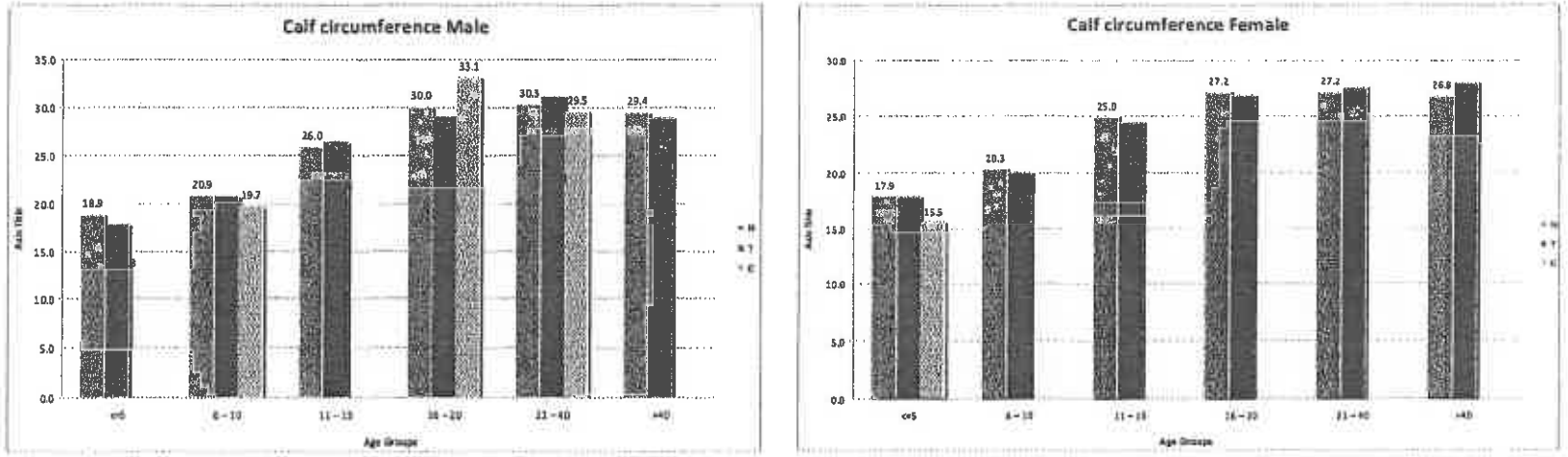


Figure-13

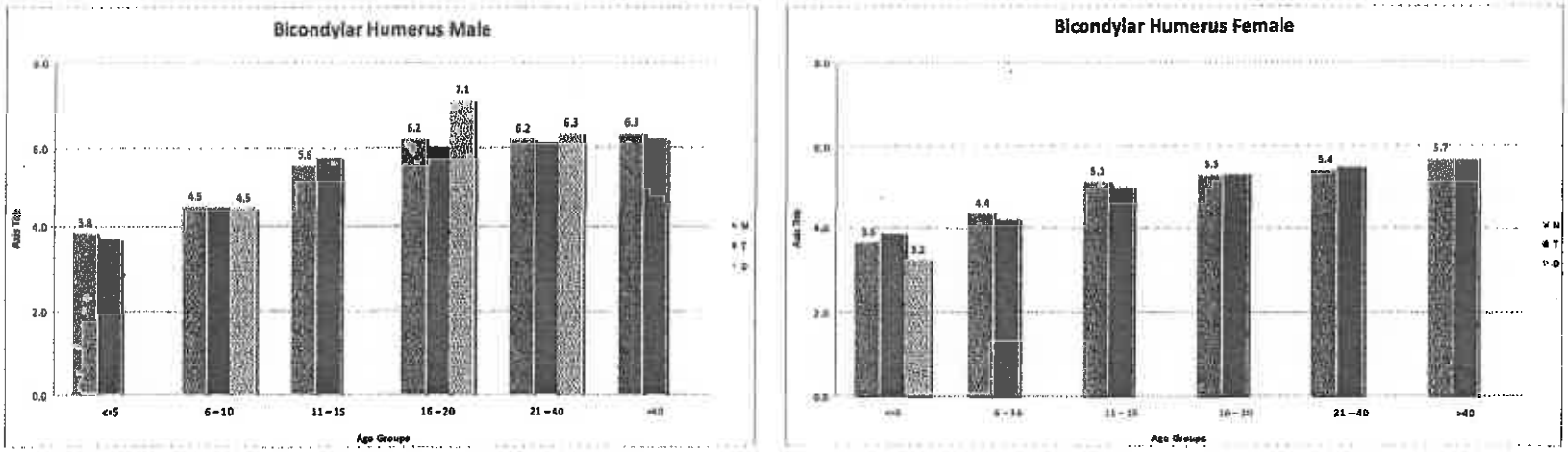
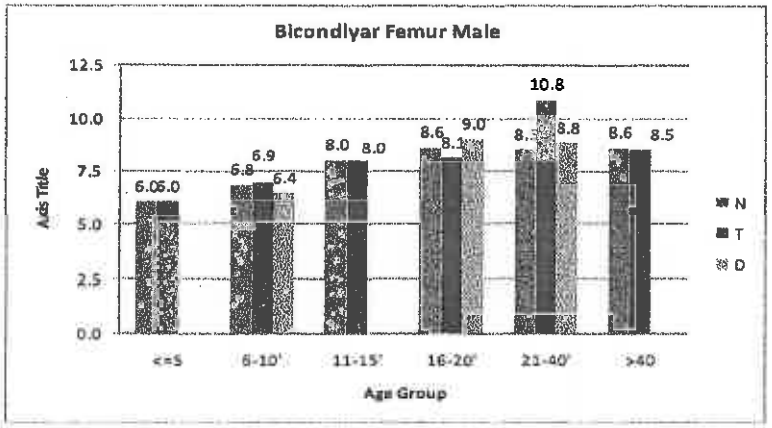


Figure-14



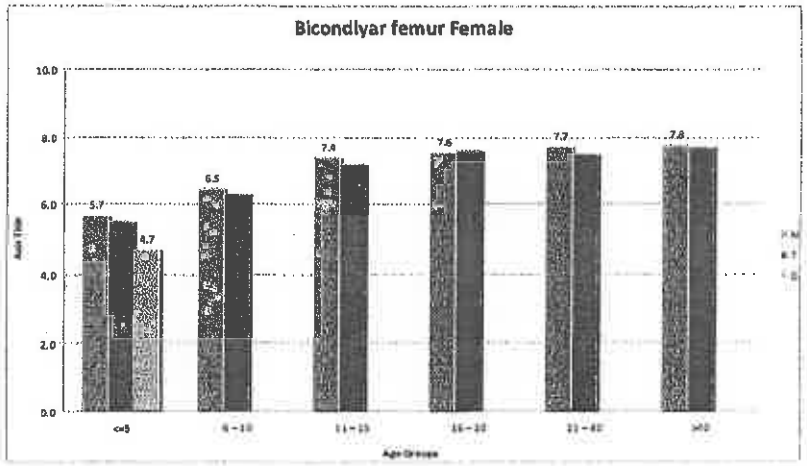
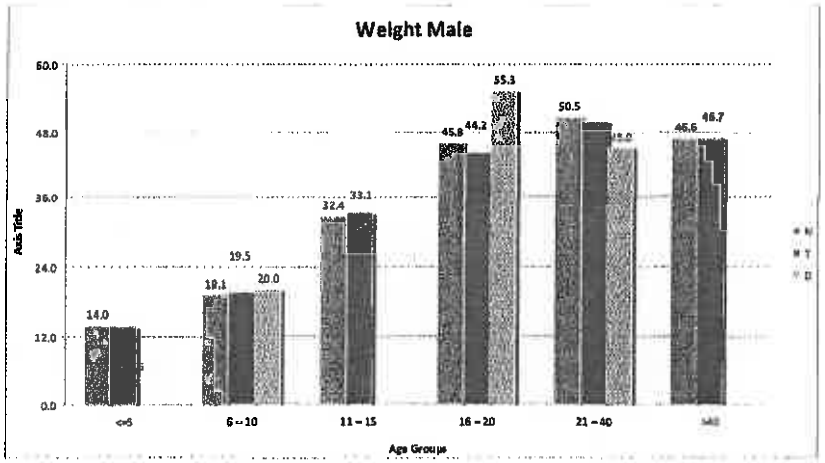
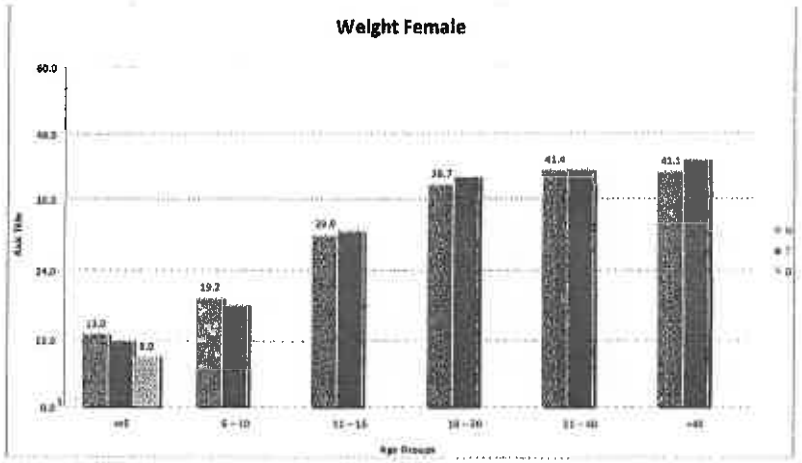


Figure-15





Total gain in Bicondylar Humerus is 1.78 cm or 48.6% in females whereas in males it is 2.35cm or 61.8%. In both the sexes' fastest growth is observed in 6-15 years with females reporting 64 per cent and males 76.17 per cent of overall gain (Fig 13).

Bicondylar Femur registers an overall increase of 2.09cm (37.2%) in females and 2.46cm (40.86%) in males. Like the previous measurement it also shows maximum gain in 6-15 years that is with the inception of pre pubertal and adolescent spurts. Sex differentials in growth become more apparent after 15 years of age in both the measurements when boys exceeds the girls by nearly one cm. and unlike all other measurements the marginal increase is noted even after 40 years of age (Fig 14).

Weight:

Weight for females at 21-40 years age is 41.42 kg whereas for males it is 50.34 kg (Fig 15). Total gain is 28.78 kg or 227.7% and 36.43 or 261.89% respectively for girls and boys. While boys are one kg heavier to girls at less than 5 years cohort, the difference took a faster pace in the cohort group of 11-15 years and beyond with a multiple of 3 (i.e.3 kg, 6kg and 9kg) in the subsequent age groups. It is observed that the variable compared well with the figure for Tribal population of Gujarat. Females show nearly same value at all age groups whereas males are heavier than the reference value at all age groups. With the ICMR data also the growth in boy's weight show the similar gradient while that of females lag behind in the age cohort of 11-15 and 15-20 years onwards. They are nearly four kg lighter to the Indian girls.

As is seen from the data, different body dimensions grow with varying pace. Such differentials are also affected by age and sex. Head dimension appeared to have attained maximum development by the age of five whereas the weight measurements were the lowest in maturity at this age. All the body parameters except skin fold variables the growth is fastest between the 6-15 years registering early or pre pubertal as well as pubertal spurt during this period. In skin fold measurements the values appear little later i.e. at the 11-20 years age cohort. Sex differentials is also observed in 6-10 years age group as females register higher gain at this stage whereas post 15-20 age cohorts

measurements for male recorded higher values than females. The phenomena seems to corroborate the findings that puberty sets early in girls and is 2 years ahead of males whereas boys mature later but their growth is more vigourous after 14 years of age .

The Warli males though record a better value for height and weight; they show poorer growth in rest other physical parameters when compared with general tribal population of the state. With Indian population they are shorter in stature but are equal in weight attainment. Warli females however reflect more improvised figures when compared with the above data. They are at par with Gujarat tribes though their development is little slow during 11-20 years showing a deficit of two points in both the parameters. Girth measurements and skin fold variables again have poorer value showing less than adequate muscle and adipose tissues rendering their propensity to vulnerability.

Hematological Characteristics and Variation in the Population:

Blood is a part of our evolutionary heritage. The components of blood show remarkable variation in their frequency at the ethnic and regional level revealing characteristics specific to population. Blood group which is determined by the presence of red cell antigens categorizes the population in four groups namely A, B, AB and O. The Rh factors further divide them into positive and negative depending upon its presence in the blood cells. All over the world frequency of ABO as well as Rh factor varies and reveal a pattern that show gradual decline in the frequency of B blood group and increase of A blood group as one proceeds westwards from the pacific coast of Asia to the Atlantic coast of Europe. The geographical gradient of ABO reveals that blood groups are subject to natural selection. In India also the frequency varies a great deal. It shows preponderance of B in the northern states of the country.

Blood group distribution of Warli in the present study is presented in the table below.

Table 8: Distribution of Blood Group along with their Rh (positive or negative) status

Blood groups	Male			Total Male	Female			Total Female	All
	Normal	Carrier	Disease		Normal	Carrier	Disease		
A+	86	13	2	101	82	16	1	99	200
A-	0	0	0	0	1	0	0	1	1
B+	53	9	0	62	82	13	0	95	158
B-	0	0	0	0	0	0	0	0	0
AB+	18	4	0	22	17	6	0	23	45
AB-	1	0	0	1	0	0	0	0	1
O+	68	12	1	81	86	13	0	99	180
O-	0	0	0	0	0	0	0	0	0
All	226	38	3	267	268	48	1	317	584

By and large the population is Rh positive. Proportion of negative type is just 0.3 per cent. There is a preponderance of blood group A (34.4%) followed by blood group O (30.8%) and B (27.5%). A small proportion (7.8%) of population belongs to AB blood group. The frequencies of blood groups show a substantial variation when compared with the tribal population of the state (Majumdar 1950). In the tribal population (miscellaneous) of the state the reported frequency for the blood group A was much lower to the present study (23%) while that of B was much higher (35%) than the present population. AB and O groups also reported higher frequency at 9 and 33 per cent respectively. The other tribal groups like Bhils of Rajpipla and Panchmahals too reported lower proportoion of A (24-27%) and higher values for O (37-38%) blood group. B blood group registered near similar value (28-26%) while frequency of blood group AB varies between 8-9 per cent (ibid).

The blood parameters also show variation with respect to sickle cell status of the people. To examine the same details of blood parameters are obtained by the Hematological test (CBC or complete blood count) taken upon the sampled population. For a comparative account nine parameters are considered to find out significant difference if any between three genotypes i.e. Normal, Trait and Disease individuals. These nine parameters include White blood count, Red blood count, Haemoglobin count, Packed Cell volume or Heamatocrit, Mean Corpuscular Volume, Mean Corpuscular Haemoglobin, Mean Corpuscular Haemoglobin Concentration, Plateletes and Lymphocytes. With regard to variation in reference range of certain variable like lymphocyte count, RBC, haemoglobin and hematocrit for adult and children, data have been analysed accordingly.

Table 9 below presents the value for sampled male, females and children with respect to their sickle cell status.

Table 9: Statistical values for Haematological variables by gender and sickle cell status

Male

SCT status	WBC (4,000 – 12,000/MM^3)	RBC (4.6 – 6.2 Mill/mm^3)	HGB (13 – 18.0 gm/dl)	PCV(HC) (40 – 54%)	MCV (80 – 96fl)	MCH (27 – 31 pg/cell)	MCHC (32 – 36 Hb/cell)	PLT (1.5 – 4 lakh/ cm^3)	LYM (20 – 40%)
D	7250 ± 636.4	5.21 ± 0.72	11.9 ± 1.55	37.85 ± 5.72	72.6 ± 0.98	22.85 ± 0.21	31.5 ± 0.70	2.72 ± 1.84	29.5 ± 4.9
N	7451.2 ± 1889	5.62 ± 0.60	13.44 ± 9.30	40.79 ± 4.12	76.92 ± 56.0	22.74 ± 2.32	31.27 ± 1.61	2.63 ± 0.77	29.82 ± 8.01
T	8266.7 ± 2174.7	5.83 ± 0.80	12.71 ± 1.98	40.44± 6.10	69.14 ± 4.90	21.737 ± 2.17	31.37 ± 1.28	2.92 ± 0.71	29.00 ± 8.36
p value	0.07	0.19	0.36	0.77	0.07	0.03*	0.72	0.05	0.62

Female

SCT status	WBC (4,000 – 12,000/MM^3)	RBC (4.6 – 6.2 Mill/mm^3)	HGB (12 – 16..0 gm/dl)	PCV(HC) (40 – 54%)	MCV (80 – 96 fl)	MCH (27 – 31 pg/cell)	MCHC (32 – 36 Hb/cell)	PLT (1.5 – 4 lakh/ cum^3)	LYM (20 – 40%)
D		-	-	-	-	-	-	-	-
N	8271.3 ± 2156	5.18 ± 0.75	11.48 ± 1.70	37.10 ± 5.10	71.35 ± 6.94	22.08 ± 2.64	30.95 ± 1.69	2.89 ± 0.91	28.57 ± 7.73
T	9035 ± 2414.5	5.42 ± 0.59	11.70 ± 1.50	37.12 ± 3.97	68.50 ± 5.14	21.57 ± 2.32	31.43 ± 1.57	3.26 ± 0.80	28.31 ± 6.63
p value	0.06	0.03*	0.44	0.96	0.00*	0.21	0.14	0.03*	0.49

Child

SCT status	WBC (4,000 – 12,000/MM^3)	RBC (4.6 – 6.2 Mill/mm^3)	HGB (11.5 – 13.5 gm/dl)	PCV(HC) (40 – 54%)	MCV (80 – 96fl)	MCH (27 – 31 pg/cell)	MCHC (32 – 36 Hb/cell)	PLT (1.5 – 4 lakh/ cum^3)	LYM (25 – 40%)
D	12600 ± 1979.9	4.31 ± 0.62	9.45 ± 0.35	29.05 ± 0.91	67.95 ± 7.70	22.1 ± 2.40	32.55 ± 0.21	5.15 ± 1.53	38.4 ± 5.51
N	9377.6 ± 2799.3	5.34 ± 0.53	11.32 ± 1.23	36.28 ± 3.65	68.06 ± 4.34	21.24 ± 1.80	31.19 ± 1.06	3.27 ± 0.89	38.63 ± 8.45
T	10050 ± 2789.2	5.54 ± 0.56	11.1 ± 1.37	35.31 ± 4.04	63.35 ± 4.87	20.11 ± 2.26	31.40 ± 1.58	3.84 ± 1.63	38.19 ± 8.73
P value	0.32	0.15	0.50	0.32	0.00*	0.04*	0.56	0.14	0.83

WBC-White blood cell, RBC-Red blood cell, HGB-Haemoglobin, PCV-Packed cell volume, MVC- Mean corpuscular volume, MCH-mean Corpuscular haemoglobin, MCHC- Mean corpuscular haemglobin concentration, PLT- Platelets, LYM- Lymphocytes.

* statistically signifacant

WBC: While blood cells are first line of defense to protect body from any infections. The normal range for WBC varies between 4,000 to 12,000 cell counts. In the present study except for the children falling in the disease group wherein the values are higher than the given range, all other population group lie within the reference range. There was no significant difference between the haemoglobin variant groups as well. The correlation value reveals differentials with gender and sickle cell status. In the normal females it shows negative correlation with all other variables but a weak positive association with platelets. For females with trait, negative association was found only with MCV, MCH and Lymphocytes whereas with all other variables it has weak bonds. Among normal males negative values are recorded for MCV and Lymphocytes whereas with trait and disease individuals it was with RBC,HGB, PCV, MCV and Lymphocytes. The association among children also varies. For normal children positive but very weak association is seen with RBC, Pletlets and Lymphocytes whereas with traits the same s found MCV, MCH, MCHC and platelets. Among the children with disease all other variables but MCV and MCH show positive correlation.

RBC: It refers to actual count of red blood cell per cubic mm of blood. Higher value indirectly refers to higher haemoglobin concentration. Except for the children with sickle cell disease, the RBC is within the reference range for all groups. Though the differences between the three haemoglobin variants are insignificant among males and children, it is otherwise in females with trait and the normal adult women. The p value is significant at 1% level.

Haemoglobin: These are oxygen carrying molecules of blood. As indicated earlier, mutation in Hb gene significantly reduced its oxygen carrying capacity and person with mutant allele generally experience sickling of cell when they are stressed by low oxygen. Low level of haemoglobin is also indicative of anaemia. As the table indicates the proportion of haemoglobin is little lower in person with trait and disease. Difference between trait and disease is significant only in children (p .003).

Packed Cell Volume (PCV) or Hematocrit: The hematocrit measures percentage by volume of packed red cell in the blood. Less than normal value of hematocrit generally means low count of RBC or smaller size of RBC, which further may signifies hemorrhage or other problems. It is observed that hematocrit is lower than the normal value in person with disease. The statistical test is significant in children with normal and disease status and between those with trait and disease. In all other group the values are not significant with respect to their sickle cell status.

Red Cell Indices: Individual characteristics of red cells are ascertained by MCV,MCH and MCHC. These are considered to understand the nature of anaemia caused by the abnormality in the value of the these indices.

Mean Corpuscular Volume (MCV): It indicates the volume and relative size of average RBC. Across the population the MCV has shown lower than the reference range. Yet the values are further lowered with trait and disease group. The difference is significant between males with trait and disease ($p < .01$), between normal and carrier women ($p<.001$) and between normal and carrier children ($p<.002$).

Mean Corpuscular Haemoglobin (MCH): MCH refers to weight of haemoglobin in the RBC. Value of this variable is substantially lower than the optimal range across all groups mentioned above. It is significant between normal and carrier men ($p < .01$), carrier and disease men ($p < .01$) and between normal and carrier children ($p < .02$).

Mean Corpuscular Haemoglobin Concentration (MCHC): The variable reflects the concentration of hemoglobin in the average RBC. It is dependent upon the size of the RBC as well as the amount of hemoglobin in each cell. Data reveal that the values are lower than the standard range and is statistically significant only among the children with normal and disease ($p < .008$) and with carrier and disease ($p < .004$) genotypes.

Platelets: Platelets or thrombocytes are the binding factors in the blood. It promotes coagulation and work as a haemostatic plug when suffered a vascular injury. All groups

show figures that go with the reference range except for the children homozygous for the mutant allele. The value is significant statistically only between the normal and carrier women ($p < .01$).

Lymphocytes: Lymphocytes are part of WBC and their unusual value causes concern for the presence of infection and other debilitating diseases. Mean value for this variable are well within the prescribed range in all groups and no significant difference was observed between the groups.

It can be seen from the table that the mean value of almost all the blood parameters has reported the lowest limit or values lower than the reference value in the population. This is especially true for red cell indices like MCV, MCH and MCHC indicating substantial prevalence of anaemia in the population. Variation is also observed between gender group and between the normal, trait and disease individuals with respect to certain parameters and more so with sickle cell individuals. Thus while Haemoglobin and Hematocrit (PCV) is lower than reference value in all samples it is poorer for person (adult male and children) with sickle cell disease. Among children with sickle cell disease, the RBC and PCV are much lower than the reference value but are higher for white blood count and platelets suggesting probability of contacting some infectious disease. However, the statistical test for different variables did yield some significant difference between the three haemoglobin variant groups. Studies have also revealed significant difference in some parameters like Hb, PCV and WBC whereas variables like MCV, MCH, MCHC and Leucocytes remains insignificant for normal and other variants (Omran 2010).

Treating Joint pain: Dam (Brand**ing**) applied on all fingers of the Patient (**Ra**waniya)

CHAPTER - V

MORBIDITY AND MANAGEMENT OF SICKLE CELL DISEASE

The focus of this chapter is on the morbidity and nutritional status of the tribe under study. Since studies have found considerable morbidity even among the carrier individuals besides the person with disease (Tsaras G. et al), the chapter tries to reflect on the same by comparing the reporting of morbidity by haemoglobin variants. Morbidity among the population is discussed as per the specific problems related to sickle cell anemia and also the general morbidity experienced by the people during last 30 days. It will also focus on the management of sickle cell disorder in the population under study.

Sickle cell specific morbidity

Specific problems related to sickle cell anemia were asked to the people to ascertain the occurrence of these problems in general and their frequency as per the population's sickle cell status. Table 10 presents the figures

Table 10 :

Reporting of Sickle Cell Specific Problems by Gender and Sickle cell status

Problem	Gender	Sickle Cell Status			Total (% of total pop. of Female and Male)
		Normal	Carrier	Disease	
Excessive weakness	Female	12 (4.5)	3 (6.2)	-	15 (4.7)
	Male	8 (3.5)	2 (5.2)	2 (66.6)	12 (4.5)
Acute Pain in bone	Female	7 (2.6)	1 (2.1)	-	8 (2.5)
	Male	18 (7.9)	1 (2.6)	1 (33.3)	20 (7.5)
Malaria	Female	7 (2.6)	1 (2.1)	-	8 (2.5)
	Male	6 (2.6)	1 (2.6)	-	7 (2.6)
Jaundice	Female	15 (5.6)	5 (10.4)	1 (100.0)	21 (6.6)
	Male	16 (7.1)	2 (5.2)	1 (33.3)	19 (7.1)
Dactylitis	Female	11 (4.1)	1 (2.1)	-	12 (3.7)
	Male	8 (3.5)	2 (5.2)	1 (33.3)	11 (4.1)

Problem	Gender	Sickle Cell Status			Total (% of total pop. of Female and Male)
		Normal	Carrier	Disease	
Frequent severe pain in abdomen	Female	9 (3.3)	1 (2.1)	-	10 (3.1)
	Male	41 (18.1)	5 (13.1)	-	46 (17.2)
Fever with Chest pain	Female	21 (7.8)	2 (4.1)	1 (100.0)	24 (7.5)
	Male	63 (27.8)	4 (10.5)	-	67 (25.1)
Respiratory problem	Female	3 (1.1)	1 (2.1)	-	4 (1.2)
	Male	2 (0.9)	-	-	2 (0.7)
Blood Transfusion	Female	1 (0.3)	-	-	1 (0.3)
	Male	2 (0.9)	-	-	2 (0.7)
Swelling in foot	Female	-	-	-	-
	Male	3 (1.3)	1 (2.6)	-	4 (1.5)
Sudden pain in joints	Female	16 (5.9)	5 (10.4)	-	21 (6.6)
	Male	41 (18.1)	7 (18.4)	1 (33.3)	49 (18.3)
Stroke	Female	-	-	-	-
	Male	-	-	1 (33.3)	1 (0.4)

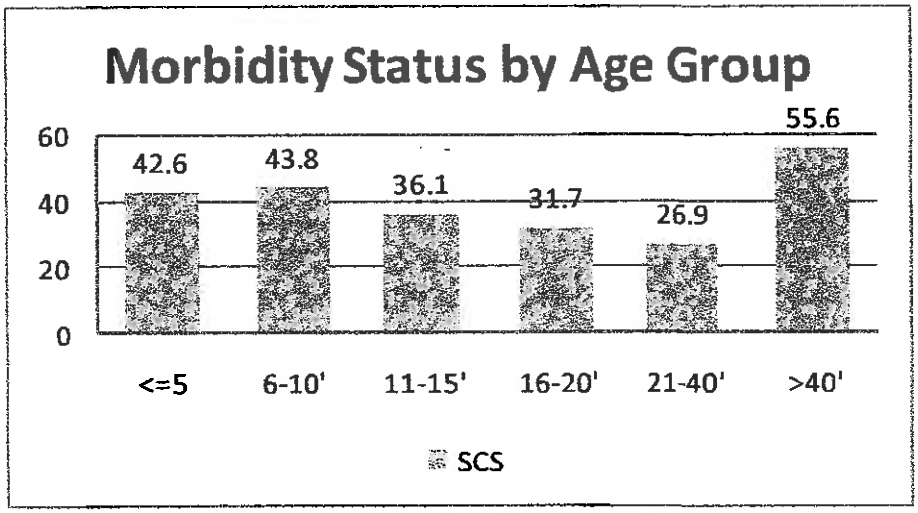
(Figures in parentheses are percentage to respective population of the category)

Altogether 39.2 per cent people reported the problems. Proportion wise 75 per cent among disease individuals, 32 per cent among carriers and 40 per cent of normal individuals reported one or more problems mentioned above. In sickle cell disease individuals, two i.e. (50%) of the people were reported to have suffered from two problems while one i.e., (25%) had reportedly been affected by 5 of the above listed problems. One individual did not report any problem. Among normal and carrier individuals proportion for one and more problems were 25.1%, 15.0% and 19.0% and 12% respectively. Statistical test reveal that the reporting of problem is significant with respect to sickle cell status among women (p=.01) while no association was found in the men.

Highest proportion or 15 per cent of the population reported fever with chest pain followed by 11 per cent who had sudden pain in joints while frequent severe pain in abdomen was reported by 9.5 per cent and Jaundice had affected 6.8 per cent of the population. Excessive weakness and pain in bones were found in nearly 5 per cent of the people. Thus fever with chest pain comprised of a quarter of the total reported problems while that of sudden pain in joints is one fifth of all problems.

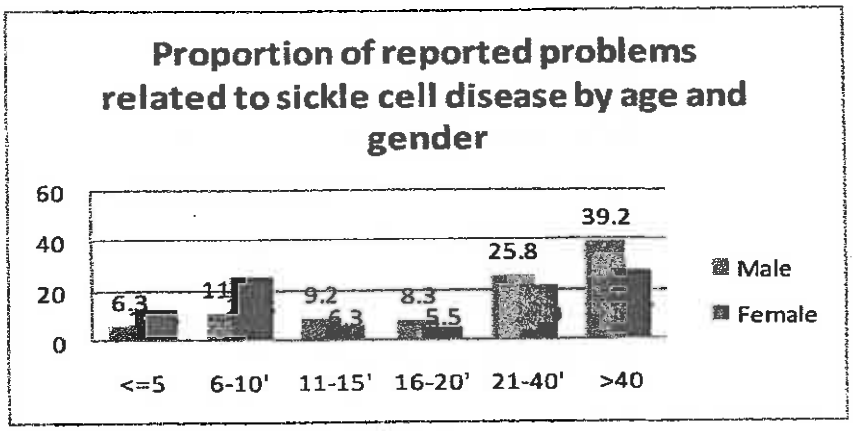
Age group wise highest proportion (55.6%) was reported from the oldest age group while lowest proportion (26.9) from the 21-40 years age group. At the age of 10 or less the proportion was little higher (nearly 43%) which gradually declined with the advancement in age up to 21-40 years and again show a steep rise after 40 years of age. The figure below presents the age group wise distribution of morbidity.

Figure No. 16



Gender wise, girls are twice more likely to fall sick from the above problem than the boys below the age of ten. The trend reversed in the following years and more males than females reported the problems. Children below ten years reported highest proportion of fever with chest pain (10.7%) followed by Jaundice (4.4%). About 3.5 per cent of girls in this age group complained of joint pains compared to boys (0.4%) of the same age group. Figure 17 below present the proportion of problems reported by males and females belonging to different age groups.

Figure No. 17



The above figure shows that men in 40 plus age group figured high as compared to women and the difference was as high as 12 percentage points. Problem wise disaggregated data show that they are more vulnerable to acute pain in abdomen (8.3%), sudden and excruciating pain in joints (10.0%) and fever with chest pain (8.8%). Women on the other hand are twice more likely to report problems like excessive weakness (11.7%), malaria (6.3%), Jaundice (16.4%) and swellings in hand and feet (9.4%).

Utilisation of Health Service:

For the above mentioned problems it was found that though a majority (33.2%) sought help from the private service providers little less than one fifth (18.4%) also approached the public health service. Health service requirements were also sought from indigenous medicine man, trust and a combination of various health services. As is clear from the data indigenous medicine man (Bhua/Bhagat) appears to have a significant place among the providers of health services. One in eight individuals had accessed his services. He is most sought for the treatment of jaundice. Sixty per cent approached him while 21 per cent sought his services along with the public and private service providers. Similarly, in case of malaria the public health services generated more trust as nearly 50 per cent (8 individuals) visited the same for treatment. Probably the outreach support system in PHC are working well. Along with the help provided by these practitioners people keep on trying a combination of various services provisions for the cure of their ailments. Most

preferred among them is to visit public as well as private medical services among other combinations. However, 6.3 per cent did not go for any health services. Table 11 presents the relevant figures

Table No. 11

Gender	Utilisation of Health Services						
	Services not accessed	Public Health services	Private health services	Indigenous health services	Public and private services	Other combined services	Total
Female	10 (8.06)	27 (21.7)	35 (28.2)	19 (15.3)	13 (10.5)	20 (16.1)	124 (100)
Male	13 (5.4)	40 (16.6)	86 (35.8)	26 (10.8)	62 (25.8)	13 (5.4)	240 (100)
Total	23 (6.3)	67 (18.4)	121 (33.2)	45 (12.3)	75 (20.6)	33 (9.06)	364 (100)

Generally women are more likely (8%) to avoid taking health services for their ailments. Unlike men, a large number of them (21.7%) go for public facility while a sizeable section (15%) seeks services from indigenous medicine man (Bhuva/Bhagat) along with various other health practitioners. Though private health practitioners are consulted by both sexes, the utilization is markedly more by men (36%) than women (28%). Men are two and half times more likely to access formal health facilities that include public along with private services. Women on the other hand seem to prefer alternatives cures for their ailments. Apparently they prefer the utilization of informal services which are easily accessible and cost effective.

Morbidity in last 30 days

In the last 30 days (since the date of interview) morbidity, nearly 34 per cent people experienced one or more problems. Among the reporting individuals 8.5 per cent mentioned two or more ailments and it was observed that a little over sixty per cent (62.8%) women and nearly 30 per cent (29.9%) among men reported morbidity. Thus women are twice more likely to suffer from sickness compared to men.

Age group wise oldest (>40 years) and youngest (<=5 Years) age group reported highest morbidity. It was 39.7% and 38.2% respectively. Except for the age group 6-10 years and 16-20 years, burden of illness at all other age groups are more than 30 per cent. With regard to sickle cell status greater proportion of normal individuals (34.4%) reported problem compared to the carrier individuals (29%). However, half of the persons with disease (SS) also reported problems in the last 30 days.

Altogether 29 ailments were reported. Illnessesses with low occurance were clubbed together under 'Other' category. Frequency of various ailments reported by the people is presented in table 12. The most prevalent among them are fever, sore throat and cough, abdominal and joint pains. Of these two third cases were of fever, while one in ten had complaints of cough and sore throat.

Table No.12 Reported morbidity for last 30 days by gender

Illness	Men	Women	Total (%)
Joint pain	9	2	11 (7.0)
Sore throat and cough	4	15	19 (10.05)
Pain in extremities	3	4	7 (6.7)
Jaundice	4	0	4 (2.0)
Weakness	4	3	7 (6.7)
Abdomen ache	7	9	16 (8.5)
Fever	15	63	78 (66.3)
Diarrhea	3	6	9 (5.5)
Other	31	18	49 (24.6)
All	80 (40.2)	119 (59.7)	199(100)

Regarding the nature of the ailments it was found that 16 (8.04%) persons among the reported individuals or 2.7 per cent among the total population were suffering with chronic ailments like joint pain, respiratory problem, skin problem (scabies and chronic itching) and hearing impairment. Prevalence was two times higher in men than women.

Utilization of services reflect a little higher use of private services as 38.7 percent visited private practitioners against 30 per cent for the public services. Unlike the use of services in the one year duration illness where private services were accessed two times to the public services, illness during last 30 days registered utilization nearly at par with the public service. Home remedy was registered at 6.0 per cent as compared to the treatment by traditional healer. Though nearly 14 per cent did not seek any treatment yet the proportion of men was two and half times higher than women. Table 13 contains detail

Table No. 13. Gender wise use of various health services

Gender	Use of health services								
	Not used	Public services	Private services	Trust	Traditional	Home remedy	Public+ private	Other combined	Total
Men	20	10	37	0	3	3	5	2	80
Women	8	49	40	6	4	9	2	1	119
All	28 (14.0)	59 (29.6)	77 (38.7)	6 (3.0)	7 (3.5)	12 (6.0)	7 (3.5)	3 (1.5)	199 (100)

A visit to more than one practitioner for an ailment was also much lower compared to previous reporting. It was 3 per cent for public and private combined and merely 5 per cent for overall various combinations of health providers.

Gender differential is also apparent for the use of health services which reflects more reliance on cost effective treatment by women. Thus in case of public service, two fifth (41.1%) of women opted for public services while just 12 per cent of men accessed the above service. The reverse is true for the private services as almost half or 46.2 per cent men visited the private service in comparison to one third of women who had reported the problem. The traditional healer was more often consulted by women who also adopted home remedies for treatment.

Management of Sickle Cell Anaemia:

The State's Initiatives:

In view of substantial prevalence of sickle cell carriers and disease, the state government undertook the Sickle cell anemia control programme in 2006. However it picked up momentum in 2008. The project was started with four tribal districts of south Gujarat which is now extended to all 12 tribal dominated districts with the goals set under this programme as (www.gujhealth.gov.in/sickle-cell-anemia-control -programme.pdf)

- No Child birth with Sickle Disease by 2020
- Prevention of death from Sickle Cell Crisis
- To improve health status and quality of life of Sickle Cell Anemia patients.

In pursuance of above goal, the state government has adopted following strategies

- New Born Screening
- Screening of Eligible Tribal Couple
- Children, Adolescent and Geriatric Screening
- Prenatal diagnosis
- Necessary Laboratory investigations
- Counseling, Treatment and Follow up.

The Sickle Cell Anaemia Control Programme is funded through a grant from Department of Health and Family Welfare and Department of Tribal Welfare of Government of Gujarat and also receives resources under the National Rural Health Mission (One world foundation India 2011).

Under the mass screening programme up to march 2012, from a total of 89,12,623 tribal population, 17,70930 or 19.8 per cent of tribal population has been screened. Among them 2,05,365 or 11.6 per cent are carriers and 12,086 or 0.6 per cent are diagnosed with disease (www.pipnrhm.nic.in/index_files). Sickle cell cards are provided to the screened individuals for their proper treatment.

Provisions have been made for comprehensive care of sickle cell anemia patients. Till date 414 centers, including medical colleges, General hospitals, CHC, PHC and NGO have been involved for the purpose. As per our interview with senior officials training of doctors, field health workers and other personnel are being done on regular basis. To create awareness among the mass, IEC activities have been taken up on large scale by using pamphlets, banners, radio talks and booklets mentioning symptoms and the management of disease. Door step care delivery being the motto of government, folic acid tablets and pain killers are regularly distributed. Counseling with regard to health care, marriage and child birth are made available to the suffering people.

With respect to implementation of the programme, a number of personnel are appointed on contractual basis. As of now the status of personnel is as below

	Counselors		**Lab Technicians**		**Data entry operator**	
	Sanctioned	**Filled**	**Sanctioned**	**Filled**	**Sanctioned**	**Filled**
Valsad	13	10	6	3	1	0
Navsari	8	7	4	4	1	1
Dang	4	0	7	0	1	1
All (12 Dist)	**66**	**46 (70%)**	**32**	**13 (40%)**	**12**	**9 (75%)**

Source: produced from www.pipnrhm.nic.in/index_files

The counselor collects blood samples and subjects it to DTT test. The positive sample is then delivered at Valsad Rakt Dan Kendra (VRK), a nodal agency (NGO) entrusted with carrying out HPLC test to identify the carrier and sickle cell disease individuals. Other organization involved is Red Cross Society. The report is then sent to respective PHC. Sickle cell card is accordingly prepared and affected person are informed and counseled. Counseling includes care about disease related problems, distribution of folic acid and counseling about marriage. It therefore appears that government has taken the problem very seriously and all efforts are being made to check the growth of sickle disease and provide health services to the affected people. However, a close look at the village level reveals short comings at the implementation level.

Realities at village level:

Awareness:

Though sickle cell anaemia is widely prevalent in the tribal areas of the state and IEC activities have been continuously taken up, awareness about the disease in the studied population is very poor. Just six individuals had heard about the problem of which 3 persons were suffering with sickle cell disease and the rest three had heard it from their relatives who had come across person suffering from the disease. Except for the immediate kin of the patients, other villagers were ignorant about the problem. Despite the mass screening programme, people could not recall about blood camp organized for the purpose.

Manifestation of Disease

The disease has varied manifestation which also differs with age of onset of the problem. The detailed case study of four patients has shown that the problem had struck them at different ages and there was a difference in the severity of disease. In all the individuals though the specific age could not be ascertained it was generally reported during their school days in between the age of 5-15 years. The symptom is not reported in one girl aged 3 years while in one individual the symptom appeared after his marriage. All individuals with sickle cell disease reported weakness, excruciating pain and immobility during the crises. As told by one of our participant sometimes they experience crisis 3-4 times in a season. Loss of school/working days is frequently mentioned. Though there is no specific time and season for the occurrence of these problem, yet the sudden occurrence of pain in joints and sometimes in chest renders them immovable. There is a marked frequency of crisis during the winter season. As we have mentioned earlier, all these individuals were low on physiological growth and had poor hematological values compared to their counterparts.

Treatment:

The first line of treatment begins with a visit to bhagat as the occurrence of the problem is sudden and severe and the cause could not be identified. Hence it is generally attributed to the evil design of spirits. The Bhagat after studying the rice grain touched by the

patient, identify the spirit and ascertain the course of action. This is the normal procedure for any kind of problem. However, when there is no improvement in sight the next step is to approach the medical prctioner; but visit to bhagat is continued and attempts are made to propitiate the spirits. Many a times the treatment is constrained by inadequate medical support available at the village. Despite claim of health facility in the public sector, treatment is mostly favoured at private clinics as government hospital reportedly pay attention only when the visit is assisted by counselor or the person will have some contacts there. In Dharampur we came across a sickle cell patient who had visited the Civil hospital as MO at the PHC was not available. Since many of the villages are located far away from the PHC, people prefer to visit nearby doctors and thus incur substantial expenditure, to the tune of Rs. 500-600/-. For blood transfusion patients are generally directed to Valsad Rakt Dan Kendra if they are admitted in public hospitals as the transfusion there is free of cost now. One of the respondents mentioned that the tablets (folic acid) are given to them at the PHCs but many a times it is difficult to reach PHC when one is suffering from pain. At times the pain does occur even if one continues taking the medicine. During that period they are directed to go to the district hospital. A hospital stay not only drains their financial resources but it also keeps them in perpetual anxiety as no one can say how long they will have to stay there. The economical and physical hardships leave them so drained off that one of the parent in our study said,

I am monetarily and physically so exhausted that I fear getting my other children tested for the sickle cell despite being advised by the doctor. I cannot sustain this burden and hope God will help me and will take care of well being of my family.

Performance of Health functionaries at the village

Interviews with doctors, lab technicians and counselors reveal certain discrepancies in the implementation of programme. Though it is said that doctors have been trained for sickle cell management, many doctors confided that they were not much aware about the specific course of treatment. The momentum regarding the disease was seen some two years ago but now there is not much emphasis on the problem. It also seems to be supported by the fact that the electrophoresis machine given for testing the sickle cell

status could not be repaired since it got damaged two years ago. However, a general impression is that the programme is basically the responsibility of counselors who are employed to pay attention to the requirement of patients and doctors will step in only when crisis will occur.

Counselors as of now are appointed on the contractual basis and are not much satisfied with the wok profile and workload. As we can see from the table that even the appointment of counselors is yet to reach the desired number which obviously compounded the responsibility of the existing personnel. Each counselor is expected to cover 3-4 PHCs and each PHC normaly covers 20-30 villages. One can easily guess the enormous work load and the counselors admitted that it is impossible to visit the affected person even once in a month. Not surprising that many patients are not aware of regular intake of folic acid tablets. Apart from counseling and care, they have to organizing blood camp under mass screening programme and deliver the samples at Valsad for HPLC test. After getting the report, the card has to be prepared and distributed. So far they are not given TA (travellling allowance) for visiting the patients, though a hike in their salary is recently announced. Given the job profile, many among them are looking for better job options.

An interview with one of the recently appointed counselor at Dhrampur, reveals that as per the training he was given just a kit with all the literature on the sickle cell. There was no formal interaction or sessions with the training personnel and he was asked to carry on the job responsibilities. He said that he does not give his phone number to the patient as they are not supposed to contact him directly. ASHA workers are given the number who can contact them if required. However such was not the case with other counselor from Navsari. We had a mixed response in this regard as some patients carried the contact number while others were not aware of phone numbers. Dang does not have any counselor and patient mostly rely on the some trust or other private health facility. Neither the ASHA worker was aware or trained in this regard nor was the visit of field health worker found regular and responsive. Yet in Navsari and Valsad district where counselors have been appointed to follow up the sickle cell disease persons, intervention

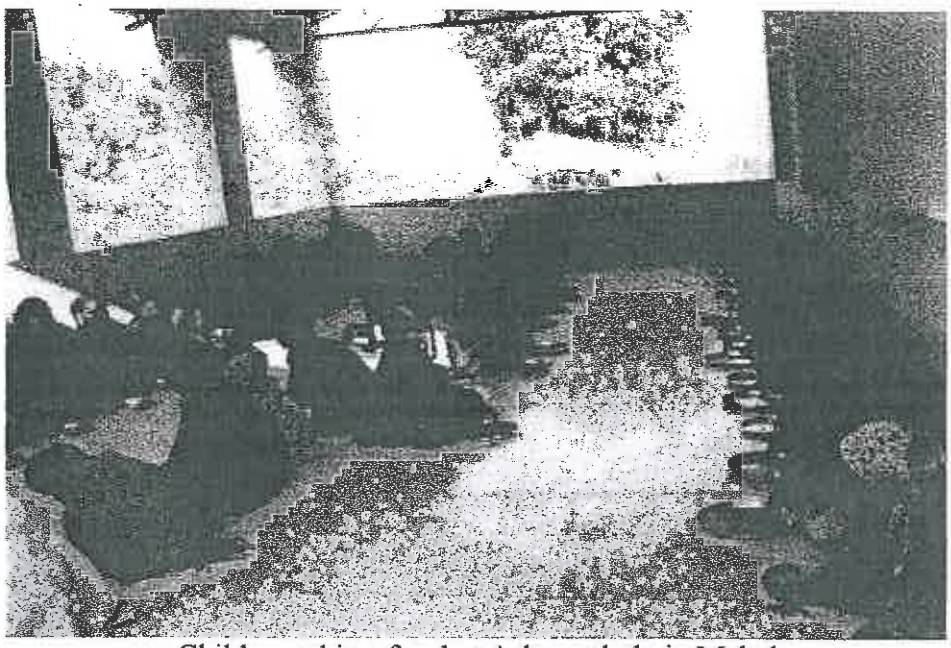
like counseling and distribution of Folic acid tablets are being carried out. Thus in the villages Rawania, Ghodmal, Hanumatmal and Bopi attention have been drawn towards the problem but as we have mentioned, it is yet to reach the people in general and affected individual in particular.

Marriage counseling is another area of concern. Though the counselors responded correctly about who are not supposed to marry as per their sickle cell status (with respect to sickle cell card), the mode of conveying risk perception appears to be difficult for the population to understand. Generally pictorial methods are used and risk is conveyed in terms of percentage but probably it is not well understood by people. Thus the queries like why one child is affected and other is not; or, even if both parents are carrier or half yellow card holder (high risk couple and advised against marriage), how come they get normal child, are not uncommon. There have been cases where the advice for screening the SC status of baby before birth and subsequently termination if couple would desire, was not accepted. Based on above instance another couple with same status too does not want to go in for tests and expect that their child could also be a normal one (interview with the counselor). There is also an apprehension that if the sickle cell status of the boy or girl will be divulged, marriage would be difficult for such children. Further facility of prenatal screening being available at Mumbai, some couple does not opt for the same despite the financial support offered by the Government. Thus according to one counselor out of 40 such cases only 10 opted for prenatal testing. They are ready to accept what ever will be the outcome of pregnancy. Cases of conception after a long wait (5 years or more) in some carrier couples also make them reluctant to go for testing.

Under the mass screening programme, blood camps are organized in villages and it was conveyed that normally 80-100 people visit these camps, however in none of the village we are informed about such camps by the people. Besides, blood of ANC mother and school children are also sent for testing in order to create a data base for proper monitoring of the problem. As district data shows, substantial number of ANC and Children have been screened at Valsad and Navsari but no effort has been made to screen the family members of the positive persons. Cases were abounding where despite one or

two members of the family having tested with disease, no effort was made to test other members for better care of the family. In some cases though one child has already died of sickle cell, yet other children have not been tested for the disorder. Data on household members screened goes blank (Form No 3). In case of ANC mothers, who are tested positive, blood sample of their husbands were not tested. As per data of Valsad, as against the 702 DTT positive mothers just 143 samples collected from husbands were tested for the same. Children in most of the primary schools located in the sample villages have been screened for the sickle cell disease by the PHC doctors but reports at some of the schools are awaited for more than one month.

Thus though the efforts are underway to identify the individuals with sickle cell trait and disease, a more comprehensive strategy is required to meet the challenge.



Children taking food at Ashramshala in Mahal

A malnourished child at village Girmad

CHAPTER - VI

NUTRITIONAL ASSESSMENT OF THE POPULATION

Nutrition is one of the most important factors that provide important nutrient to the body for its proper functioning. Less than adequate food leads to undernourishment while that of excess intake causes obesity, another form of malnutrition. Poor nutrition not only impairs growth in children but is also detrimental to the health of the population. Nutritional aspect of the population is dealt by looking at the Body Mass Index (BMI) derived through anthropometrical height and weight measurements and by the haemoglobin level to ascertain the status of anaemia.

Body mass Index:

Body mass index is calculated as weight in Kilograms divided by height in square meters or Body Mass Index = Weight/Height2

Various grades of malnutritions on the basis of BMI are as under

BMI value	Interpretation of nutritional status
< 16.0	CED* Grade-III (Severe)
16.0 – 17.0	CED Grade – II (Moderate)
17.0 – 18.5	CED Grade – I (Mild)
18.5 – 20.0	Low weight Normal
20.0 – 25.0	Normal
25.0 – 30.0	Obese Grade – I
> 30.0	Obese Grade – II

*CED - Chronic Energy Deficiency

Distribution of Population under various grades of malnutrition based on their BMI is as follows:

Table No.14 Nutritional status by age group for men and women

Gender	Age-group	Nutritional status based on Body Mass Index					Total
		Severe <=16	Moderate 16.1-16.99	Mild 17.0-18.49	Normal 18.5-25.0	Overweight >25	
Men	<=5	19	2	0	0	0	21
	6-10	36	3	0	0	1	40
	11-15	15	6	6	1	0	28
	16-20	2	3	5	9	0	19
	21-40	1	3	24	37	3	68
	>40	8	11	23	42	1	85
	All	81(31.0)	28(10.7)	58(22.2)	89(34.1)	5(1.9)	261(100.0)
Women	<=5	19	1	1	0	0	21
	6-10	47	2	0	0	0	49
	11-15	18	4	9	2	0	33
	16-20	6	3	5	9	1	24
	21-40	12	17	36	60	3	128
	>40	7	6	20	27	0	60
	All	109(34.6)	33(10.4)	71(22.5)	98(31.1)	4(1.2)	315(100.0)

Prevalence of under nutrition is wide spread in the community. It can be seen from the table that one third of total population is severely undernourished. Just one third of the people qualify for normal nourished category. It is also corroborated by the girth and skin fold measurements discussed earlier. Though, gender wise differential is not much yet under-nutrition is little higher in women.

Age group wise differences are glaring. All children under the age of 10 years suffer from chronic energy deficiency. An alarming proportion or 92.3 per cent belongs to CED grade III or are severely undernourished. The Upper arm circumference measurement too show less than adequate value for children belonging to <= 5 years age group. 35 per cent children in this age group show arm girth less than 14 cm. which reveal poor nutritional

status. However, improvement in the nutritional status appears with the age advancement. Proportion of severely undernourished population came down to half (54%) in the next age group (11-15 years). It further declines to 18.6 per cent (men 10%, women 25%) and 16.6 per cent (men 5.8%, women 22.6%) in the successive age groups for grade III and grade II CED. In the 40 plus age group, the proportion of severe and moderate category again rises to 21 per cent. Notwithstanding the substantial relative decline in overall proportion of grade II and III for age group16-20 and 21-40, it is still unacceptably high (25% and 22% respectively) for women.

BMI index for haemoglobin variants show a little higher proportion of under nutrition in normal than carrier individuals. It is also high for sickle cell disease individuals. Figure 18 and 19 present the gender wise BMI status for normal, carrier and disease person.

Figure No. 18

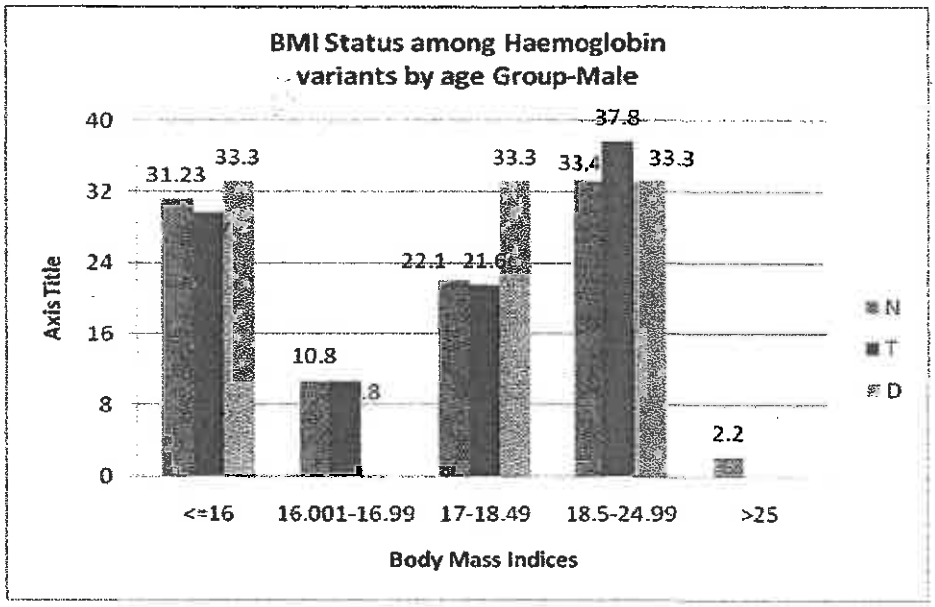
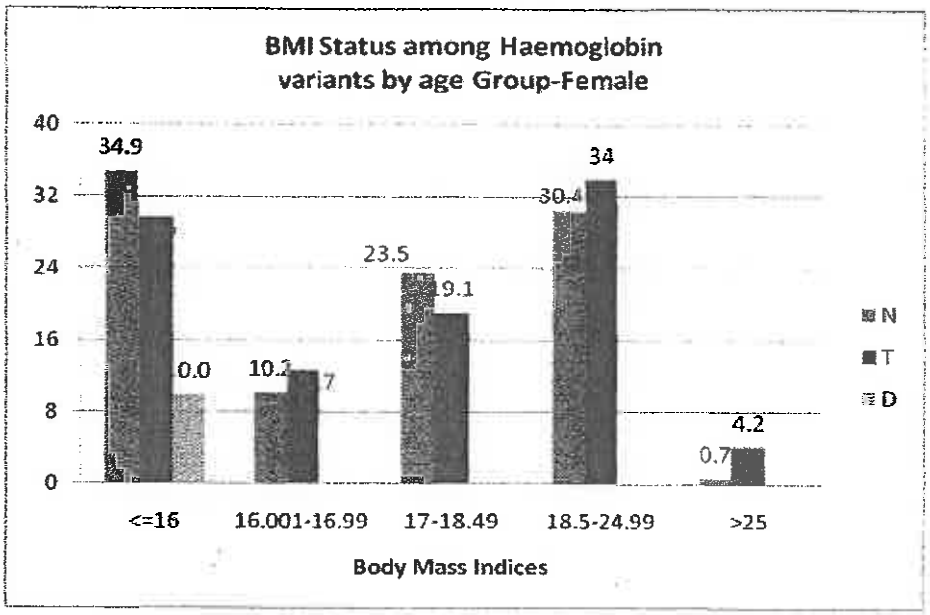


Figure No. 19



No statistical significance was observed between the normal, carrier and disease individuals with respect to their BMI status (Chi square test 0.973 for males and 0.914 for females). However, among the normal individuals BMI value with regard to age was significant (p = .000).

Status of Anaemia:

Low haemoglobin or Iron deficiency is one of the important indicators of poor nutritional status. Anemia as the condition call, leads to impairment of immune response, functional impairment of organs and propensity to contracting various infections. Disorders like frequent illness, weakness, and fatigue as also greater risk of severe cardiac arrest are some of the fall outs of the problem. In children it leads to growth deficit, motor and cognition impairment. According to WHO haemoglobin level less than 12gm/dl in female and 13gm/dl in male are considered as 'anemia'.

Among the Warlis, the prevalence of anaemia seems to be wide spread. More than 50 per cent of the population suffer from some kind of anaemia. It was more prevalent among women though more men than women suffer from severe anaemia. Little less than half of the children belong to anaemic category as they are below the standard value of

haemoglobin (more than 11gm/dl). Half of all men and 3/5 th of all women are anaemic with the haemoglobin level lower than 13 and 12 gm/dl respectively. To understand the magnitude of anaemia, Table 15 presents distribution of population as per their haemoglobin status.

Table No.15 Status of Anemia in Different Population Group

Grades of anaemia*	Children (1-10 years) n= 137	Women (>=11 years) n=245	Men (>=11 years) N=202
Severe	0	4 (1.6)	7 (3.4)
Moderate	14 (10.2)	20 (8.2)	32 (15.8)
Mild	50 (36.5)	128 (52.2)	64 (31.6)
Any anaemia	64 (46.7)	152 (62.0)	103 (50.9)

Figures in the parenthesis are percentage to their respective column
* **Severe**- <7 gm for women and children, <9 gm for men; **Moderate** - 7.0-9.9 for children and women, 9.0-11.9 for men; **Mild** - 10.0-10.9 for children, 10.0 – 11.9 for women and 12-12.9 for men; **Any anaemia**- <11 for children, <12 for women and <13 for men (NFHS-3).

Since anaemia is likely to be more prevalent in person with sickle cell, it was imperative to examine the status of anaemia in individuals with variant haemoglobin. Table 16 show the figures

Table No. 16 prevalence of Anemia by sickle cell status

Children (1-10 years)	Severe	Moderate	Mild	Any Anaemia (sev+mod+mild)	No anaemia	Total
Normal	0	11	44	55 (47.8)	60	115
Carrier	0	1	6	7 (35.0)	13	20
Sickle Cell	0	2	0	2 (100.0)	0	2
Women (aged-11 onward)						
Normal	3	19	105	127 (61.9)	78	205
Carrier	1	1	23	25 (62.5)	15	40
Sickle Cell	0	0	0	0	0	0

Men (aged-11 onward)						
Normal	6	27	59	92 (53.1)	81	173
Carrier	1	4	5	10 (37.0)	17	27
Sickle Cell	0	1	0	1 (50.0)	1	2

It is seen from the table that prevalence of anaemia is more in the normal individual than in the carriers with the exception of women. Among disease individuals 75 per cent had recorded anaemia of moderate category. However, the difference in anaemia among the variants were not significant (p value for children, females and males are 0.164, 0.95 and 0.284 respectively).

CHAPTER -VII
SUMMARY AND CONCLUSION

Sickle cell anaemia is a widely prevalent haemoglobinopathy world over and has substantial presence in the Indian subcontinent also. Studies have reported high prevalence of this disorder among tribal population of the country. Gujarat with its 15 per cent tribal population contains sizeable proportion of people suffering with this disorder.

The investigation carried out in this regard indeed points to significant prevalence of this problem in the Warli community. It was found that prevalence of carrier is 14.7 per cent in the population and 6 -7 diseased person for every 1000 individuals. As the problems likely to be associated with this disorder not only physically sap out the vitals but it also put considerable mental stress on the family and drain out resources.

The study found out that though the morbidity in general is high in the population, it is more so with the person suffering from sickle cell disease. These people show more than two symptoms of disease, most prominent being severe pain in joints and other parts of the body. A person suffering with this disorder and was a participant in this study recently succumbed to death as he was diagnosed to have contracted malaria. Since the likelihood of contacting the infectious disease increases significantly, the burden of disease is high and it requires greater attention to health care provisions. Not withstanding the sickle cell status it was observed that other morbidities are no less and there is less reliance on the pubic services. Sizeable proportion of people opts for private health service as necessary infrastructure is lacking at the village level. In the management of health problems and particularly sickle cell disorder role of *bhagat* is still high. Counseling services though have been started; need to be adequately deployed all over the area. Other health facilities too remain wanting in this regard.

It was clearly revealed in the study that growth and nutrition status of the population is weak. In comparison to other population group there has been growth faultering on various anthropometric parameters especially among children. It is also reflected in the poor nutritional status of the people under study. Substantial proportion of people suffers

with growth deficit which is unlikely to improve the health and living. Undernutrition is rampant and one third of the population suffers from severe form of Chronic Energy Deficiency. Altogether more than 60 per cent of the population is underweight. Status of anaemia is more disturbing. More than half of the population is anemic. Nearly 46 per cent children, half of all men and $3/5^{th}$ of all women are anaemic. However severity of anemia is no less in men and was found to be on the higher side.

Though, proportion of sickle cell anemic person in this study were very small and could not allow for applying statistical test to ascertain significant difference with other group regarding health parameters, the proportion of all indices were lower for them as against the general population. We also could not find the statistically significant difference among carriers and normal population which is in agreement with the literatures available on sickle cell disorder (Kramer et al 1978, Rehan 1981).

Looking into all the above aspects related with the sickle cell disease a comprehensive health strategy is required to meet the demands of appropriate health support for the people. Interventions are likely to be made at the community and Institutional level. Though the government has taken initiatives in this regard there were several discrepancies in meeting the health needs of the population. Some of the **recommendations** in this regard are as follows

At the community level:

Awareness:

Awareness as we mentioned earlier was very low in the population. Even though it was known somewhat among the men folk, women were completely unaware about the problem. It is ironic that main health care givers in our society are women. It is therefore of utmost importance to provide them adequate knowledge about the disease and its management. At Anganwadi centers the counselors could apprise the women as well as men about the disease at least once a month. IEC materials are generally given in printed form but it will be more effective if audio visual presentation will be made before the population. It could be followed by quiz or other gaming activities related with subject to increase the involvement of people. They will thus pay more attention to the problem.

Gram sabhas can also be used as a platform to disseminate the information in audio visual mode. It can be followed by question answer sessions or people could be invited to share their experiences in this regard.

Counseling:

The role of counselor is very important in sensitizing the population about the expected outcome of marriage and pregnancies. However it also requires adequate empathy towards the prospective parents. While marriage counseling will be good to avoid marriage between carriers and between carriers and disease, it is meaningless until whole population is screened and made aware of the problem. In the present scenario it should be limited to providing information rather than putting emphasis on its compliance.

Further, as hereditary disorders are neither well understood nor taken kindly, prospect of marriages in the affected person's family is likely to be constrained which may impact kinship and interpersonal relationship. As one of my informants who is diagnosed with the disease shared

When I said in my family that doctors had told me that it is an inherited disorder and I have got it from my parents; my father became so enraged that I had to run away from there. He said since he does not have any problem, how come he be said to have given this to his son, I am lying to give him bad name.

As the community also practice cross cousin marriage, denouncing the practice (some of the counselor ridicule the practice) will leave the people confused and will lower their self esteem. Rather than asking the people to shun this practice it is advisable to ask them to see the doctor in case of conception. Adequate counseling and offer of various options will help the people to decide on the continuation of pregnancy or favouring its termination.

The state government has set an ambitious goal of arresting the birth of sickle cell babies by 2020 but its aggressive compliance could lead to unethical medical practices. Therefore emphasis in counseling should be more on the support to the management of disease than against the termination of pregnancy to avoid the birth of such child.

Studies have demonstrated that in these type of balanced polymorphism it takes few generation to shift the balance against the mutant allele and that too when ecological condition favours.

Initiatives required at Institutional level

At the institutional level health infrastructure need to be properly synchronized. Health personnel and delivery of health services play an important role in the disease management.

Health personnel:

As we have seen there has been shortage of key personnel like counselors and lab technicians. Workload being high it is difficult for the counselor to visit villages frequently. Awareness programme could work well when frequent visit and activities could be taken up by the counselors, ASHA worker and Anganwadi worker collectively. Similarly more lab technicians are required to test the collected samples. Appointment of personnel therefore should be taken up on priority basis.

Proper training of health worker is also lacking. Emphasis of training appears to be more on the theoretical aspect of disease and is absent in psychosocial aspects. Helping individual and family to cope with the trauma is generally not taken into consideration hence counselors are not aware of the strategy to comfort the family. As Asha workers are the first point of contact at the village level, a regular monitoring of the patient's condition is also expected by them. However such initiatives were not seen in the villages. They were not even informed about the result of school screening programme hence were not aware of the children affected by the disorder. Doctors at PHC or other referral units too need to be properly trained given their ignorance about the actual course of action. At the institutional level therefore synergy between outreach health worker, counselor and doctor is required.

Screening of family

Mass screening programme could be more useful if at least all the members of the affected household could be screened and advised. It will thus systematically lead to the objective of screening and could be more focused on the adequate allocation of resources. Surveillance and counseling in such families could be effectively done to ensure better management of disease. A village wise record of affected family is the need of the hour.

Attention to immunization:

Since childhood mortality is high in children underfive (Makani et al 2011) management of disease requires full immunization in childhood to protect them from recurrent infection, the village record was poor in this regard. Nearly 30 per cent children in the age group 3-5 years in our sample were not fully immunized. Poor status of immunization as also reflected in the recent survey (NFHS-3, 2005-06) is a cause of concern. It has serious implication for the children succumbing to sickle cell disease aggravated by infectious disease. Nutrition too being poor, more attention need to be focused on the issue. Thus a close cooperation between Asha worker, Anganwadi worker and FHW should be imperative to monitor the health and growth of affected children regularly.

Data maintenance:

At present though an effort is underway to prepare the data base for the trait and affected individuals, it falls short on other significant information. Besides, entries have not been properly done in respective columns. Though the forms are very comprehensive, it clearly reveals that a number of relevant columns are not filled up. Thus household member tested for the disease remain vacant which reflect little attention to this vital information. Village wise record of trait and affected individuals need to be maintained. Similarly **there is no record of morbidity and mortality** suffered by affected individuals. These information are significant to device better health interventions.

The PHCs therefore should collect and keep a record of requisite information of each affected individual and their families for better monitoring and providing health facilities to the affected individuals.

References:

Adekile AD, Kitundu MN, Gu LH, Lanclos KD, Adeodu OO, Huisman TH. 1992. 'Haplotypes in SS patients from Nigeria; characterization of one atypical beta S haplotype no. 19 (Benin) associated with elevated HB F and high G gamma levels'. *Ann Hematol* 65:41-45.

Adekile, A.D. & Haider, M.Z., 1996: 'Morbidity, bs haplotype and a-globin gene patterns among sickle cell anemia patients in Kuwait'. *Acta Haematologica*, 96, 150–154.

Aidoo M, Terlouw DJ, Kolczak MS, McElroy PD, ter Kuile FO, Kariuki S, Nahlen BL, Lal AA, Udhayakumar V, 2002: 'Protective effects of the sickle cell gene against malaria morbidity and mortality'. *Lancet*, **359:**1311-1312.

Allison, A. C. 1954: 'Protection afforded by sickle cell trait against subtertian malaria infection'. *British Medical Journal,* 290-294.

Asakitikpi Alex. E. 2008: 'Born to Die: The *Ogbanje* Phenomenon and its Implication onChildhood Mortality in Southern Nigeria', *Anthropologist*, 10(1): 59-63.

Balgir RS, Dash BP, Das RK. 1997: 'Fetal outcome and childhood mortality in offspring of mothers with sickle cell trait and disease'. *Indian J Pediatr.* Jan-Feb;64(1):79-84.

Ballas, SK, et. al. 1988. 'Rheologic predictors of the severity of the painful sickle cell crisis'. *Blood* 72: 1216-1223.

Dalmia Yashodhara 1988: *The Painted World of Warlis*. Lalit Kala Academy, New Delhi.

Daniel J. Odenheimer, Sharada A. Sarnaik, Charles F. Whitten, Donald L. Rucknagel, and Charles F. Sing. 1987: 'The Relationship Between Fetal Hemoglobin and Disease Severity in Children With Sickle Cell Anemia'. *American Journal of Medical Genetics* 27 : 525-435

Desai,D. V. , Hiren Dhanani 2004: 'Sickle Cell Disease: History And Origin. *The Internet Journal of Hematology.* Volume 1 Number 2. DOI: httpp://dx.doi.org/10.4314/thrb.v13i5.4

Dominic Edoh, Charles Antwi- Bosaiko, and Dominic Amuzu 2006: 'Fetal hemoglobin during infancy and in sickle cell adults'. *Afr Health Sci.*; 6(1): 51–54. PMCID: PMC1831961

El-Hazmi, M.A.F., 1992a: 'Clinical and haematological diversity of sickle cell disease in Saudi children'. *Journal of Tropical Pediatrics*, 38, 106–112.

Elizabeth M Barden, Deborah A Kawchak, Kwaku Ohene-Frempong, Virginia A Stallings, and Babette S Zemel, 2002: Body composition in children with sickle cell disease. Am J Clin Nutr 2002;76:218–25

Embury, SH, et. al. 1982. 'Concurrent sickle-cell anemia and alpha-thalassemia: effect on severity of anemia'. *N. Engl. J. Med.* 306: 270-274.

Enthoven, R. E. 1922 : *The Tribes and Caste.* Cosmo publication, Delhi

Godfrey M. Mubyazi and Kato J. Njunwa 2011: 'Is sickle cell disease sufficiently prioritized in policy and socio-economic research on diseases in Tanzania? Lessons for the past 50 years'. *Tanzania Journal of Health Research,* Volume 13 (Suppl 1),

Grosse, S.D., Odame, I., Atrash, H.K., Amendah, D.D., Piel, F.B. & Williams, T.N. 2011 : 'Sickle cell disease in Africa: a neglected cause of early childhood mortality'. *American Journal of Preventive Medicine* 41(Suppl 4), S398-405.

Haldane,JBS 1949 : Disease and Evolution, *Ricerca Science supplememt* 19, 3-10.

Hisham Moheeb, Yasser A. Wali and Mahmoud S. El-Sayed, 2007 : 'Physical Fitness Indices and Anthropometrics Profiles in Schoolchildren With Sickle Cell Trait/Disease', *Americaln Journal of Haematology* 82:91–97.

Indian Council of Medical Research (ICMR), 1989: *Growth and Physical development of Indian Infants and Children.* Technical Report Series No.18, ICMR, New Delhi.

Keith Wailoo 2001 "Dying in the city of blues. *Sickle cell anemia and the politicas of race and health*". University of North Carolina Press, US.

Khayyam, U. Khalid, Khan, S.Y., Khan, M. Y., Muzammil S. 2012: 'Prevalence of obesity in an urban population- A community based study'. *Indian Journal for the Practising Doctor,* Vol. 5, No. 5

Kramer MS, Rooks Y, Pearson HA. 1978: Growth and development in children with sickle-cell trait. A prospective study of matched pairs. *N Engl J Med* , **299:**686-689.

Konotey-Ahulu FID 1968: 'Hereditary qualitative and quantitative erythrocyte defects in Ghana: an historical and geographical survey'. *Ghana Med J.*,7:118.

Konotey-Ahulu FID. Effect of environment on sickle cell disease in West Africa: epidemiologic and clinical considerations. In: Sickle Cell Disease, Diagnosis, Management, Education and Research. Abramson H, Bertles JF, Wethers DL, eds. CV Mosby Co, St. Louis. 1973; 20; cited in Desai, D. V.; Hiren Dhanani (2004). "Sickle Cell Disease: History And Origin". *The Internet Journal of Haematology* 1 (2). ISSN 1540-2649. http://www.ispub.com/ostia/index.php?xmlFilePath=journals/ijhe/vol1n2/sickle.xml.

Latahm, R, B. 1859: *Ethnology of India.* J.Van Voorst, London.

Lehman H, Catbush M. 1952: 'Sickle cell trait in southern India'. *British Medical Journal*, 1: 404-405.

Livingstone, F.B., 1958: 'Anthropological implications of sickle cell gene distribution in West Africa'. *Amer. Anthrop.*, **60**:533–562.

Majumdar, D. N. 1950: *Race Realities in Cultural Gujarat.* Gujarat Research Society, Bombay1.

Makani, J., Cox, S., Soka, D., Komba, A.N., Uruo, J., Mwamtemi, H., Magesa, P., Rwazaula, S>,Meda, E., Mgaya, J. et al, 2011: Mortality in Sickle Cell Anemia in Africa: A prospective cohort study in Tanzania. *PloS One* 6 (2): DOI: .1371/journal.pone.0014699

Malay B. Mukherjee , Chang Yong Lu , Rolande Ducrocq , Raman R. Gangakhedkar , Roshan B. Colah , Megha D. Kadam , Dipika Mohanty , Ronald L. Nagel , Rajagopal Krishnamoorthy 1997: 'Effect of α-thalassemia on sickle-cell anemia linked to the Arab-Indian haplotype in India'. *Am. J. Hematol.* 55:104-109.

Marek Cyrklaff, Cecilia P. Sanchez, Nicole Kilian, Cyrille Bisseye, Jacques Simpore, Friedrich Frischknecht, Michael Lanzer. 2011: 'Hemoglobins S and C Interfere with Actin Remodeling in *Plasmodium falciparum*–Infected Erythrocytes'. *Science Magazine*, 334 (6060): 1283-1286

May J, Evans JA, Timmann C, Ehmen C, Busch W, Thye T, Agbenyega T, Horstmann RD, 2007: 'Hemoglobin variants and disease manifestations in severe falciparum malaria'. *JAMA* ,**297**:2220-2226.

Nagel, R.L., Fabry, M.E., Pagnier, J., Zohoun, I., Wajcman, H., Baudin, V. & Labie, D. 1984 : 'Hematologically and genetically distinct forms of sickle cell anemia in Africa. The Senegal type and the Benin type'. *New England Journal of Medicine*, 312, 880–884.

Nagel, RL, et. al. 1991. 'The Senegal DNA haplotype is associated with the amelioration of anemia in African-American sickle cell anemia patients'. *Blood* 77: 1371-1375.

National Nutrition Monitoring Beuraeu (NNMB) 2000: Diet and nutritional status of tribal population.Report on first repeat survey. NNMB Technical Report No.19. National Institute of Nutrition, Hyderabad.

Oner C, Dimovski AJ, Olivieri NF, Schiliro G, Codrington JF, Fattoum S, Adekile AD, Oner R, Yuregir, GT, Altay C, et al. 1992. 'Beta S haplotypes in various world populations'. *Hum Genetics* 89:99-104

OneWorld Foundation India, 2011: Sickle cell anaemia control programme, Gujarat: Documentation of best practice. www.indiagovernance.gov.in

Oscar A. Barbarin, Charles F. Whitten, Sandy Bond Rhonda Conner-Warren 1999: 'The Social and Cultural Context of Coping With Sickle Cell Disease: II. The Role of Financial hardship in Adjustment to Sickle Cell Disease'. *Journal of black psychology*, Vol. 25 No. 3, 294-315

Padmos, M.A., Roberts, G.T., Sackey, K., Kulozik, A., Bail, S., Morris, J.S., Serjeant, B.E. & Serjeant, G.R. 1991: 'Two different forms of homozygous sickle cell disease occur in Saudi Arabia'. *British Journal of Haematology*, 79, 93–98

Pandya Gaurishankar, 1992: *Warli Jatino Samajmanvshastriya Abhyas* . Gujarat Vidyepeeth, Ahmedabad.

Pauling C. 1949 Itano et al: 'Sickle cell anaemia a molecular disease'. *Science*; 110: 543.

Rehan N. 1981: Growth status of children with and without sickle cell trait. *Clin Pediatr (Phila)*, 20(11):705-709. PubMed Abstract

Save, K.J. 1945: *The Warlis*, Padma publication, Bombay.

Shyama Parda patil and Murali Dhar Raut 2000: 'Outcome of pregnancy in sickle cell trait and disease in western Orissa' , *The journal of Obstetric and Gynaecology of India* , Vol 50 No.1, PP 50-53

Singh, Bhagwat 1954: *Bhawandro-Mandal*. Praveen publication, Rajkot.

Singh, N. Kh. 2006: *Health and Nutrition of Tribal Children*. Vatsala Baliram Prakashan Kendra, Latur, India.

Singhal Atul, Peter Thomas, Robert Cook, Klaas Wierenga, Graham Serjeant, 1994: 'Delayed adolescent growth in homozygous sickle cell disease'. *Archives of Disease in Childhood;* 71: 404-408.

Steinberg M. H., H. Hsu , R. L. Nagel , P. F. Milner , J. G. Adams , L. Benjamin , S. Fryd , P. Gillette , J. Gilman , O. Josifovska , S. Hellman-Erlingsson , S. Safaya , L. Huey , R. F. Rieder 2006: 'Gender and haplotype effects upon hematological manifestations of adult sickle cell anemia'. *Americaln Journal of Haematology* Volume 48, Issue 3 , Pages 175 – 181.

Steinberg, M.H., Ballas, S.K., Brunson, C.Y. & Bookchin, R. 1995b: 'Sickle cell anemia in septuagenarians'. *Blood*, 86, 3997–3998.

Williams TN, Mwangi TW, Roberts DJ, Alexander ND, Weatherall DJ, Wambua S, Kortok M, Snow RW, Marsh K, 2005: An immune basis for malaria protection by the sickle cell trait. *PLos Med* , 2:e128.

Wilson, J., 1876: *Aboriginal Tribe of Bombay Presidency*, Government Central Press, Bombay.

World Health Organization: 2006: Fifty-ninth world health assembly a59/9, Provisional agenda item 11.4

Somatometric Variation by Age, Gender and Sickle Cell Status

MALE

Age Group	SCT		HT	HL	HB	HC	BICEPS	TRICEPS	SUBSC	SUPIL	CALFSF	UAC	CCR	BCH	BCF	WT
<=5	N(16)	Mean	97.569	14.37	11.36	46.7	3.653	6.82	5.027	3.68	5.8667	13.77	18.85	3.833	6.027	14.0063
		Std. Error	1.2244	0.163	0.111	0.761	0.294	0.349	0.241	0.226	0.2811	0.233	0.37	0.092	0.109	0.32742
		Std. Deviation	4.8974	0.63	0.431	2.947	1.139	1.352	0.935	0.877	1.0887	0.902	1.434	0.356	0.423	1.30969
	T(5)	Mean	97.14	14.56	11.06	47.64	4.3	7	6.12	3.34	6.44	14.22	17.8	3.68	5.98	13.6
		Std. Error	2.948	0.196	0.448	0.63	0.697	1.31	0.488	0.227	0.9908	0.545	0.532	0.351	0.258	0.87178
		Std. Deviation	6.5919	0.439	1.001	1.408	1.559	2.929	1.092	0.508	2.2154	1.219	1.19	0.785	0.576	1.94936
6-10	N(33)	Mean	114.43	15.13	11.18	48.61	2.976	5.436	5.033	3.436	5.797	14.68	20.85	4.542	6.791	19.1182
		Std. Error	3.2551	0.144	0.376	0.232	0.151	0.239	0.158	0.139	0.2082	0.198	0.531	0.075	0.085	0.68183
		Std. Deviation	18.699	0.825	2.159	1.332	0.868	1.373	0.909	0.796	1.1962	1.139	3.052	0.43	0.487	3.91683
	T(6)	Mean	115.92	14.68	11.58	48.38	2.467	4.817	4.717	2.967	4.9	14.73	20.73	4.533	6.85	19.5333
		Std. Error	2.6975	0.348	0.206	0.28	0.246	0.626	0.22	0.28	0.6445	0.386	0.526	0.128	0.157	1.58843
		Std. Deviation	6.6074	0.852	0.504	0.685	0.602	1.534	0.538	0.686	1.5786	0.946	1.288	0.314	0.383	3.89084
	D(1)	Mean	120.20	15.00	11.80	49.00	2.80	4.00	5.20	3.00	6.00	13.40	19.70	4.50	6.40	20.00
11-15	N(25)	Mean	143.1	15.68	12	50.64	2.876	5.364	6.004	3.772	6.54	18.17	25.96	5.568	7.98	32.4
		Std. Error	2.9223	0.198	0.104	0.375	0.127	0.262	0.288	0.171	0.3549	0.504	0.851	0.123	0.127	1.69371
		Std. Deviation	14.611	0.988	0.522	1.875	0.633	1.309	1.439	0.855	1.7744	2.518	4.256	0.614	0.635	8.46857
	T(3)	Mean	141.63	16.33	12.47	50.63	4.5	6.8	7.333	5.533	8.5333	19.13	26.43	5.733	7.967	33.0667
		Std. Error	2.8638	0.353	0.067	0.788	0.964	1.732	1.453	1.462	1.4438	0.644	0.984	0.176	0.088	2.04641
		Std. Deviation	4.9602	0.611	0.115	1.365	1.67	3	2.517	2.532	2.5007	1.115	1.704	0.306	0.153	3.54448
16-20	N(15)	Mean	158.54	16.01	12.32	52.24	3.387	6.58	8.933	5.127	6.52	22.79	30.03	6.173	8.607	45.8467
		Std. Error	1.5596	0.213	0.139	0.372	0.434	0.918	0.693	0.686	0.844	0.536	0.748	0.084	0.171	1.94892
		Std. Deviation	6.0403	0.825	0.537	1.44	1.68	3.555	2.684	2.656	3.2689	2.077	2.897	0.324	0.663	7.54812
	T(3)	Mean	157	17.5	13.03	52.67	2.767	6.133	9.533	4.067	7.7667	22.13	29.03	6	8.133	44.1667
		Std. Error	4.4602	0.764	0.742	0.664	0.167	1.277	1.392	0.133	0.441	0.94	1.637	0.231	0.296	4.04489
		Std. Deviation	7.7253	1.323	1.286	1.15	0.289	2.212	2.411	0.231	0.7638	1.629	2.836	0.4	0.513	7.00595
	D(1)	Mean	162.70	17.60	12.40	54.20	3.00	7.80	9.30	3.60	7.40	24.60	33.10	7.10	9.00	55.30
21-40	N(60)	Mean	160.69	16.66	12.26	51.96	2.8	5.562	9.212	5.689	5.0833	23.79	30.27	6.157	8.492	50.515
		Std. Error	0.8543	0.097	0.072	0.485	0.14	0.49	0.511	0.747	0.4631	0.225	0.626	0.064	0.077	0.91477
		Std. Deviation	6.6173	0.754	0.559	3.757	1.087	3.794	3.96	5.789	3.587	1.744	4.849	0.493	0.6	7.08579

Age Group	SCT		HT	HL	HB	HC	BICEPS	TRICEPS	SUBSC	SUPIL	CALFSF	UAC	CCR	BCH	BCF	WT
	T(7)	Mean	158.86	16.93	12.03	52.97	2.886	5.614	9.6	5.343	5.0143	23.2	31.14	6.086	10.83	49.6429
		Std. Error	2.224	0.197	0.246	0.457	0.392	0.663	1.301	0.644	0.7796	0.512	1.765	0.106	99.79	2.17046
		Std. Deviation	5.8841	0.522	0.65	1.209	1.038	1.755	3.443	1.704	2.0627	1.354	4.671	0.279	264	5.74249
	D(1)	Mean	156.60	16.50	12.70	52.20	2.20	3.60	7.00	4.00	4.20	21.80	29.50	6.30	8.80	45.00
	N(72)	Mean	158.73	16.58	12.08	52.09	2.521	4.994	7.885	4.144	4.6	22.45	29.43	6.307	8.572	46.5972
		Std. Error	0.7524	0.079	0.057	0.174	0.068	0.17	0.239	0.142	0.3248	0.229	0.493	0.048	0.06	0.6136
		Std. Deviation	6.3841	0.672	0.482	1.48	0.579	1.446	2.03	1.207	2.756	1.94	4.182	0.404	0.508	5.20655
>40	T(13)	Mean	158.1	16.58	12.31	52.35	2.438	4.815	8.508	3.915	3.6615	22.52	28.93	6.169	8.462	46.6615
		Std. Error	1.441	0.143	0.157	0.179	0.087	0.323	0.547	0.189	0.2005	0.504	0.584	0.081	0.092	1.07068
		Std. Deviation	5.1957	0.516	0.568	0.644	0.315	1.165	1.973	0.683	0.7229	1.817	2.105	0.293	0.331	3.86038
	P value		0.20	0.23	0.25	0.10	0.60	0.82	0.04*	0.78	0.53	0.85	0.52	0.27	0.36	0.43

HT – Height, HL – Head Length, HB – Head Breadth, HC – Head Circumference, BICEP – Biceps, TRICE – Triceps, SUBSC – Subscapular skin fold, SUPIL – Supra Ilac Skin fold, CALFSF – Calf skin fold, UAC – Upper Arm Circumference, CCR – Calf circumference, BCH – Bicondylar Humerus, BCF – Bicondlyar femur, WT – Weight. * P value significant

Somatometric Variation by Age, Gender and Sickle Cell Status

FEMALE

Age Group	SCT		HT	HL	HB	HC	BICEPS	TRICEPS	SUBSE	S4PIL	CALASF	UAC	CCR	BCH	BCF	WT
<=5	N(16)	Mean	95.906	14.69	11.31	46.71	4.267	7.367	5.82	4.687	6.7933	13.79	17.93	3.64	5.653	13.0118
		Std. Error	1.5282	0.314	0.177	0.341	0.229	0.289	0.302	0.249	0.3741	0.238	0.28	0.052	0.076	0.56639
		Std. Deviation	6.113	1.255	0.71	1.364	0.888	1.12	1.171	0.964	1.4489	0.953	1.083	0.203	0.295	2.3353
	T(3)	Mean	88.167	14.37	10.83	46.83	4.233	6	6	4.067	7	13.6	17.8	3.85	5.5	11.8667
		Std. Error	7.5581	0.12	0.338	0.726	0.578	0.503	0.902	0.291	1.2	0.666	1.114	0.35	0.5	2.01025
		Std. Deviation	13.091	0.208	0.586	1.258	1.002	0.872	1.562	0.503	1.6971	1.153	1.929	0.495	0.0707	3.48186
	D(1)	Mean	84.00	13.80	11.00	45.40	2.20	8.40	6.40	5.00	7.80	12.00	15.50	3.20	4.70	9.00
6-10	N(43)	Mean	118.08	14.87	11.32	48.47	3.453	6.121	5.505	4.051	6.4605	14.93	20.34	4.386	6.47	19.2372
		Std. Error	1.2837	0.104	0.076	0.207	0.147	0.188	0.2	0.153	0.2095	0.171	0.213	0.052	0.064	0.52017
		Std. Deviation	8.4176	0.681	0.5	1.358	0.963	1.234	1.313	1.001	1.3739	1.124	1.394	0.338	0.419	3.41098
	T(5)	Mean	114.3	14.76	11.22	47.88	3.6	6.6	5.64	3.58	4.92	14.5	20	4.22	6.32	18.16
		Std. Error	4.0803	0.262	0.185	0.801	0.316	0.494	0.676	0.564	0.7338	0.345	0.684	0.185	0.116	1.3677
		Std. Deviation	9.1239	0.586	0.415	1.792	0.707	1.105	1.513	1.262	1.6407	0.771	1.53	0.415	0.259	3.05827
11-15	N(27)	Mean	138.74	15.77	11.63	50.66	3.696	7.67	8.278	5.537	7.9704	18.2	24.96	5.144	7.404	29.8556
		Std. Error	1.8672	0.126	0.097	0.276	0.205	0.513	0.423	0.397	0.5624	0.355	0.439	0.064	0.081	1.28147
		Std. Deviation	9.7023	0.655	0.502	1.434	1.066	2.667	2.2	2.064	2.9222	1.844	2.284	0.334	0.419	6.65873
	T(6)	Mean	132.97	15.45	11.5	49.97	3.883	6.8	7.883	5.017	6.5	18.42	24.5	5.017	7.2	30.4833
		Std. Error	6.7638	0.177	0.175	0.502	0.628	1.136	1.009	0.739	0.7638	0.841	1.114	0.176	0.318	2.82565
		Std. Deviation	16.568	0.432	0.429	1.231	1.539	2.783	2.473	1.809	1.8708	2.061	2.73	0.431	0.78	6.92139
16-20	N(20)	Mean	145.98	15.89	11.7	51.26	3.795	9.595	12.27	6.645	8.775	20.99	27.15	5.3	7.565	38.705
		Std. Error	1.9833	0.134	0.075	0.315	0.267	0.857	0.848	0.466	0.777	0.461	0.6	0.07	0.101	1.48055
		Std. Deviation	8.8696	0.599	0.334	1.407	1.192	3.832	3.792	2.085	3.4749	2.061	2.684	0.311	0.451	6.62122
	T(4)	Mean	149.03	15.43	11.68	50.98	4	11.03	13.73	7.6	9.525	21.05	26.88	5.325	7.6	40.125
		Std. Error	2.61	0.21	0.155	0.645	0.424	1.762	1.682	0.726	1.1456	0.527	0.739	0.111	0.334	3.76594
		Std. Deviation	5.2201	0.419	0.31	1.289	0.849	3.524	3.364	1.451	2.2911	1.054	1.477	0.222	0.668	7.53188
21-40	N(105)	Mean	149.13	15.65	11.72	50.86	3.374	9.027	11.32	5.82	7.1226	21.52	27.19	5.435	7.721	41.4047
		Std. Error	0.6227	0.073	0.045	0.178	0.113	0.331	0.359	0.213	0.2457	0.17	0.298	0.04	0.034	0.47885
		Std. Deviation	6.4108	0.746	0.464	1.831	1.161	3.407	3.701	2.172	2.5296	1.746	3.067	0.413	0.349	4.93009
	T(22)	Mean	147.47	15.962	11.71	51.19	3.286	7.923	11.69	5.923	6.6455	21.76	27.63	5.491	7.527	41.5045

Age Group	SCT		HT	HL	HB	HC	BICEPS	TRICEPS	SUBSE	S4PIL	CALASF	UAC	CCR	BCH	BCF	WT
		Std. Error	1.5122	0.129	0.076	0.245	0.291	0.618	0.859	0.446	0.6492	0.408	0.493	0.075	0.104	1.64596
		Std. Deviation	7.093	0.604	0.356	1.149	1.363	2.897	4.028	2.091	3.0449	1.916	2.312	0.353	0.49	7.72026
>40	N(52)	Mean	148.12	15.68	11.88	51.39	3.092	7.153	9.634	5.083	5.7453	21.75	26.8	5.692	7.774	41.0774
		Std. Error	0.7511	0.198	0.058	0.189	0.175	0.391	0.499	0.314	0.3591	0.329	0.582	0.072	0.064	0.97221
		Std. Deviation	5.4678	1.443	0.419	1.375	1.273	2.847	3.632	2.283	2.396	2.396	4.236	0.522	0.466	7.07777
	T(17	Mean	146.64	15.83	11.71	51.46	3.114	6.871	9.943	4.714	5.0286	22.59	28.03	5.686	7.729	43.2143
		Std. Error	2.5099	0.18	0.135	0.475	0.548	0.639	1.372	0.451	1.327	1.327	1.138	0.179	0.071	3.18078
		Std. Deviation	6.6405	0.475	0.358	1.257	1.451	1.692	3.63	1.194	3.512	3.512	3.011	0.474	0.189	8.41555
	P-Value		0.11	0.30	0.08	0.34	0.20	0.54	0.22	0.55	0.20	0.52	0.78	0.97	0.02*	0.55

HT – Height, HL – Head Length, HB – Head Breadth, HC – Head Circumference, BICEP – Biceps, TRICE – Triceps, SUBSC – Subscapular skin fold, SUPIL – Supra Ilac Skin fold, CALFSF – Calf skin fold, UAC – Upper Arm Circumference, CCR – Calf circumference, BCH – Bicondylar Humerus, BCF – Bicondylar femur, WT – Weight. * P value significant

APPENDIX – 2

સેન્ટર ફોર સોશિયલ સ્ટડિઝ, સુરત

ગુજરાતની વારલી આદિવાસી જાતિમાં સિકલસેલ એનિમિયાનો વ્યાપ અંદાજવાને સંબંધિત સંશોધન

સંમતિ પત્રકઃ

કેમ છો? નમસ્તે! હું _____, ગુજરાતની વારલી આદિવાસી જાતિમાં સિકલસેલ એનિમિયાને લગતા એક અભ્યાસ પર કામ કરું છું. આ અભ્યાસ, સુરત સ્થિત સેન્ટર ફોર સોશિયલ સ્ટડિઝ, કે જે આઈ.સી.એસ.એસ.આર. સાથે સંલગ્ન સંશોધન સંસ્થા છે, તેના દ્વારા અમદાવાદની "આદિવાસી સંશોધન અને તાલીમ સંસ્થા (ગુજરાત વિદ્યાપીઠ)"ના નાણાંકીય સહયોગથી હાથ ધરવામાં આવ્યો છે.

સિકલસેલ એનિમિયા એક વારસાગત રોગ છે કે જે મા-બાપ દ્વારા બાળકોમાં ફેલાય છે અને ઘણીવાર તેનાથી આરોગ્યની અમુક સમસ્યાઓ સર્જાય છે. આ અભ્યાસમાં અમે સિકલસેલના લક્ષણો ધરાવતા અને આ રોગથી પીડાતા લોકોનું પ્રમાણ અંદાજવાનો પ્રયાસ કરી રહ્યા છીએ. આ રોગ સાથે સંકળાયેલા પ્રશ્નોનું પ્રમાણ અને સમુદાયની આરોગ્ય સેવા પ્રત્યેની પહોંચની પણ અમે તપાસ કરીશું.

આ રોગ વિષે ઝીણવટભરી માહિતી એકત્ર કરવા માટે, અમારે સોય દ્વારા તમારા લોહીના થોડાક ટીપાં (બે મિલિ.) લેવા પડશે અને ત્યાર બાદ આ રોગ માટે તેનું પરીક્ષણ કરવુ પડશે. હું તમને ખાત્રી આપું છું કે આ રીતે લોહી લેવાની પ્રક્રિયા બિલકુલ સલામત છે, કારણ કે તે બારડોલીના 'સિકલસેલ ફાઉન્ડેશન' માં કામ કરતી કુશળ વ્યક્તિ દ્વારા કરવામાં આવશે, જે સિકલસેલની હાજરી માટે લોહીની તપાસ પણ કરશે. આ તપાસનું પરિણામ ખાનગી રહેશે અને ફક્ત તમને જ તેની જાણ કરાશે. એની પણ હું બાંહેધરી આપું છું.

આ ઉપરાંત, તમારા અને તમારા કુટુંબના આરોગ્યની સમસ્યાઓ અંગે અને અન્ય વિગતો મેળવવા માટે કેટલાંક પ્રશ્નો હું તમને પૂછીશ. આ માહિતી પણ કોઈપણ અન્ય વ્યક્તિને આપવામાં આવશે નહીં. તમારા લોહીની તપાસનો રીપોર્ટ તથા આરોગ્ય સંબંધિત પ્રશ્નો સરકારને જણાવવામાં આવશે કે જેથી તેને આરોગ્ય સંબંધિત કામગીરીનું આયોજન કરવામાં મદદ મળે. પ્રશ્નો

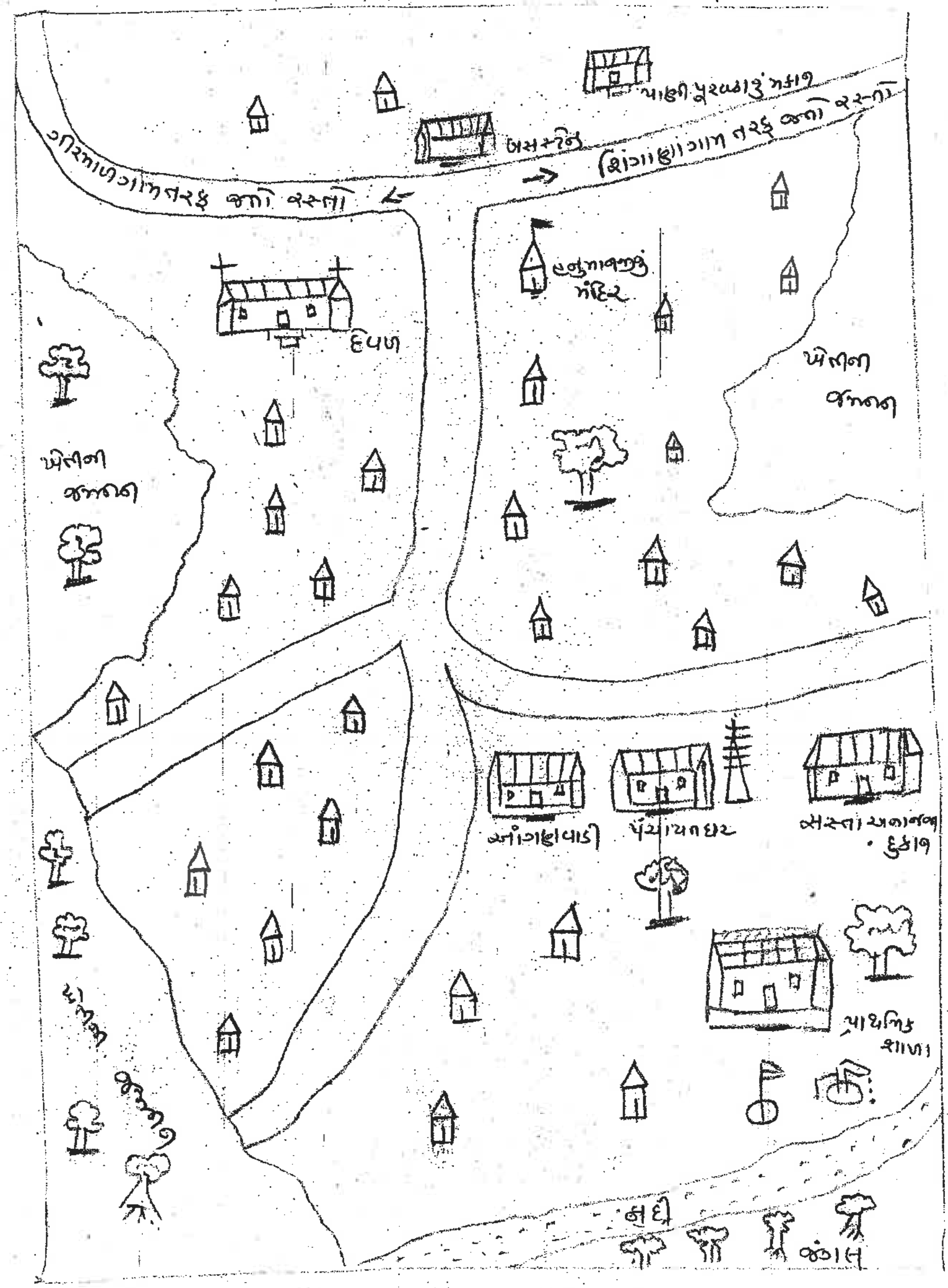
આ અભ્યાસ સફળતાપૂર્વક પૂરો કરવામાં આપના સહયોગની આવશ્યકતા હોવાથી, હું આપને આપનો સહકાર આપવા માટે વિનંતી કરુ છું. જો તમને આમાં રસ ન હોય તો તમે આ સંશોધનમાં ભાગ લેવાનો ઈન્કાર કરી શકો છો, કારણ કે તેમ કરવાનો તમને અધિકાર છે અને અમે તમારી સ્વતંત્રતાને માન આપીએ છીએ. તમે આ સંશોધનમાં ભાગ લેવા માંગતા હો તો (ગામના વડીલો સમક્ષ) 'હા' પાડીને અથવા આ પત્રક પર તમારી સહી કરીને, તે અંગેની સંમતિ આપી શકો છો. આ સંશોધન દરમ્યાન ચાલતું હોય તે જો તમે તેમાંથી ખસી જવા માંગશો તો પણ તમારા નિર્ણયને અમે માન્ય રાખીશું.

મૌખિક રીતે સંમતિ આપી છે : ---------- ઉત્તરદાતાની સહીઃ _____

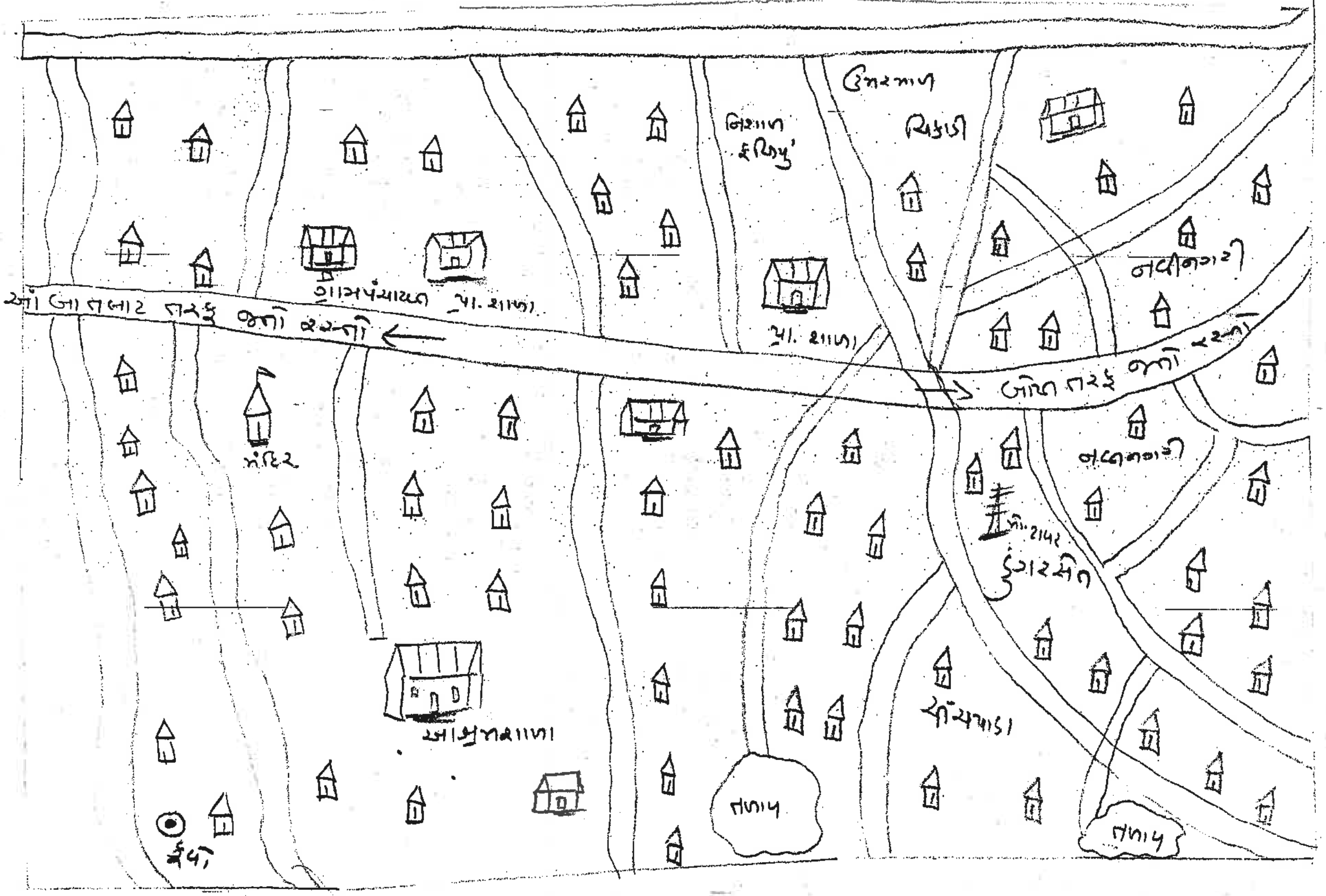
વાલીની સહી : ----------
(જો ઉત્તરદાતા સગીર હોય તો)

APPENDIX-3

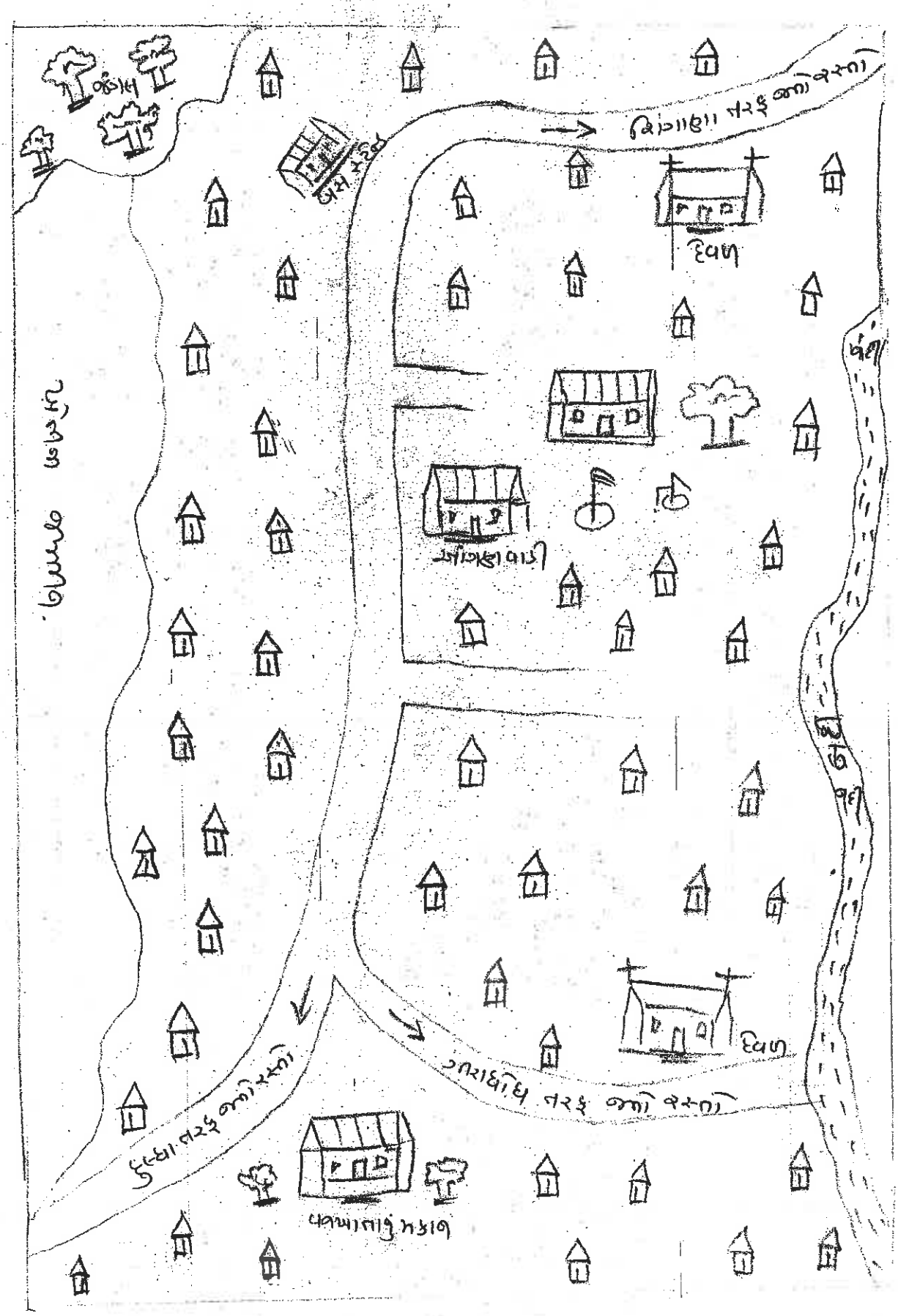
ગાંવદહાડ ગામનો નકશો જિ- ડાંગ

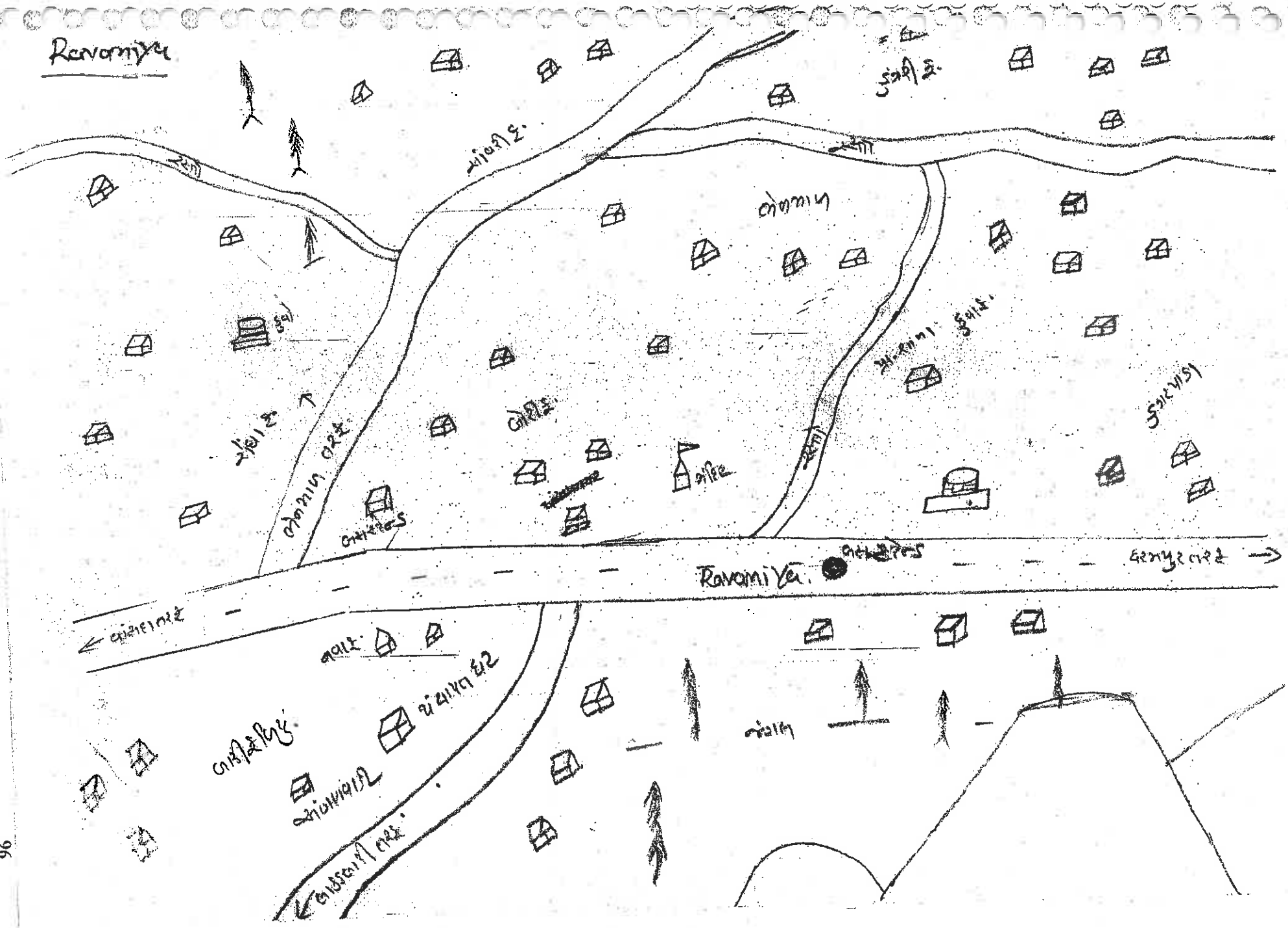


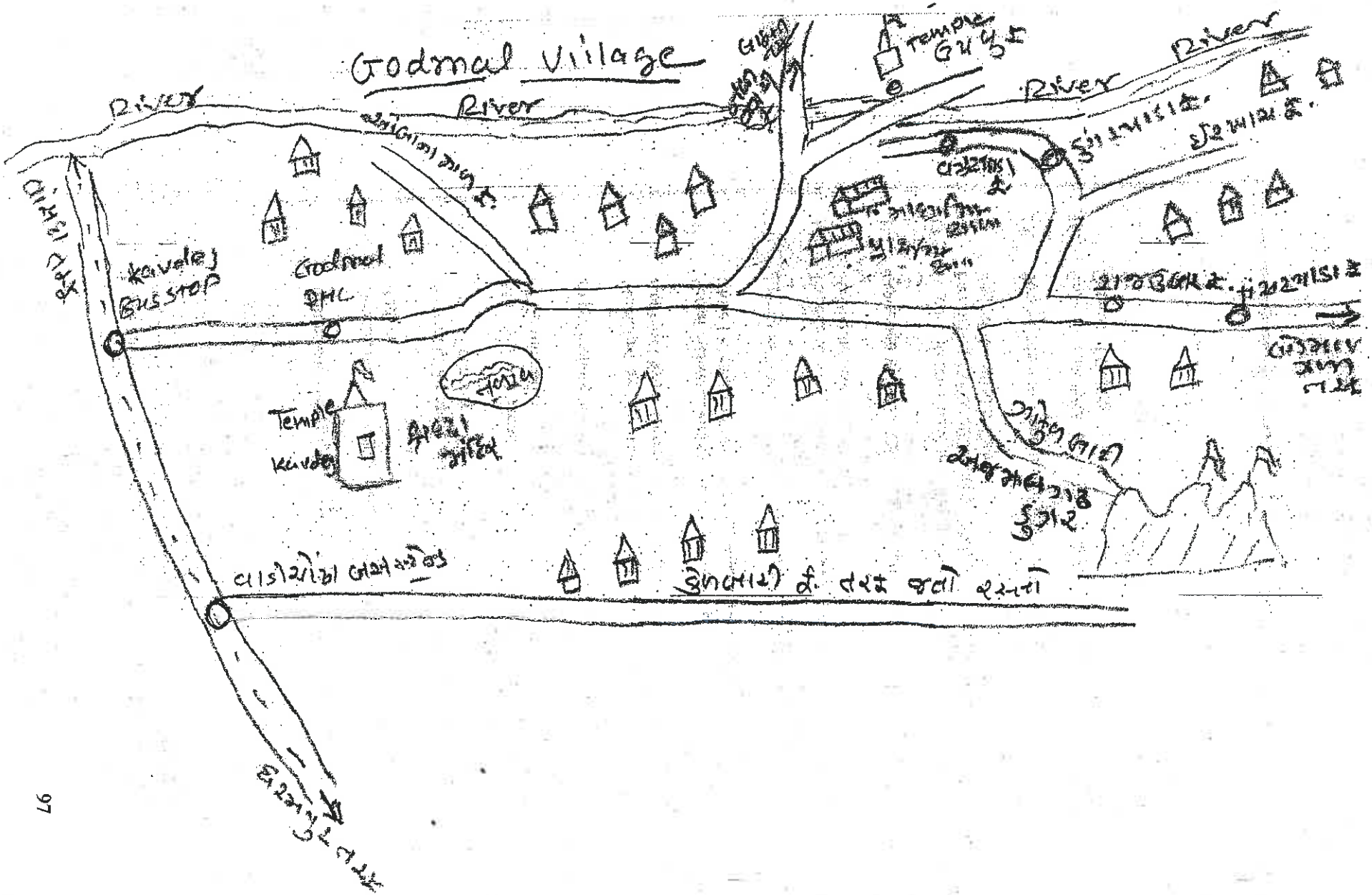
જાડા / અવાડા ગામનો નકશો

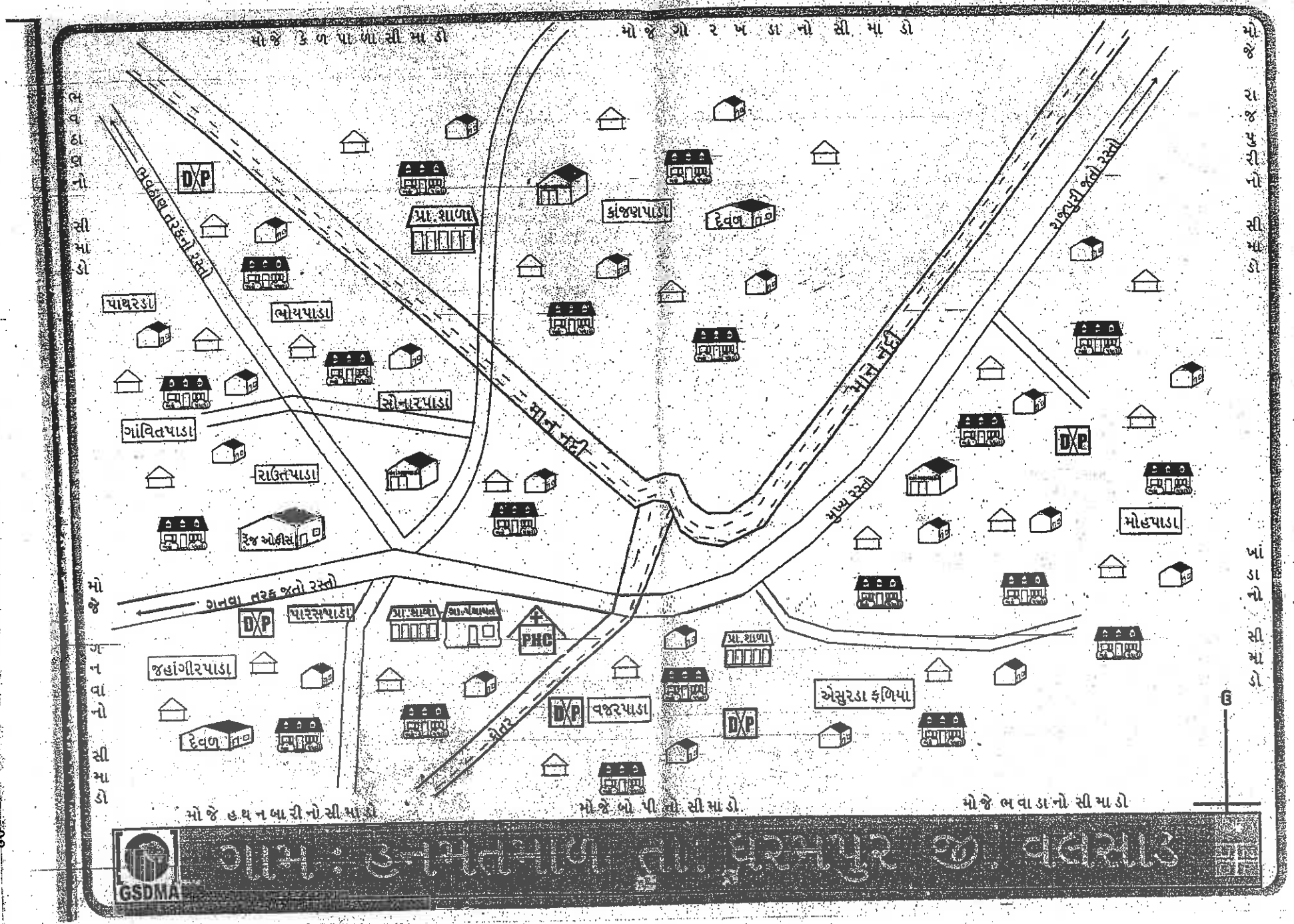


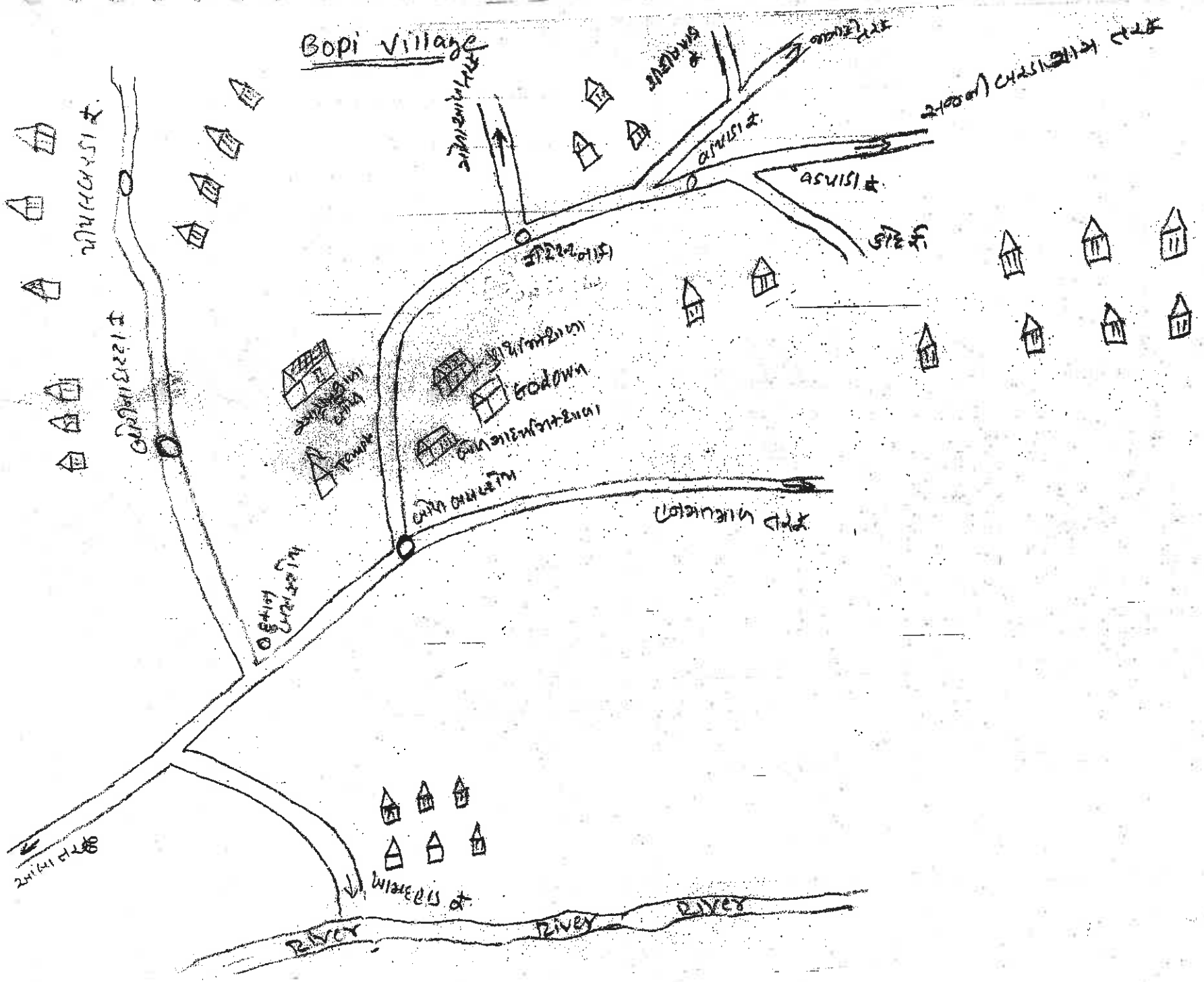
ગરમાળા ગામનો નકશો ધો- 5 ના




Ravaniya
Ravaniya


Godmal Village
River
River
River
Temple
Kavalej
BUS STOP
Godmal
PHC
Temple
Kavalej


મોજે કેળપાળા સીમાડો
મોજે ગોરખડાનો સીમાડો
મોજે રાજપુરા સ્ટેટનો સીમાડો
ભવઠાણનો સીમાડો
ગનવાનો સીમાડો
ખાંડાનો સીમાડો
મોજે હથનબારીનો સીમાડો
મોજે બોપીનો સીમાડો
મોજે ભવાડાનો સીમાડો
ભવાંબા તરફનો રસ્તો
પ્રા.શાળા
કાંજણપાડો
દેવળ
પાથરડા
ભોયપાડા
સોનારપાડા
ગાવિતપાડા
રાઉતપાડા
રેજ ઓફીસ
મોટી નદી
મુખ્ય રસ્તો
ગનવા તરફ જતો રસ્તો
પારસપાડા
PHC
જહાંગીરપાડા
વજરપાડા
એસુરડા ફળિયા
મોહપાડા
DP
GSDMA


Bopi Village
GODOWN
RIVER
RIVER
RIVER