A Medical Anthropological Study of Fluorosis in Marriguda Mandal, Nalgonda District of Telangana Region

by

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DEPARTMENT OF LIBERAL ARTS

INDIAN INSTITUTE OF TECHNOLOGY HYDERABAD

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Venkatesh Boddu

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Declaration

I declare that this thesis represents my ideas in my own words and where others' ideas or words have been included, I have adequately cited and referenced the original sources. I also declare that I have adhered to all principles of academic honesty and integrity and have not misrepresented or fabricated or falsified any idea/data/fact/source in my submission. I understand that any violation of the above will result in disciplinary action by the Institute and can also evoke penal action from the sources that have not been properly cited or from whom proper permission has not been taken when needed.

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Dedicated to

My beloved parents Sri. (late) Jangaiah Boddu and Sandamma Boddu

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ABSTRACT

This thesis is an ethnographic study about fluorosis, a disease which is caused due to excess fluoride in water, and which causes disability, in villages of Nalgonda district, in Telangana region. The main aim of the thesis is to explore local perceptions about fluorosis, and the experience of people who are disables due to fluorosis, and the impact of that on their family members, who are the care-givers. There are two types of fluorosis- dental fluorosis and skeletal fluorosis. Dental fluorosis results in dental decay whereas skeletal fluorosis replaces calcium in the bones with fluoride, which results in crippled limbs. The effect of fluorosis is acute on the bones and kidneys and the disease can affect a person at any stage of life. Those affected by skeletal fluorosis suffer from chronic physical pain, and in some cases renal failure due to prolonged use of painkillers, and physical disability.

In Nalgonda District, existence of fluorosis was identified long ago, in 1945. Out of the twenty-three districts in Andhra Pradesh, eighteen districts are affected by this problem. Around thirty thousand habitations are affected in the state. In Nalgonda district alone, nine hundred and seventy five villages are affected. This research Fieldwork was conducted in five villages of Marriguda mandal from May to July 2013. Data was collected using qualitative research methods. From the ethnographic information, victimized for their health condition and suffer from social stigma. Family members play a crucial role in providing care for the disabled people. Fluorosis victims are also involved in activism to get relief from state agencies, and are helped in this by some civil society organizations. But the problems still persist. The thesis argues that in order to provide relief to those suffering from fluorosis, social, cultural, economic and political factors that play a role at the household and village levels, have to be taken into consideration.

SYNOPSIS

This thesis is an ethnographic account of understanding sociocultural context of endemic fluorosis in rural Telangana region. Fluorosis is not contagious. But there is no known cure, to my knowledge, in any medical practice (biomedicine, Ayurveda, etc). Yet there is confusion among the people about understanding the disease and approaching health professionals. The thesis looks at the experiences of the disabled persons and their family members in day-to-day activities, the role of caste, religion, socio-economic conditions of the fluorosis patients and various kinds of social activism and politics in the study area. This thesis consists of five chapters. A brief summary of the chapters is given in the following paragraphs.

Chapter one is an introduction to this research, which talks about the objectives and the significance of the study. It also gives a brief introduction to the severity of the disease in the region, to the field site, difficulties in accessing the field, and fieldwork. Fluorosis has multiple effects on the body. The thesis looks at why people consume contaminated water though they know about its ill effects. How is fluorosis affecting marriage alliances in the region? These are some of the questions the thesis tries to answer. The significance of this research is that it looks at socio-cultural aspects of fluorosis and experience of disability among the patients. This chapter also includes review of literature specific to topics such as stigma that are relevant for this study.

Chapter two (Ethnographic profile) describes in detail about the physical and geographical features of the study area, ethnographic and demographic profiles of the villages, environment, food consumption, economy, housing patterns, political and

administrative systems, socio-cultural relations in the villages, literacy and education, and healthcare facilities available. Nutritious food is important in fighting fluorosis but the social-economic conditions of the people results in malnutrition and thus more people get affected by the disease. This chapter also talks in brief, history of Nalgonda district starting from Maurya period (230 BC) to the Nizams' rule in early 20th century.

Chapter three discusses the crux of this thesis. This chapter focuses on lay understandings of fluorosis as a disease of disability. These local perceptions are different from the medical reasons given for the disease. The argument here is that these local perceptions are important in caregiving. This chapter looks at the factors contributing to care-giving for people disabled with fluorosis. The care-givers do not consider looking after their disabled family members as a burden. Perceptions about causal factors and about disabled persons play an important role in kinship relations between families and in marriage alliances. Later the chapter discusses how people differentiate between contaminated water and uncontaminated water, and fluorosis from other forms of disability. It also looks at stigma with regard to fluorosis, issues related to migration from the village, and health care decisions by both family members and disabled persons themselves. Local notions such as "*karma siddhantha*", divine punishment and "*grahanam morri*" are some of the important determinants of care giving and family dynamics. This chapter also looks at gender related disability issues such as participating in activism and maintaining social and political relationships. It looks at the reasons for neglecting health care in the initial stages of the disease and consumption of painkillers resulting in renal failure. In order to avoid taunting and teasing, disabled persons' parents prefer to stay home avoid meeting their relatives.

Chapter four discusses various kinds of social activism and politics related to fluorosis taking place in the field sites. The main argument of this chapter is that politicians, civil society members and disabled persons themselves represent fluorosis and the problem of fluoride contamination in different ways to the state. Social activists are accused of deriving benefits from fluorosis patients. This chapter looks at why only a few people get benefit from the activism but not others. The difficulties in representing fluorosis to the state and the state's reaction to them are discussed in detail. Later the chapter gives details about current government schemes for disabled people, and fluorosis victims, and aid agencies working in the region. It shows how the influential caste groups utilize such government schemes and fluoride mitigation activities for their benefit. It also looks at the difficulties fluorosis patients face in applying for disability certificate, which is very crucial in getting benefit from other government schemes in the region.

Chapter five gives a brief summary of the thesis and suggestions for further research. It looks at why the various schemes and mitigation activities in the region failed and how lack of leadership from fluorosis patients made it easy for social activists in taking over the issue. It also highlights people's perceptions towards local social activists and political leaders. Though the problem of fluorosis has been highlighted in local and national media, and politicians at the state and the center know about it, , the question remains as to why the problem still persists, and why the state is interested in providing temporary measures rather than permanent solutions. Since there is no cure, the future of those affected is unclear. This thesis suggests that, the state government should come forward to make appropriate policies such as establish disability homes and care centers in the region. The challenges faced by people in their daily lives due to fluorosis should be taken into consideration because

fluorosis patients are not just disabled individuals but are members of families and societies. They are also citizens who also have aspirations to lead lives with dignity and without stigma, of being disabled and dependent on others for their survival.

Chapter - I
Introduction

In most houses in the Marriguda mandal, we can see at least one person lying on the bed. There is no connection between his or her stature and age. Crippled limbs and bent in backbones. Some cannot walk; some can for a distance of few feet. Water is poison there. The people know it is not safe to drink, they know it eats away their bones but they still drink it. This basic need for water is forcing them to consume contaminated water. This is not the story of a single village; almost all villages in this region here have a similar story. For almost seven decades people in these areas have been suffering from fluorosis. The prevalence and severity of fluorosis is not only restricted to Nalgonda District. Twenty-three nations in the world and twenty Indian states are facing the problem of excess fluoride content in drinking water resulting in endemic fluorosis (Susheela 2002). Sixty six million people including six million children under the age of fourteen years are at risk of acquiring fluorosis (Chakma and Rao 2004).

Significance of the study:

Supply of safe drinking water may help to prevent fluorosis in the future but there are many people who are already affected and suffering from fluorosis. Since there is no treatment for the disease, they are suffering for a long time and struggling to survive. This study looks at the experience of fluorosis patients as "disabled persons" and the socio-cultural dynamics of fluorosis in relation to disability and stigma. No anthropologist or sociologist to my knowledge has looked at this issue in India, till now. Public health experts have conducted some studies on community water fluoridation (S.R.Srinivas, S.R.Srikrishna and M.Rao 2010) and some studies were conducted on assessment of ground water quality with respect to fluoride (Singh

2011). There are only a few ethnographic studies on disability in India (see Barrett 2005 and Staples 2011). The uniqueness of the disease is that, it is not contagious, it does not have a cure and it affects a person at any stage of his/her life. In some cases people get affected right from the fetal stage.

> "Early stages of skeletal fluorosis start with pain in bones and joints, muscle weakness, sporadic pain, stiffness of joints and chronic fatigue. During later stages, calcification of the bones takes place, osteoporosis in long bones, and symptoms of osteosclerosis where the bones become denser and develop abnormal crystalline structure. In the advanced stage the bones and joints become completely weak and moving them is difficult. The vertebrae in the spine fuse together and the patient is left crippled which is the final stage. Skeletal fluorosis is usually not recognized until the disease reaches an advanced stage." Brinda and Ealngo 2011:7.

Reasons for choosing this topic:

I was interested in studying a health related issue. This issue was repeatedly telecast in local media for the past few years. It appeared to be both interesting and important topic. There is an urgent need to study the condition of people affected by fluorosis from a social science perspective. Most studies that appear in scholarly publications, journalistic reports, and in visual media are rarely from social science scholars. As far as I know, no systematic sociological or anthropological study has been conducted in this region on fluorosis and the disabled people. Fluorosis results in crippled limbs, which indicates physical disability. Since these physical deformities are visible, people generally understand it as a disability than a disease. Other interesting thing is that, government schemes such as disability pension and Antyodaya Anna Yojana are implemented on the basis of disability certificate.

Fluorosis in Nalgonda:

Fluorosis Vimukti Porata Samithi, a non-governmental organization (NGO) in the region claims that fluorosis in Nalgonda was identified in the year 1940s. Most of the

ground water sources in the region were identified with fluoride contamination. Reasons cited were over use of ground water and the decrease in the surface water bodies due to lack of rain. Decreased ground water level resulted in absorption of fluoride from soil and rock structures from the earth's crust in to water table, which resulted in increased fluoride content in ground water sources. According to World Bank Report (2004) fluoride content in this area is up to 8PPM (parts per million), while the desirable limit is 1.5PPM. The World Bank report was highly criticized by scholars like Susheela on the use of the term "desirability" (Susheela 2002:396). The desirable level of fluoride content is not uniform across the world; it depends on the environment and the food habits of the natives. According to social activists and organizations in the region, 975 habitations with about 7.5 lakh people in the district are under threat and twenty thousand people are already affected. Almost all the people in the region suffer from body pain, which is a primary symptom of fluorosis.

Consumption of excess fluoride results in different types of deformities. Fluorosis cannot be cured completely. Prevention is better than cure. The major forms of fluorosis can be categorized under dental, skeletal and non-skeletal (Chakma and Rao 2004). Dental fluorosis results in discoloration of teeth, black marks and dental decay. Skeletal fluorosis affects the bones of the human body. In skeletal fluorosis, fluoride in drinking water gets accumulated on the bones and slowly replaces calcium. As a result bones become brittle. Fluorosis results in severe body and joint pains. Apart from this, fluoride also affects the soft tissues, kidney, liver, adrenal gland and reproductive organs of the body (Chakma and Rao 2004).

> "Consumption of drinking water with high fluoride by children may affect their intelligence. Tang et al. (2008) who studied this phenomenon however could not come out with a mechanism by which the IQ of children is lowered. Guan et al. (1999) suggested that when phospholipids and ubiquinone contents gets altered in the brain of rats affected by chronic fluorosis, changes in their membrane lipids may be the cause of this problem. Several other studies carried also comply with this fact (Trivedi et al., 2007; Ge et al., 2010). The presence of excessive fluoride in groundwater has its impact not only on humans but also on soil fertility and plant and animal growth."- Brinda and Elango 2011:7.

When fluorosis was first discovered in Nalgonda district, the area was under the rule of the Nizam of Hyderabad, Mir Osman Ali Khan (Asaf Jah VII). He ruled Hyderabad between 1911 and 1948. He initiated digging of lakes and ponds to increase surface water sources but this attempt failed because of lack of rain in the area.

According to an article published in a local newspaper Namaste Telangana (10th July 2012)[1] and the World Bank report (2004), an international aid agency called the Royal embassy of Netherlands allocated 375 crores to develop fluoride mitigation activities in the region during 1970s. With this money residents of a village called Batlapally shifted to another place a kilometer away and the de-fluoridation activity famously known as 'Nalgonda Technique[2]' was introduced. In 1992 the chief minister of Andhra Pradesh N.T. Rama Rao issued orders to construct a primary health center in the Marriguda tehsil, with thirty-bed capacity. It has now become the community health center and provides services to the people. The Andhra Pradesh high court as part of its judgment in 2001 directed the state government to look in to the problem and provide safe drinking water to the affected villages and increase

[1] See Appendix- II.IV

[2] a common household process: alum (aluminium sulphate) and lime (calcium oxide) are added and mixed with contaminated water to remove fluoride from it.

release of water from the river Krishna. This resulted in safe drinking water facility coming to 450 of 975 effected villages.

World Bank report of 2004 suggests that, the fluoride mitigation activities like domestic de-fluoridation units[3] failed because of problems with replacement of candle and the slow filtering capacity. The roof water collecting systems constructed by social organisations have not helped. Non-existence of suitable roofs[4], lack of rains in the region could be the reason for failure of rainwater collecting systems. The owners use them for domestic purposes by filling them with contaminated waters. They have converted rain water-collecting tanks into overhead tanks. Sometimes, the local politicians and social organizations supply drinking water through water tankers. If there is an emergency, people buy water from private entrepreneurs at a cost of fifty paise per liter.

As I mentioned earlier people know it is not safe to drink contaminated water, they know it will spoil their health, but still they will drink because there is no alternative. The effects of fluoride on human body is not universal. It affects a person in different types and forms. A person of age twenty or more will look like child of three to five years of age and a thirty year old young person may look like a sixty year old person. In some cases, there is physical growth but no mental growth and in other cases, there is mental growth but no physical growth of the body. Though there is mental growth in some cases, their body doesn't support them to lead a normal life like others because of paralyzed limbs and bent back. They don't have the strength to walk on their own because of crippled legs. It restricts them to their beds. Some people call them as "*jeevachavaalu*" (living dead). The parents and family members

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[3] Domestic water filters

[4] See Appendix- II.III

have to treat them like little children and provide service throughout their life. For some families, only income-generating source is their physical labor and ability to work as manual laborers. The body pains resulting from fluorosis interferes with their ability to work, their economic condition and livelihood.

Most people in the region cannot work after forty years of age. They feel it's a crime "to be born in the region" (*ee prantham lo puttadame neram).* The children can't play like other children; they can't go to school on their own. Some will be on their bed from the day they are born. They can't go out of the village without wheel chair. They can't speak; their body doesn't support them to walk a distance of four feet. It is extremely demoralizing to lead a life like this.

The excess fluoride consumption not only affects the human body but also social life of the fluorosis patients and their families. For example, the fluorosis patients and people from "fluorosis villages" are excluded from marriage alliances with villages where fluorosis is not an issue. According to the data gathered, there is a notion among the people that the disease is contagious but according to medical practitioners it is not contagious. Now there is some awareness among the people about causation of fluorosis. The suffering of the people from fluorosis resulted in a social movement for safe drinking water, irrigation facilities and better living conditions for fluorosis victims. Socio-cultural factors such as caste, class, gender, region and religion are responsible for stigma related to marriage alliances. The stigma related to fluorosis is unlike other stigma (Staples 2012, Van Hollen 2010) because fluorosis is an endemic disease, which does not spread by touch, inter-dining or involving in-group activities.

The stigma related to fluorosis depends entirely on the cause of the disease and social relations of the fluorosis victim. It depends on how people (both disabled

and others) interpret and responds to it. For example some people think it is a result of a person's deeds in previous life. So they tease or stigmatize fluorosis victims as "*paapi*" (sinner), on the basis of causation but this kind of stigmatization is not universal. It does not happen always because most of the people in the villages are aware of the fact of fluoride contamination. Since they know about fluorosis, they take pity on those affected by it and try to help them.

This study also looks at how family members and kinship relations help fluorosis patients. Both fluorosis patients and their family members know that the disease is not curable and consider the diseased people as burden to family. Still family members play a major role in care-giving to the fluorosis victims. The family members, especially the parents, of the fluorosis victims feel that it is their duty to take care of them and that this duty is assigned by God. In some cases, the parents have only one child who suffers from fluorosis so they give a lot of care. Some informants said that if they don't take care of their kins that are suffering from disability, neighbors and other people would scold or blame them for neglecting. This consciousness of social blame could be one reason for care-giving to fluorosis victims.

Later my focus shifted to understanding how people represented the problem of fluorosis to the state through various social movements and how the sate responded to them. As mentioned before, in the 1940s fluoride problem was discovered in Nalgonda district but still people continue to suffer. Why are people not going away from this place? What is special about this place, which is making them to stay back? Is it the resources available, properties, health policies or developmental programs? The seven-decade long history of the fluorosis problem makes it important to know the reasons for the continuous presence of fluorosis. Is it the people's failure to

represent it to the state? If not, why is the state failing to solve this problem? These are some questions I wanted to explore in my research. Basing on this I framed the following research questions this thesis attempts to address:

1. What are the local perceptions about fluorosis according to fluorosis patients, general public, heath care practitioners and social activists?
2. What are the challenges fluorosis patients and their family members face in their daily lives?
3. What role does kinship play in care- giving for disabled people?
4. How does fluorosis impact marriage alliances in the region?
5. Is there a stigma associated with fluorosis? How is that stigma experienced? In what ways do people represent this issue to the state? How does the state respond to them?
6. What is the role of various stakeholders- politicians, policy-makers and civil society members- in attempting to provide solutions to alleviate the problems of fluorosis patients?

Field Sites and Methodology:

I undertook fieldwork in five villages in Marriguda mandal, Nalgonda district of Telangana region, between May to July 2013. I personally conducted the research in multiple locations: in disabled people’s homes, in the hospital, and in public places. Major data was collected from fluorosis victims, their parents, caregivers and social activities. The informants were drawn from different socio-economic groups and they were also broadly representative of age, gender and religious groups of the region (Muslim minority, converted Christians, with a major composition of Hindus). The study villages are namely, Marrigudem, Shivannagudem, Sarampeta, Vattipally and Kudashpally. The reason for choosing these five villages is that the fluorosis victims

are spread among these villages and transportation is easier compared to other villages.

I explored socio-cultural factors associated with fluorosis. The initial focus of this research was to understand the experience of disability; everyday difficulties faced by the fluorosis victims as members of society and lay understandings of fluorosis among local people. To this end I conducted interviews with disabled persons, their family members and other residents in the villages. I also observed daily activities of disabled people and caregivers of disabled people.

Qualitative Research

For this thesis project, I used qualitative research methodologies commonly used by sociologists and anthropologists in India and elsewhere. For this study, I conducted research among fluorosis patients and their families in five villages of Marriguda mandal, Nalgonda district. The study does not focus on drawing generalizations to the larger society. It aims to understand problems associated with fluoride contamination and fluorosis on a small-scale, at the village level. The main focus of this study is to explore the experiences of being disabled due to an external factor, such as excess fluoride content in water, and the effect of that experience on an individual's daily life and the impact of care-giving for disabled persons on the family. Therefore, this study involved in-depth interviews with fluorosis patients and their family members. Only a qualitative study can bring out in detail, the subjective experience and meaning of disability at the level of the individual, family and community.

For this fieldwork, I spent two months last summer in the villages. I stayed there, ate the food available there, and spent a lot of time getting to know the informants and building a rapport. "Qualitative research involves hanging out, talking to people and gaining their trust, and generally letting people know that you're in for

the long haul with them" (Bernard, 2006:385). This "hanging out" with the people and gaining trust is very important in qualitative research in order to collect the kind of in-depth data required for this topic. In some villages, for example, the resident did not trust outsiders because they believed that media reports about fluorosis have stigmatized entire villages. In such cases, it takes time to gain the trust of people and get them to reveal their experiences and difficulties due to disability.

The important elements in the qualitative research are ethnography and participant observation. The method of ethnography involves people describing their culture from their point of view. But as Clifford Geertz (1974) says, "the ethnographer does not, and, largely cannot, perceive what his informants perceive" (Geertz, 1974:30). We cannot fully understand things from the informant's point of view. But the ethnographic method helps us to understand people's representations, for example, "words, images, institutions, behaviors in terms of which people actually represent themselves to one another" (1974:30). In the words of anthropologist Russell Bernard (2006), the ethnographic method is "a narrative that describes a culture or a part of culture and usually a phenomenology, and there is still no substitute for a good story, well told, especially, if you are trying to make people understand how the people you've studied think and feel about their lives" (Bernard, 2006:24).

Another important method in doing an in-depth ethnographic study is participant observation, where the researcher goes to the people and gets himself involved in day to-day activities of his respondents and becomes part of the society during the course of fieldwork. It is not easy for a researcher to participate in the daily lives of people without knowing them well and gaining their trust. But by spending a lot of time in the area, one can understand the place and people more closely.

Participant observation also includes the following: “field notes taken about things you see and hear in natural settings; photographs of the content of people’s houses; audio recordings of people telling folktales; videotapes of people making canoes, getting married, having an argument; transcriptions of taped, open-ended interviews, and so on” (Bernard, 2006: 344). Though I conducted household surveys using structured questionnaires (see appendix- I), the time I spent in the field allowed me to “collect life histories and talk to people about sensitive topics” (Bernard, 2006:344)

Sampling Techniques

To identify key informants, and especially people and families with fluorosis patients in the five villages, I employed snowball-sampling technique. Bernard recommends this sampling method as useful to study those who consider themselves to be “stigmatized” (Bernard, 2006:385). In this method, I explained about my project to some of the key informants and asked them to introduce me to people they know who would be willing to speak to me. Through this method, “you get handed from informant to informant and the sampling frame grows with each interview. Eventually, the sampling frame becomes saturated—that is, no new names are offered” (Bernard, 2006: 385).

Apart from people with fluorosis and their family members, I also spoke to health care providers, and social activists in the region. I conducted a basic household survey of hundred households. Out of these, I further conducted in-depth interviews in fifty five households with individuals I spoke to thirty seven men and eighteen women. Thirty four interviews were conducted with disabled people and twenty one interviews, with disabled person’s family members. The following tables provide information on socio-cultural composition of the informants, their educational qualifications and age distribution.

Table 1.1: Religious composition of informants.

S.no	Religion	Number
1	Hindu	41
2	Christian	13
3	Muslim	01
Total		**55**

Table 1.2: Caste composition of informants.

S.no	Caste	Number
1	SC	23
2	ST	5
3	BC	24
4	OC	03
Total		**55**

Table 1.3: Educational qualification of informants.

S.no	Class	Number
1	0	28
2	1 – 5	5
3	6 – 10	6
4	11 – 12	8
5	Bachelor's degree and above	8
Total		**55**

Table 1.4: Age-wise distribution of informants.

S.no	Age	Number
1	20 -30	11
2	31 – 40	15
3	41 – 50	11
4	51 – 60	14
5	61 – 70	4
Total		**55**

Out of the thirty four disabled people interviewed, there were twenty men and fourteen women. The caste composition of disabled persons interviewed is as follows:

seventeen from scheduled castes, fourteen from backward castes, and three people from scheduled tribe. Twenty four people were Hindu, nine, Christian and one Muslim. As for educational levels, twenty three of the thirty four disabled persons were illiterate and 11 were literate with one person qualified with a bachelor's degree.

I tried to obtain village maps and details of the geographical area at the panchayat office in the villages but I could not get them.

Difficulties in accessing the field:

In the initial stages of fieldwork, it was very difficult to enter the villages and enquire about fluorosis victims. One has to know someone in the village to go there. People of these villages do not prefer to talk to outsiders. They suspect outsiders of having spoilt their village name. In some villages, people get angry and drive visitors out of the village if they see a camera in the visitor's hand. The villagers feel that, outsiders take photos and videos to publish them in local newspapers and television; it affects chances of marriage with people in other villages. So, to overcome this hurdle I took help from Amsala Satyanarayana, father of Amsala Swamy (a fluorosis victim) to get introduced to the villagers. It took me ten to fifteen days to gain trust from people in all five villages. For this reason, prior permission is taken from the people while taking the photographs. All the informants are given pseudonyms except those who are well-known within and outside the village.

Review of Literature:

It is evident from sociological and anthropological research that disability is a socially constructed phenomenon. According to Helman, "a disabled body is not necessarily a sick body"(2007:35). Though all of them are not sick, disabled people are discriminated by others and the degree of discrimination varies from society to

society. As we know, disability is associated with the body; the conceptions about the human body vary in different cultures. “In every society, the human body has a social as well as a physical reality” (Helman 2007:19). The body is not just a biological organism. Based on its role, position and status, the body has a value in society. Abled bodies are more valued because of their role and contribution to the progress of society. This is also true in the case of fluorosis patients. Some of them are respected for their involvement in social movements. Others who are not capable of speaking in public meetings and attracting the masses are not given much importance by the people as well as the social activists. Because of this reason, only a few people are well known among all other fluorosis victims in this area. Some people criticize social activists for using fluorosis victims for personal benefit.

That is a different aspect of research but, apart from participating in social movements, fluorosis victims also participate in household work. For example Tirupatamma, a thirty-five year old unmarried woman manages to wash her clothes, cooks her food and does all the domestic labor. Since her parents’ death, she managed to live on her own. Similarly, Swamy, a thirty-three year old man, helps his father. He sits in his father’s barbershop in his absence. He makes customers wait till his father comes back by talking to them. Ramya, a twenty four year old woman severely suffering from fluorosis, manages to clean utensils and floor in the house. They are all abled in some or the other sense and are respected by society and family members for their positive aspects of disability.

In some societies there are positive aspects to disability. “Stigmatization of all physical impairment is not universal, in many cultures different forms of impairments are seen in a more positive light, and disabled people play a full role in community life” (Helman, 2007:37). Some people believe disabled people have special powers

and they also relate causation of disability to curse of god, divine punishment, sorcery etc. (Fadiman 1997; Helman 2007:37). "The socio-cultural particularities that render disability are different in different places (Ghai 2001; 2002; see Das & Addlakha 2007: 128 cited in Staples 2011: 547)".

I also encountered such beliefs regarding fluorosis. Some of the oldest people believe that fluorosis is result of an affliction (*grahanam morri*). But the younger generations do not agree. Young people say that scientifically there is some effect of affliction on human body but fluorosis is not related to it because fluorosis is a disease. They see a clear difference between fluorosis and "*grahnam morri"*. These differences will be discussed in detail in the later chapters of the thesis. The social activists say that earlier everyone believed in superstitious beliefs regarding fluorosis but now they are in a position to identify the difference between a disease and the supernatural act. Though there is a difference in opinion about "*grahanam morri",* most of them believe in "*karmasiddhantha*" (law of karma). The parents or the relatives of the fluorosis victims often refer to this concept. They say that though it is because of water contamination, why should their loved ones suffer? Why not others? So they conclude that gods must be testing them or punishing them for their previous deeds. Some people even relate this to religious conversions.

The theories about causation and how people interpret and respond are important in understanding disability and stigma. There are two models of disability; the medical and the social. There is a standardized classification of disability given by WHO called International classification of Impairments, Disabilities and Handicaps of 1980 (Helman, 2007:35). According to this classification, the human body is treated as a biological organism and disability is measured in terms of size, shape and deformities of the body. The social model includes curses or divine punishments and

sorcery. "Most people attribute disability to '*karma*' according to Hindu mythology; the current circumstances are consequences of previous deeds" (Staples 2011: 547). Staples, who studied leprosy in south India, argues that, in India parents of the children born with physical disability relate it to '*karma*'.

According to Ron Barret (2005), an anthropologist who worked on leprosy patients in the Indian pilgrimage city, Varanasi, people with leprosy are treated as almost untouchable in Indian society. "Indians with HD[5] are often permanently ascribed to the most untouchable categories of humanity" (Barret 2005: 216; Fristst 2000). Barrett traces three ways in which stigma is physically expressed; "first is concealment leading to under treatment, second is dissociation and self-neglect and third is self-mutilation under the conditions of extreme poverty" (2005:217). Barrett further says that social mark of leprosy is harmful and heritable; the children of these patients are also treated as untouchables.

Though fluorosis is not a contagious disease, it has a similar stigma related to "*karma siddhantha*". Some people believe that parents or the fluorosis victims themselves have committed some sin at some point of time and it has resulted in this disease. Some people do think it is heritable and refuse marriage proposals from these villages. Unlike leprosy patients, most of the fluorosis victims do not take any drugs except painkillers. But some of the parents of the victims use liquor to get rid of familial pressures. The stigma related to fluorosis is different from Barret's framework because stigma related to leprosy comes out of the fear of contagion, which is not possible in fluorosis. But stigma about disability is not without problems.

Stigma varies depending on time and space. It is not the same at home and social spheres. Paternal kins stigmatize more than the maternal kins at home. For

[5] Hansen's Disease (Leprosy)

example, in Van Hollen's work on HIV/AIDS in south India (2010), she found that mothers-in-law blame their daughters-in-law for getting infected with AIDS but there are certain instances where fathers-in-law support daughters-in-law and give property rights to them in the case of death of their son (2010: 649).

I have come across such instances in my fieldwork. It happens when paternal kins visit fluorosis patient's house for functions and festivals. When all the paternal kins sit together and have conversations about fluorosis victims, they often try to provoke disabled person's grandparents. For example, they say, "why are you are taking care of this unproductive child? Why don't you send them to a government hostel and get rid of this unproductive labor?" Whereas, the maternal kins do not think it is unproductive labor. The parents and siblings of the disabled person think it is their duty to take care. They do not want to leave victims in the hostel with fear of poor care. The parents of the children want them to be at home in front of their eyes because they do not expect the same kind of care from an unknown person in a hostel. They are also worried about the society in the case of a single child. They worry that they may be chastised for neglecting an only child. Usually, parents play an important role in taking care of the victims. Siblings of the disabled people are not that involved in care taking. In most of the cases they try to escape from this duty. In Tamilnadu, a HIV positive woman prefers to stay away from her unmarried siblings (Van Hollen 2010:644). She thinks that the stigma associated with the disease may prevent the marriage of her younger siblings. In case of fluorosis also it becomes very difficult to find spouse for their siblings because it is directly linked to care giving. In order to escape from this duty, the male siblings and their spouses go away from the family.

Rapp and Ginsburg (2011), anthropologists, share their own experience of difficulties and as parents of 'atypical' children (Rapp and Ginsburg 2011:379). In

most cases of fluorosis the parents keep their disabled children away from other people because of the state of personal hygiene. Most victims are not in a position to take care of their personal hygiene. These patients defecate, pass urine and spoil their clothes; so the neighbors and relatives behave rudely with the parents of disabled children very differently. There are certain instances where people have stopped visiting such families. For example, during the marriage of Narayana's son, he left his disabled daughter under a tree in the village as if she did not have any relation with the family and completed the marriage rituals in her absence. He did not want guests to feel uncomfortable during the marriage ceremony because of his daughter's appearance and the condition of her personal hygiene. Such situations make it very difficult for family members but they feel obliged to undertake such steps for the sake of society.

Mathew Kohrman (1999) is another anthropologist who has worked on disability issues, in China. In looking at the gender dynamics of disability, he says disabled men face more problems in finding partner than a disabled woman. In case of fluorosis it is not the same. Both men and women face the problem in finding partners but there is a possibility that if the man is capable of earning his livelihood, as in case of Suresh, a television mechanic who is economically settled, he can get married. Though he faced many rejections in the initial stages, the poor economic condition of the woman and the professional background of Suresh made it possible to bring them together and they are living happily. This is in line with Kohrman's argument: the importance of narrating disability and the role of *neng li*. *Neng li* refers to the ability of a disabled man (Kohrman 2000:893). If the disabled man is able to work and earn his livelihood, he has better chance to find a partner.

Kohrman in his work on Deng Pufang, the eldest son of Deng Xiaoping, one of China's top government leader in the 20th century and his struggle towards authorizing disability in China, shows how a disabled man from an influential political background managed to succeed and established China's first disabled persons' federation. The poor background of the fluorosis victims could be the reason behind the survival of the problem for about seven decades from now. In the words of one of the informants,

> "If any politician had a child like me, they would have known how difficult it is to be father of a disabled child and they would have solved this problem long back" - Amsala Swamy.

Swamy mentions this point in almost all the political meetings he attends. He complains about political leaders for their inaction because they do not have personal experience of fluorosis. The absence of negotiating power and lack of political background of fluorosis victims is a major factor to be considered in understanding the logic behind the existence of fluorosis in the region for so long.

The data gathered from the field illustrates vividly that socio-cultural beliefs and kinship relations make it challenging for families to provide care for fluorosis victims. Since it is very difficult to include all the fluorosis cases in this thesis, I will be presenting a few case studies in the forth-coming chapters of this thesis.

Chapter - II

Ethnographic Profile

Study Area:

Nalgonda district is in the southern part of Telangana region of Andhra Pradesh with geographical area of 14,240.sq. km. And it has a population of 3,483,648. The name is derived from the words *nalla* (black), *konda* (hill) i.e. Black hills. The district headquarters Nalgonda is about 104 k.m from Hyderabad and connected by both rail and road transport. Nalgonda district is recognized as backward district of the sixth five-year plan (1980-85). The Andhra Pradesh government receives funds from Backward Region Grant Fund (BRGF) program of the Government of India. Most of the drinking water sources in the district are based on ground water.

Table 2.1: Water amenities in the district.

S.no	Type of amenities	Numbers
1	Hand pumps	16403
2	Piped water supply schemes with storage reservoirs	713
3	Mini PWS/ direct pumping	1591

Source: World Bank Report (2004).

History of the region:

Nalgonda region was under the rule of Mauryas till 230 BC (Sastri 2009). Then, it came under the rule of the Satavahanas who ruled between 230 BC to 218 AD. Later Ikshvakus ruled from 227 AD to 306 AD. After Ikshvakus, Pallavas and then the Vishnukundins took over the region. Vishnukundins ruled from first quarter of the fifth century A.D to the first decade of the seventh century A.D. Later Kubja Vishnuvardhana ruled this territory with Vengi as his capital. Next came the

Chalukyas of Badami (543-757A.D) and then the Rashtrakutas. Rashtrakutas fell in A.D 973 and gave room to the Chalukyas of Kalyani. The Chalukyas continued till the end of 12th century.

During the medieval period, the district came under the control of the Kakatiyas. During Prataparudra's time the kingdom was annexed to the Tughluq Empire in A.D. 1323. During Muhammad-bin-tughluq's period, Musunuri chief Kapayanayaka ceded a part of Nalgonda to Ala-ud-din Hasan Bahman Shah. Later the region came under the rule of Recherlas of Rachakonda and Devarakonda. During Ahmad Shah I's period the region was annexed to Bahmani kingdom. Jalal Khan in A.D 1455 declared himself king at Nalgonda, but it was a shortlived affair. The region was brought back to Bahmani kingdom. During the Bahmani Sultan Shihabud-din Mahmun's time Sultan Quli was appointed as tarafdar of Telangana. After him, his son Jamshid took over the rule. Later the district came under the control of Qutub Shahis till A.D.1687.

During the modern period, the Mughals & the Asaf Jahis starting with Nizam-ul-Mulk (Asaf Jah I) defeated Mubariz Khan in the year 1724 at Shakarkhelda in Berar and ruled the Deccan in an autonomous capacity. This district, like the other districts of Telangana, passed under the reign of Asaf Jahis and remained under them for a period of nearly two hundred and twenty five years.

The field site constitutes of five villages of Marriguda mandal of Nalgonda district. The mandal headquarters Marriguda village is also included the study. These villages were selected based on the good transport facilities available and distribution of fluorosis victims across the villages. There is at least one person from each family suffering from body pain, which is a symptom of fluorosis. The villages included in

the study are namely, Marriguda, Vattipally, Shivannagudem, Sarampeta and Kudashpally.

Profile of the villages:

Marriguda mandal consists of fifteen villages. This place is ninety-six kilometers away from Hyderabad and is well connected with road transport. According to 2011 census available at Mandal Revenue Office Marriguda, the total number of households in the village is 822 with a population of 3602 and the total population of the Marriguda mandal is 36710. Total number of settlements in the mandal is 77.

The following table shows the population distribution of the study villages. This data is taken from the census records of 2011. The table also represents the number of males and females in all the villages. The average sex ratio comes to 961 females for 1000 males.

Table 2.2: Village wise total population

S.no	Name of the village	Number of households	Total number of persons	females	males	Sex ratio
1	Marriguda	822	3602	1738	1864	932:1000
2	Vattipally	525	2247	1060	1187	893:1000
3	Shivannagudem	1456	6111	3052	3059	997:1000
4	Sarampeta	314	1201	590	611	965:1000
5	Kudashpally	860	3285	1622	1663	975:1000
Total		**3977**	**16446**	**8062**	**8384**	**961:1000**

The following table shows the number children below six years of age in the villages. The sex ratio among the child population is 91 females for 100 males. This is a bit low when compared with total sex ratio of the villages. It could be because of instances of the foeticide in the villages but there is no clear evidence. Only social activists in the region referred to this. There is a need for further research to probe into this issue.

Table 2.3: Village wise child population below 6years of age.

S.no	Name of the village	Total number of children	Males	Females	Sexratio
1	Marriguda	321	165	156	94:100
2	Vattipally	225	135	90	67:100
3	Shivannagudem	629	326	303	93:100
4	Sarampeta	111	53	58	101:100
5	Kudashpally	331	166	165	99:100
Total		**1617**	**845**	**772**	**91:100**

The average sex ratio of the villages seem interesting when compared to the sex ratios of the state and the country. As per census 2011 sex ratio of India is 933 with rural sex ratio 946 and urban sex ratio 900. The sex ratio of Andhra Pradesh state is 992. In the study villages, the average sex ratio is 961. When we look at village-wise sex ratios, Vattipally has low sex ratio of 893 and child sex ratio of 67:100. Shivannagudem accounts for its highest ratio and Sarampeta ranks high for its child sex ratio of 101:100.

According to 2011 census, the average child sex ratio for India is 92. The child sex ratios of some of villages are quite low when compared to total sex ratios of the villages. The average sex ratio is 96 females per 100 males whereas child sex ratio is only 91 females per 100 males.

Environment:

Fluoride is a mineral, which is naturally present in the earth's crust. It is one of the useful mineral like calcium, potassium and sodium, which the body needs. The nominal content of fluoride strengthens bones and teeth. But excess fluoride content will result in fluorosis. The fluoride content in the region exceeds the minimum

permissible levels. It ranges from 2ppm to 14ppm in some villages, whereas minimum permissible level depends on the health status and food habits of the people. Decrease in surface water bodies and decrease in ground water table lets fluoride content in the rock beds of the earth's crust enter the ground water table. This affects people when they drink contaminated water.

Economy

The major economic activity of the village is agriculture-related labor along with "traditional" occupations such as leatherwork, pottery, basket making, gold smithy, back smithy etc. According to official records a total of 14,23,423 hectares is agricultural land in the district and more than 50% of it is cultivable land. The main crops grown in the district are paddy, jowar, bajra, ground nut, red gram, green gram, castor and sugar cane is being grown some places, which are far from the study area.

The economy of the region is dependent economy. The region does not produce enough food required. This is due to scarcity of water and poor irrigation facilities. The people, therefore, do not depend on agriculture. They grow dry crops like cotton, jowar and groundnut. Some people do cultivate vegetables and paddy in the fields through bore well irrigation and provide employment to other villagers. Even though they have MGNREGA[6] cards, which assure them hundred days of employment per year, village residents engage in construction work under private contractors. Some even collect forest produce but not as often or as much as before. Some cattle herding communities[7] depend on forest mainly for grazing, fire wood collection, timber and tamarind collection. The agriculture season is between July to

[6] The Act of 2005 provides enhancement of livelihood security, giving at least 100days of guaranteed wage employment in every financial year to every household, whose adult members volunteer to do unskilled manual work.

[7] Golla and Kuruma caste (Yadavs)

February. After that some of them migrate to Hyderabad and other urban places and work as wage laborers. Some of the disabled people migrate to the city for begging.

Food consumption:

Food is one of the most important factors in the context of fluorosis. Food not only suppresses hunger but it also prevents a person from getting affected from fluorosis, strengthens the body to fight against it and helps in getting adjusted to the environment. Food also plays a key role in the organization and stratification of society. Scarcity of food makes people depend on each other. At the same time certain food habits of the people divide them too. Most of the elderly people and some of the fluorosis victims in the region have food only two times a day. The reason for this could be low appetite and digestive capacity because of disease. The children and young people have three meals per day. The people in the villages do not have proper irrigation facilities and therefore are not in a position to grow enough food.

People mostly depend on the weekly market to meet their food needs. The staple food is rice (*biyyam/annam*), vegetables and sometimes meat. Most people do not have the habit of breakfast. The major meal is at noon and in the evening. During every meal, rice with curry is eaten. Food is cooked twice a day, morning and the other is in the evening. The meal cooked in the morning is consumed both in the morning and afternoon and the meal, which is cooked at night, is consumed only once. Sometimes the leftover meal in the night is consumed during the morning meal. Some sections of scheduled castes consume all varieties of meat including beef whereas certain castes consume only chicken and mutton and do not consume beef as they believe consuming beef is a sin. There are some food items which are affordable for people from the lower socio-economic groups, which can help in resisting

fluorosis. However these food sources should be grown in fluoride free soil so that contamination could be reduced. The recommended food by the doctors and dieticians to fight against the fluorosis can be seen in the following table.

Table2.4: Showing presence of minerals in foods.

General Name	Telugu Name	Calcium (mg/100G)	Magnesium (mg/100G)	Vitamin C (mg/100G)
Ragi	Ragulu	344	-	-
Agathi	Avisalu	1130	169	-
Amarath	Thotakura	530 - 800	4.2	179
Colacasia leaves	Chama Aku	1546	12.8	-
Curry leaves	Karivepaku	836	-	-
Poppy feed	Ghasalu	1584	9.9	-
Jiggery	Bellum/ Gur	1638	-	-
Gingelly Seeds	Nuvvulu/Til	1450	5.2	-
Jowar	Jonnalu	-	171	-
Cumin	Jeelakara	1080	475	-
Amla	Usirikaya	-	-	600
Green chilly	Pachimirchi/ Harimirchi	-	-	111

Source: National Institute of Nutrition, ICMR Hyderabad (1971). Quoted in D. Raja Reddy's booklet on endemic skeletal fluorosis.

Calcium, Magnesium and Vitamin C rich food along with safe drinking water can help the people living in the region to fight against the disease.

Housing Pattern:

The houses in all the five villages vary from kacca to pacca houses. In the scheduled caste colony of Sarampeta and scheduled tribe colony of Vattipally, the houses look similar; the Christian missionaries in the middle of the twentieth century built them. In other three villages we can find a variation from thatched huts to mud walls with tiled roof, to concrete roofed houses. We can also identify the half built

structures under the Indira Awas Yojna[8] Scheme. The houses are arranged in an order with pathways in between. All the houses belonging to one caste group are in most cases located in the same place. These clusters are '*basti*'[9] with their caste names such as *madigabasti, malabasti, kummaribasti, mangalibasti* etc. This classification of colonies can be seen in all the study villages.

Polity:

Old administrative system: The region was under the rule of Nizams until 17th September 1948. Prior to that, the feudal government of the Nizams resulted in Telangana rebellion against the Zamindars and other feudal lords of the Telangana region. People of Nalgonda district are known for their active participation in the movement during 1946 (Ram.1973: 1025). 'Vetti chakiri movement' (movement against bonded labor) also known as Telangana Raithanga Sayudha Poratam started in Nalgonda against oppressive feudal lords and spread to other parts of the Telangana region. During this period, crucial political decisions and judgments would be passed by the local administrators known as *Dora* (lord). These lords were known for exploitation, high tax collection and providing loans at high rates of interest against landed property.

New administrative system: All the five villages come under Marriguda Mandal, which is under Munugodu Assembly constituency. All the villages have panchayats. The Panchayat Raj system introduced in 1958 has been the modern administrative system where ward members, sarpanch or the head of the village is elected through local body elections. The sarpanch has the power of making decisions about the

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[8] Objective is the construction of free houses to people from ST/ST categories and below poverty line.

[9] Is used as area or locality.

village affairs. The new administration includes member of the Mandal Parishad Territoreal Constituency (MPTC) at the mandal level and member of the Zilla Parishad Territoreal Constituency (ZPTC) at the district level along with Member of Legislative Assembly (MLA) at the level of constituency. These political representatives are the crucial administrative decision makers.

Caste relations in the village today:

The traditional caste relations can still be seen in the study villages. The barbers, pot makers and blacksmiths still provide services to other castes in exchange of food grains, especially to the higher castes who are engaged in agricultural activities. Caste heads play a crucial role in solving disputes. The dominant castes in these villages are Reddy and Kapu. Even today villagers address these caste people as "*dora*" which means "lord". This shows the dominance of certain castes over other castes. The scheduled tribes cannot be categorized with these castes but are nevertheless an integral part of the village community. The caste system is not restricted only to the Hindus. Even among the Christians we can see the same caste composition as Hindus. Fluorosis victims are from all caste groups and all age groups.

Literacy and Education:

The total literate male population of Marriguda is thirty-two percent and female literate population is twenty-one percent. The village wise literate population census is given in the following tables. Though these census records include all the people who can read and write, the highest education qualification among the people I interviewed is a bachelor's degree.

The following tables show the detailed information about the literacy rate of the Marriguda mandal.

Table 2.5: Total Literate Population of Marriguda mandal

		Population			Percentage	
S.no	**Category**	**Male**	**Female**	**Total**	**Male**	**Female**
1	Literates	11892	7594	19486	32.394 (32)	20.686 (21)
2	Illeterates	6760	10464	17224	18.414 (18)	28.504 (29)
	Total	18652	18058		50.809 (51)	49.191 (49)
	G.total	**36710**		**36710**	**100**	

Table 2.6: Total literate population of five study villages

S.no	Name of the village	Total number of persons	males	females
1	Marriguda	2331	1406	925
2	Vattipally	1291	813	478
3	Shivannagudem	3134	1958	1176
4	Sarampeta	630	396	234
5	Kudashpally	1676	1016	660
Total		**9062**	**5589**	**3473**

Health and Sanitation:

The primary health center (PHC) in Marriguda was started in 1992. Later a hospital was started in 1994 with thirty-bed capacity. First it was started as a PHC and later upgraded to UPHC and now it is CHC (Community Health Centre). There are six doctors in the hospital. The doctors are present in the hospital from 9 AM to 4 PM. There are six staff and field nurses in the hospital. The hospital undertakes vasectomy/tubectomy surgeries every Monday and Thursday of the week. There are TB and AIDS detection camps in the region. According to the chief medical officer, there is no other health center for around a radius of thirty-five kilometers. It is very difficult to convince doctors to come from Hyderabad to work here.

Table 2.7: Water amenities in the mandal

S.no	Type of amenities	Numbers
1	Hand pumps	252
2	Piped water supply schemes	16
3	Mini PWS	18
4	Direct pumping	7
5	OHSR tanks	22
6	GLSR constructions	42
7	Krishna water supply	To all villages

All the five villages are located in a radius of ten kilometers with Marriguda as its center. Though the district is known for fluorosis, supply of safe drinking water is helping them to fight against the disease. There are very few new cases of fluorosis in Marrigudem, for the past five years. But there is a great need to provide healthcare for people already affected by fluoride contamination. Though there is a community health center (CHC) in Marriguda, most people depend on indigenous and self-proclaimed healers and rural medical practitioners (RMP).

Chapter - III

Fluorosis- Experience and Perceptions at the local level

Swamy's aunt (his father's sister) and her husband suggested to his grandmother that he should be killed. They wanted to kill him since he was disabled and they felt he was a burden to the family. But Swamy's father says,

> "Though he is disabled, He is our only son. How can we kill him, how dare they provoke my mother to kill my son?, they are not giving food to him or taking care of him. I am feeding him and serving him all the time. I don't have any problem in doing that, I will serve him till my death and after that god knows what happens to him".

The caregivers build confidence in disabled persons by saying such things. This behavior of the relatives is hurting to the parents of the disabled person. Swamy's father Satyanarayana consumes alcohol at night to forget such taunts from relatives. He accuses his mother for causing his wife's mental illness. His mother keeps on fighting with his wife and tortures her by giving multiple tasks at a time because of which she is suffering from mental illness.

The medical understanding of fluorosis as a disease caused by excess fluoride in the body is important in diagnosing and treating the disease. But the cultural perceptions of fluorosis also play an equally important role in care giving, health care decision-making and experiencing disability. Common symptoms of fluorosis according to the people in the study area are laziness, joint pains, nerves weakness and restlessness, breathing problem, mental illness, renal failure and paralysis. Naturally, at the age of forty most people in the region start suffering from severe body pain, which excludes them from heavy manual works.

There is confusion among the people about the reasons for body pain. Some people think it is because of manual work they did throughout the day and others think it is because of water contamination. But most people, regardless of their work, suffer from these kinds of symptoms. Though most people know about fluoride contamination and fluorosis resulting from it, they strongly argue that, contaminated water is not bad for health because they are using local water for a very longtime and they are unaffected. The residents do consume "sagar water", which is supplied by the state, but some of them are unhappy with it. They say it is useful only during summer season because they believe 'sagar water' gives relief from sunstroke whereas 'fluorine water[10]'causes it. Therefore except during the summer season they consume local water during the rest of the year. This difference in view about the causation is important because some people continue to drink contaminated water because they believe that, SW[11] is not natural water. It is chemically treated and tasteless compared to natural bore well water available in the village. So people say that the chemicals mixed in water is not good for health.

Further investigation reveals that they feel they are getting used to contaminated water (*alavatu padipoyam)* and it is no longer affecting their health. They argue that, throughout the day they work in the fields and drink water from the agricultural well and it is not spoiling their health. It is true that, some of the agricultural laborers drink water from wells and it is not affecting their health because, it is less contaminated compared to ground water. Therefore some people argue that there can be other reasons for fluorosis.

[10] People use 'fluorine water' for contaminated water.
[11] SW= Sagar Water

Differentiating contaminated water from sagar water:

Yadagiri, a resident said that, the contaminated water is heavier than the normal water. One can actually see the difference in weight and can also differentiate with color and taste of the water. Contaminated water is salty. Unlike the SW supply, contaminated water is regularly supplied through domestic taps. One can also differentiate contaminated water form normal water by cooking rice. Generally rice cooked with contaminated water is yellow in color and has a strange smell whereas rice cooked with normal water is white in color.

SW has been available for the last five years. Before that, people relied on bore well waters in the village. Those who can afford purchased water. Organizations like 'Bethel Home[12]' in Sarampeta village supply water at five rupees for a pot. The head of Bethel home says that they wanted to supply water free but maintenance becomes tough and so they collect minimum charge from the users. SW is supplied through public taps and common tanks build at different parts of the village. This supply is not regular. It comes on alternate days. Even that cannot be guaranteed because there will be some damage to pipelines. If there is damage and people might have to wait for four to six days. During this period, they have to depend on contaminated water. Even if there is a regular supply of SW, there are technical problems involved in the distribution. People who stay near the tank always get more benefit than those who live far. Those who live near the tank use SW for domestic use, whereas others cannot do so since it involve lots of labor to carry water from a distance. When there is delay in supply from the water board, these people have to manage form the amount of water they filled earlier.

[12] A Christian organization in the village owns water filter.

Local perceptions of fluorosis:

There is a difference between disability resulting from fluorosis and other diseases. For example, leprosy is a contagious disease, which also results in disability. Fluorosis is not just a physical disability. As I mentioned earlier, it has multiple effects on the human body. One cannot find any wound on the patient's body but can see different kinds of deformities. Some diseases affect only a certain part of the human body but skeletal fluorosis affects the whole body of the person by replacing calcium. Some of the fluorosis patients often say that their disability is worse compared to polio. In the case of polio victims, the diseased person can walk whereas fluorosis victims don't have the strength to even stand up.

The socio-cultural perceptions of fluorosis are important to understand the health seeking behaviors and care-giving to the fluorosis patients. There were various beliefs and understandings of fluorosis in the past, which are not present in the present day context, but they are important in some cases. There are some people who still believe that fluorosis is caused by supernatural power. Some believe it is the effect of affliction, some believe it is a result of sins committed in previous birth but most people believe it is because of water contamination. Those who think it is because of water contamination also believe that fluorosis is contagious and genetically inherited form one generation to other which is not true. But this perception has an important impact on marriage alliances in particular.

There are different forms and stages of fluorosis; it could affect a fetus in utero. According to Dr. Dasya Nayak, chief medical officer, community health center, Marriguda, it is not possible to detect fluoride by ultrasound scan during pregnancy. One can detect congenital anomalies by scanning but not fluorosis. Traditional midwives (*Mantrasani/Daayi)* check a newborn baby to see whether a baby has any

deformity, immediately after the birth. Even if there is no deformity at birth, one cannot say that the baby is safe. It can affect him/her at any stage of life so parents have to take care of the child for at least till the age of ten to fifteen years. There is evidence of some people getting affected at the age of fifteen. For example, Tirupatamma went to school up to class ten. The effect of fluorosis started in 1995 when she was in class eight. In the ninth and tenth class she started walking with the support of a walking stick. Eventually she could not walk. Similarly, there are about forty children below fifteen years of age in Marriguda mandal who are suffering from various disabilities like mental illness, learning disabilities, visual and physical disabilities. There is a special school for these children, which is not functioning due to low attendance.

There are some people who believe it is a "*papam*" (sin) to give birth to disabled of children. For example, in one case a family converted to Christianity because the woman did not conceive for about five years after marriage. After conversion she gave birth to two children, both girls. One of them is a disabled child. Neighbors taunt her saying it is her sin of religious conversion that has resulted in having a disabled child (*"shapam"*).

Another local notion regarding fluorosis is "*Grahanam Morri*" (*Morri*= a fault, defect or broken edge). If a pregnant woman does any work on the day of eclipse, especially during her fifth month of pregnancy, it results in the delivery of a disabled child. Venkamma, a traditional midwife strongly believes that "*Grahanam Morri*" affected her grandchild Amsala Swamy whereas both Swamy's father and Swamy believe that it is resulted from fluoride water. Venkamma blames Swamy's mother for not listening to her and washing clothes on the day of eclipse.

> "I told her not to work. I repeatedly warned her. But she didn't listen to me. It her mistake and she is fully responsible for his disability" -Amsala Venkamma

There are also accounts of people going to indigenous medical practitioners and bonesetters for treating such disabilities. Both traditional and biomedical practitioners agree that this disease can be cured in initial stages but prevention is better than cure. Swamy's case is explained in further detail later in this chapter.

Earlier, people would link physical disability to polio but now there is an increasing awareness about fluorosis. There are two cases I found during my fieldwork, where disability resulted from polio vaccine and fever injection. The parents of these children still regret that. They say it is their mistake that they didn't tell the doctor before giving fever injection that the baby has been given polio drops. They always feel guilty for doing that and they do not have anything against god. They don't believe in divine punishment.

There are some cases, where people link mental illness to spirit possessions. They say that because of spirit possession, a person is not active like others and does not listen to parents. The victims of spirit possession do not care about anything; they are always in their own world. In such cases, their family members never link it to the fluorosis. Most people do not agree that only contaminated water is responsible for fluorosis. As I explained in Chapter one, fluorosis can also affect the mental health of a person.

Stigma or teasing:

When it comes to stigmatizing disabled people, neighbors play a major role, but there are exceptions. The neighbors are good in the case of fluorosis patients. They don't tease fluorosis patients for suffering from the disease because; they know each other

for a long time and also, the reason for getting this disease. They help the family of diseased people when they need help in taking care of the patients. They even help fluorosis patients to some extent when there are no family members are around to help. But there are instances where neighbors stigmatize fluorosis patients and their family members, when there is a fight between the families. If they have good relations with patients and their family they don't tease whereas if there is a fight between neighbors, they tease and stigmatize. Sometimes villagers tease disabled people by calling by certain names- "*Kuntodu/kuntidi*" (a person who cannot walk), "*Gunodu/gunidi*" (a person with bent in backbone), "*buddodu"* (little one) etc. It almost appears that they enjoy cracking jokes on disabled people. Relatives tease the mothers if they have disabled children. In particular, patrilineal kin always make disabled child's mothers feel guilty for giving birth to a disabled child. The mothers of disabled children are not given much preference and importance in the functions and rituals of the family. They are given tasks such as cooking and cleaning but they don't have active role in ritual performances. Sometimes disabled person's mothers restrict themselves from attending functions and rituals due to fear of taunts from people.

Examples from the field:

In this section, I will discuss in detail, the life histories of some of the informants, to substantiate the points made earlier.

Arjun's father says that Arjun was never taken to a doctor after he was diagnosed with fluorosis in 1997. Before the diagnosis, he was taken to various hospitals in the city to get treatment but when the doctors informed the family that he is suffering from fluorosis and there is no cure, they stopped taking him for further

cure. If he gets common seasonal diseases, Arjun's parents buy medicines from the medical shop and give it him. Since they know it is fluorosis and there is no cure for that, they do not make any effort to find out why he has fever or cold.

Though Arjun's parents know about his illness they still relate it to "*Karma Sidhantha*". They say that god is testing them. They strongly believe it is their duty to take care of Arjun and they are fulfilling it. Arjun's father says, "He is the only son to us and he is born like this, I will serve him till my death. After that it is god's duty to take care of him". The common belief among the people here is that a son would save his father from the hell called *"punnama narakam"*. So, it is very important to have a son. Arjun is now twenty years old. His parents have been taking care of him all these years, like a small child, from the morning to evening. When they are not around or busy with their agricultural work, Arjun's sister takes care of him. Though Arjun is twenty years old, he looks like a five-year-old child with a bony structure. He can't recognize anyone including his family members. He often cries in pain, hits on the wooden cart and beats his chest with his own hands. In order to calm him, two pillows and a number of blankets are kept around him so that he can't move (see picture in the appendix). They are removed only when his mother is at home and while feeding.

Picutre showing Arjun crying in pain.

Arjun has not been taken out of his house to visit relatives for functions. If there is a function in any of their relative's house, at least one person has to stay at home and take care of him. It is the same case with almost all the fluorosis victim's families.

In case of Kamala, a sixteen-year-old girl born with learning disability, others often teased her parents for their religious conversion but Kamala's parents do not agree because the main reason for religious conversion was that Kamala's mother did not conceive for almost ten years after marriage. It is only after their conversion to Christianity from Hinduism that she conceived and gave birth to Kamala. So the parents do not feel guilty about conversion to Christianity. They gave birth to another girl child after Kamala. Their second child does not suffer from any of the fluorosis symptoms. Kamala's mother Susheela says,

> During my first pregnancy, I came to Marriaguda. This is my mother's village. For about two or three months I consumed this water. That could be the reason for my daughter's disability because, during my second pregnancy I was in the city and consumed safe water and my second child is fine.

Kamala's parents feel that it is fluoride that is responsible for their daughter's disability, and the doctors also diagnosed her with fluorosis. But it seems that their relatives do not agree and often stigmatize them by taunting for religious conversion.

Migration:

One may wonder why people in fluorosis-affected villages are not going away from the place. What is holding them back even after experiencing the severity of disease? But it is not that simple. Not everyone can afford to move away from these villages. Their economic status does not make it possible for them to leave the place. There are

also other reasons. Some of them who knew about the disease and had money migrated to city and some migrated to earn their livelihood but some remained back home in order to give care to the affected members of the family. When the villagers take diseased persons to the city, they face problems. There is no place to leave the children while parents go to work. Most of the migrants come back to the village because they have relatives, friends, and well-wishers who will take care of them and help them in difficult times. They get help from neighbors and relatives in taking care of disabled person. They can and spend time with disabled members of the family whereas in city it is not possible because there is no one to look after the disabled person in absence of the family members.

Role of family and kin network

Fluorosis patients need someone to look after them because some of them cannot even move. It is compulsory that at least one person stay at home and take care of the victim. Some family members has to sacrifice their school, work and stop attending functions to do the same. The continuous family support helps some of the victims in participating in the struggles and agitations with the hope of solving this problem and creating a fluorosis-free society in the area for next generations. Amsala Swamy said to me,

> I hate this life, for making my father suffer. He carries me like a baby and he even cleans me after attending natural calls. I am not a child. I am thirty three year old man now. This situation should not happen to anyone. People are inheriting the disease along with other properties. I am fighting for them and the future generation, not for us. I don’t want anyone to be born like me in the future.

This gives us an idea of strong kin relationships existing in this community. Since they are experiencing the ill effects of the disease, the fluorosis victims don't want their future generation to experience the same. The family members also support the disabled people to fight against fluorosis, along with providing care.

In some cases, grandparents play a crucial role in taking care of the disabled children when the parents are at work. They take care of the child till their parents come back in the evening. Paternal relatives, especially father's sisters and their husbands provoke the grandparents and become responsible for conflicts between the parents and grandparents of the disabled child. In some cases, grandmothers join their daughters in teasing their daughters-in-law, the mothers of the disabled persons, and make fun of them. Paternal relatives come to disabled persons' home, enjoy their hospitality and then taunt them. This disappoints both disabled persons and their parents.

Understanding the cause of disability plays an important role in care giving. Some of the family members believe in *karmasidhantha* and think it's a test given by god for their sins in their previous life. This belief is quiet common among the parents of the disabled person. When they see other people without disabilities, parents conclude that it is their misdeeds in the previous birth that has caused disability to their children. So they see it as their duty to provide care to the child, irrespective of the age. Some of the siblings also actively take part in caregiving because of this belief. Most people say it is their fate to be born with disability or serve the disabled person. If there is no one to take care of the disabled person in the family, they keep food in a lunch box while going to work and ask them to eat on their own, which is possible only in some cases.

The siblings of the disabled person get relief from this after marriage by moving away but there is no option for the parents except admitting the affected persons in government hostels. But the parents are afraid that, the children may not get good care in the hostel. They also worry about what others will say. Yellamma says, “what will people think, if I leave my child in hostel? People will accuse me of not taking care of my child”. Due to this fear of societal blame, they keep their children in their homes. If the person suffering from fluorosis is an only child the care giving is entirely different. There are rumors that some children died in the hostel because of careless behavior of the staff. Naturally, parents don’t want to send their children to such hostels. They are struggling to earn their livelihood and at the same time taking care of their children. The role of caretakers differs as the child grows. Mothers take care of an adult girl and fathers take care of adult boys. The caregiver requires much patience in giving care, feeding and in understanding the need of the patient because some of them cannot speak.

Some of the fluoride victims are excluded from the family functions because of the lack of personal hygiene. Some people do not take disabled children to functions in their relative’s houses. They leave disabled children and care givers at home while other family members attend functions in other villages. If they take disabled children along, people may feel uncomfortable. The behavior of the disabled people towards neighbors is very important because in many cases neighbors play an important role in helping the disabled persons in the case of hospitalization and other emergencies. It is very crucial in the case of a single person who is disabled. They have no one to help in case of any emergency. They have to take care of themselves and their house as in the case of Mallamma.

Experiencing disability

The degree of disability caused by fluorosis differs. There are some people who cannot even move, while there are others who are more mobile and active. There is no link between age and the level of disability. Most victims said that they feel like carrying heavy weight on their bodies. Relatives who visit these families come with water bottles and leave immediately when the water which they brought gets over. There is a lot of fear in consuming local water.

The degree of experiencing disability also varies on their ability to move and their capacity to do personal things. A person who cannot move depends on the caregiver for everything. This experience of taking help in going to the toilet and bathing is very hard for the disabled person to come to terms with. When relatives visit, disabled persons feel shy and inferior. They even hesitate to go to the toilet. Due to shyness, sometimes they hold urine for hours and face gastric trouble and kidney ailments. Some people use bottle to urinate when there is no one around and the caregiver disposes it off or washes it.

The disabled people do not want to stay alone because if they stay alone they start thinking about their disability and deformities. Family members do not have the time to talk to them during the day. Some of them are tied to a pole or always lying on the bed. The disabled people hesitate to move out of their house because when they go to other villages, children gather around them and make fun of them. They feel like crying and committing suicide. Some of them even attempted suicide. Tirupatamma 35 year old woman from Vattipally once consumed powder made out of tablets past expiration date because of unbearable pain. But neighbors rescued her. A few were saved by the caregivers but some died. Most of the informants repeatedly said, "it's better to die than living this life" ("*e bathuku brathakadam kanna, chavadam melu*").

They worry about their future after the death of parents or caregivers. Since most of them are excluded from the familial discussions and decision-making, they share their feelings to caregivers only. For example, Ramya, a twenty-five year old woman from Kudashpally, shares her views with her younger sister or to her mother because other family members do not listen to her and often get irritated with her.

Other children in the family, who are not disabled, usually address a disabled person with his/her name irrespective of age. This makes the disabled person feel inferior to his/her younger siblings. Age of the disabled person is not seen as important and in some cases, due to their short stature, the disabled person addresses the younger children with respect. Swamy calls his younger sister[13] as "*akka"* (elder sister) because in this case age is not important, stature is. Disabled people prefer to stay away from quarreling in the family. Because they themselves feel that they are inferior or dependent to others. In some cases disabled person cannot argue with anyone because if they argue, they are made to feel inferior because of their disability.

Swamy suffers from this disease ("*garbhasta fluorosis")* from birth. He says his grandmother doesn't like him. It is because he argues with her in defense of his mother. He further says,

> She (grandmother) does not like me because I am disabled. She earns at least Rs.3000 per month but she never spends a penny for me but when her daughter and their children come here, she will bring fruits and snacks for them. I am the only child in the house. I don't know why she do not like me. She is not like others' grandmothers. They love their grandchildren but she does not.

In his childhood, Swamy was taken to a number of traditional and biomedical practitioners in search of cure. But it was not useful. His grandmother cited affliction

[13] See Appendix- II.II

as the reason for his disability (see pg.15). She says that during the fifth month of Swamy's mother Venkateamma's pregnancy, on the day of solar eclipse, She warned Venkatamma not to work because of the fear of "*grahanam morri*". Then she went out to some relative's house. Swamy's mother did not care about her mother-in-law's words and she started washing clothes. As she rinsed the clothes after washing, the grandmother believes that the fetus got twisted and that resulted in Swamy being born with crippled hand and legs. Swamy's grandmother remembers the incident vividly and constantly harasses Swamy's mother. She strongly believes it is the effect of affliction. She does not accept the fact that it is due to fluorosis. Swamy's mother gave birth to a girl child, also stricken with fluorosis. From that day onwards, the grandmother scolded Swamy's mother since both the children were born with fluorosis. It was very difficult to take care of the children so Swamy's father Satyanarayana started taking care of Swamy and handed over the girl child to his wife. According to Swamy and his father, Swamy's grandmother started torturing Swamy's mother by giving multiple tasks at a time and indulging in household work and making her do it again and again, Swamy's mother eventually became mentally ill and was unable to give care to her daughter. As a result the girl died in about 1993. But Swamy's grandmother rejects this accusation. She claims that Swamy's mother didn't had enough milk to feed the baby and that resulted in the girl's death. Till today Swamy's mother and grandmother don't like each other. They fight frequently which causes discomfort to both Swamy and his father. Therefore they prefer to spend most of the day at their barbershop.

Swamy had three sisters. One died of fluorosis (mentioned above), another committed suicide because of some personal issue and the third sister got married and is living with her husband in Hyderabad. Swamy is the only child left at home and his

father takes care of him. Swamy also helps his father by sitting at the shop when he goes for afternoon nap. He asks the customers to wait and gives a call to his father when there are enough customers. Till his father comes, Swamy engages the customers by talking. Apart from this, he actively takes part in meetings related to fluorosis. Unlike other fluorosis victims, Swamy is very active, hygienic and talkative. He says his cleanliness is the reason behind people talking to him. Most of the fluorosis victims are not bathed and cleaned. Swamy is very proud of his clean look and he gives all the credit to his father Satyanarayana.

Tirupatamma, another key informant and fluorosis victim, lost both her parents at different stages of her life. She is now staying with her step-mother, Sattamma, who is blind. She says,

> "How is it possible to meet household expenses with Rs.500 per month as pension? Since she can't see and I can't walk, we are managing by helping each other and staying together (*okariki okaru thodu).*"

Tirupatamma started suffering from fluorosis at the age of 12. Till that time, she was like any other child. When she was in 8th and 9th standard, she used to go to school with the help of a walking stick. Later she used tricycle to complete her 10th standard. She failed in 10th class and soon after, she dropped out of school. She used to help her mother in household work like washing clothes and cooking food.

She belongs to the caste of toddy tappers (*Goud*). Her father had a fall while collecting toddy. He suffered injuries on his head and suffered severe bleeding and died. Tirupatamma says that the social activist and convener of the NGO, 'Fluorosis Vimukti Vedika' Kanchukatla Subhash, helped her and she is very thankful to him. Apart from this she was helped by a charitable trust in setting up a telephone booth and a general store near her house. She had to close the phone booth, after increased

mobile phone usage by the people.

Like Swamy, she is also active in fight against fluorosis but she couldn't get much fame, as she can't move out of the village to attend meetings. Swamy's father takes him to attend meetings in various parts of the region on his scooter whereas Tirupatamma doesn't have anyone to take her to other villages and long distances to attend the meetings. Sometimes organizers send vehicles and sometimes Subhash takes her to attend some meetings but being a woman, she is not able to participate as actively as Swamy.

Tirupatamma is unable to accept the fact that she is suffering from the disease because when she was going to school by walk, she used to suffer from joint pain and consumed lot of painkillers form the medical shop on the way to school. When she told about her pains to her mother, in the beginning she didn't pay attention due to agricultural work. Later, she started suffering from severe pains and doctors diagnosed it as fluorosis and within two to three years, legs started crippling and she couldn't even walk with the help of walking stick.

Since she doesn't have any male family members in the family, her cross cousin (father's sister's son)[14] tried to take advantage of the situation. He is married and stays near her house. At the time of Tirupatamma's father's death he helped her with money in completing the death rituals. He is trying to gain control over Tirupatamma's personal affairs. In fact, he is ready to marry Tirupatamma. His wife and family members also support him because if he gets married to Tirupatamma, they can get her house and two acres of land. But knowing this fact, Tirupatamma didn't accept the proposal. She says,

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[14] See Appendix- II.II

> "Women are suffering after marriage. Their husbands are not looking after them. These days it is true that they are torturing their wives for extra dowry. I am disabled, I don't have legs and I can't walk, I can't work, so I don't want torture from my in-laws and husband. With this fear, I never had interest in marriage."

Since she rejected his marriage proposal, he started bothering her by stopping people going to her house, spreading rumors about her alleged affairs with people who come to her house to help her. These rumors affected her relations in and around the village. Sometimes he drinks and shouts at Tirupatamma. Sometimes Tirupatamma goes to her relatives' place in Hyderabad and spends a few days with them and comes back. She says it is very difficult to lead life without a male member in the family. Tirupatamma has to take care of herself along with her stepmother.

Begging as an occupation:

There are some villagers who go to the city of Hyderabad for begging. Only people who can walk with the help of a walking stick can move around to beg and earn their livelihood; others cannot. The people who go to city beg for about a month and come back to the village. The daily income varies from fifty to sixty rupees per day from which they spend around twenty rupees on food and save rest of the money.

They beg throughout the day and sleep near a temple or bus top or under a bridge at night. Damera Mallaiah who goes to the city to beg along with some of the villagers says that they don't carry any luggage except two blankets. Sometimes police come and enquire about them. They do not object to old people sleeping like that but they don't allow young people to sleep there. Sometimes these people go to their relatives'

house in the city and sleep there. There are so many people from the villages who work as beggars in the city but they rarely meet each other.

Problems in marriage alliance:

Most fluorosis victims are excluded from the possibility of marriage. No one comes forward to marry disabled persons. It is very difficult to get married unless the person is able to earn his/her livelihood (“*brathuku devruvu”*). Even if they have better livelihood, they have to try hard to find a person to marry. They have to make enormous contacts to find if there is any disabled person ready to marry another disabled person. If they find a person who is not disabled willing to marry the disabled, the disabled person’s family has to take care of marriage expenses. In the case of a disabled girl’s marriage, her parents are ready to give a part of their property as dowry. Most of the parents and disabled persons themselves believe that they are unfit for marriage. “Marriage is not written in their fate” says Mallamma.

Some people think fluorosis is a genetic disorder, so they do not want their children to get married to fluoride victims. They don’t even want to have marriage alliances with fluoride villages for fear of contamination. Earlier, people were not worried about the contamination because during that time the soil in these villages was fertile and offered lot of livelihood opportunities. Later when the villages started facing drought and increase in fluoride contamination, marriage preferences slowly started decreasing. Now it is very difficult. Some people argue that it is very difficult to find a spouse even for those who are not disabled because of fear of contamination. In most cases, the marriage alliances are within the region because outsiders do not wish to enter in to the alliance. People believe that media is playing a detrimental role in publicizing fear of contamination and is thus responsible for this problem.

Urmila belongs to the Lambada tribe. She is suffering from fluorosis for ten years. She is twenty years old. After her mother's death, she is taking care of the household. Her father works in the agricultural fields and her brother attends college in the city. With a short stature she looks like any other girl of her age but when seen clearly we can see her bent legs. Because of this, no one is coming forward to get her married. According to her neighbors, she is very active, capable of doing work at home and can work in the agricultural fields like any other woman but her disability is making it difficult to find a suitable spouse. Mallamma, a 40 years old woman suffers from bent backbone due to fluorosis (*gooni).* She says that she has four sisters, two of them are younger than her and other two are older. All of them got married because none of them were suffering from fluorosis. She further says

> "It is very difficult to find a spouse for normal (*sakalangulu)* woman these days. I am suffering from disability (*angavaikalyam*). You can imagine how difficult it is to get a spouse for a disabled woman. My parents tried to find a spouse for me but all the attempts failed and I remained single"

Suresh, a television technician in Marriguda, who also suffers from fluorosis and has a similar kind of bent backbone could however, find a spouse. After a number of attempts and rejections from a lot of people, he got married to an educated woman. His wife completed 12th standard before marriage and now she is in the final year of the undergraduation. Suresh says,

> I have encountered a number of people, who teased me when I went for marriage proposals; even my family members scolded me. They said you would never get a woman to marry. Finally, by god's grace, one of my relatives brought a marriage proposal. She agreed to marry me and we got married. I think my sincere efforts and professional background made it possible. There are a lot of fluorosis victims who are still struggling to get a spouse; I am very lucky compared to them.

He passed 10th class and after that, started working in a television shop and learned repair work. Now, he is earning nearly about ten thousand rupees and he is able to take care of his family. He also encourages his wife for further studies. Recently she wrote the B.Ed. examination, which would enable her to go for teacher training. If she qualifies in that exam, she will become a schoolteacher.

Decisions on health care:

There is no cure for fluorosis in any medical system. Prevention is the only way of getting rid of it. In some cases immediately after birth, babies are taken to the hospital. If they find any deformity then they find out whether it is due to fluorosis. If it is fluorosis the parents know that it is not curable. But they will take care of the child. The fluorosis victims by birth suffer the most. Since severely ill patients cannot move from the house, RMP[15] doctors treat them. The RMP doctors are available in the village and accessible at any time. The cost of the treatment varies depending on the duration of the treatment. In case of emergency and serious illness, they have to book a special auto to take the patient to hospital. People prefer RMP doctors than public health center because of number of reasons. Waiting time for allopathic doctors is more compared to RMP doctors in the village.

The hospital treatment is free but the expenses on travel are much more. Most of the fluorosis victims use painkillers from the local medical shop to get relief from body pain and thus suffer from renal failure. They also buy medicines from the local market. The first time, they get prescription from a doctor and then use the same medicine from a medical shop. There is an Ayurveda doctor in the study area called Ayyavaru who gives medicine for many diseases. He claims to be able to treat

[15] Rural Medical Practitioner.

paralysis and mental illness. To get quick results from Ayurveda, one needs to follow special diet.

It is also evident from the data that, people go to traditional medical practitioners and nomadic medicine vendors to get treatment for fluorosis and are often cheated. These medicine vendors do not stay in the villages. They keep on moving from one village to other. This medicine is available at a cost of hundred rupees per packet of tablets, which can be used for a period of one month. Since it is cheaper compared to medicine prescribed by a doctor or available at pharmacies, some people consume it. These medicine vendors are not regular to the villages. They come once or twice in a year. Since they are not available in the village, people cannot do anything if the medicine doesn't work, whereas in the case of Ayyavaru they can meet him and clarify their doubts with him since he is a resident of the village.

This chapter discussed local perceptions about fluorosis and the everyday challenges faced by both fluorosis victims and their families. The ways in which family members understand fluorosis and disability influences the care that they give to the disabled person in the family. If they believe that it is their duty to serve them and god has assigned it, they give good care. Or else, they try to avoid the responsibility. The religious belief is not important in all cases but it is one of the important factors in care giving. Such perceptions also influence their relationship with the disabled people. If they think it is because of water contamination, there is no stigma related to fluorosis whereas if they think it is a genetic disorder, there is some stigma related to marriage. Sometimes people also avoid social relations with the families of the fluorosis victims. Therefore, looking at local perceptions of fluorosis and disability caused by it has important implications with respect to family relations,

relations with neighbors, larger society, health care decision-making and experiences of disability by the fluorosis patients.

Chapter - IV

Role of Politicians, Civil society and Policies

This chapter will discuss in detail, the local politics and conflicts that emerge in the background of fluorosis in Marriguda mandal. The general perception in the villages where I conducted fieldwork is that the political representatives visit the area only during election time. Even at that time, they do not come directly into the villages. They contact the local leaders and caste heads and bribe them with liquor and money in order to win votes. Some people in the villages suffering from chronic body pain due to fluorosis and other family problems get addicted to liquor. During the election time, politicians exploit this situation. Kanchukatla Subhash, Convenor, 'Fluorosis Vimukthi Porata Samithi' says, "People in the villages are surviving on *gudumba*". *Gudumba* is locally brewed liquor, made from rice and jiggery, and much cheaper than alcohol sold in shops. Some politicians visit villages with the help of local leaders and ask disabled people about their requirements. If people explain their problems, they will be given assurance that their problems will be taken care of. There is also a feeling that the village sarpanch is not proactive.

Social Activism:

There are many civil society organizations in the region but only two are visible. One is called 'Fluorosis Vimukti Porata Samithi' and the other is 'Jala Sadhana Samithi'. The literal meaning of FVPS is 'Association fighting for freedom from fluorosis' and JSS stands for 'Association fighting for water'.

> It is not a tourist place and we are not museum objects. All the political leaders visit but they are not showing interest to solve this issue. They are wasting lots of money on political tours. Instead, if they use that money

> to solve the fluoride problem, it will be very helpful to the people. Hundreds of political leaders and ministers visited Nalgonda in the past six decades and thousands of crores were spent on these visits. It is a complete waste of public money. They would have solved it if they used this money to solve the fluoride problem. They are using these political tours for election campaigns to get votes but do not really intend to provide a solution to the problem." – Kanchukatla Subhash.

Fuorosis Vimukti Porata Samithi:

FVPS was started in the year 2000 with a committee of eight members- Kanchukatla Subhash, Mallepalli Krishnaiah, Chinta Krishna, Sharadha, Linga Swamy and Ramesh. Subhash claims that FVPS is not an NGO. He prefers to call it as "organization fighting for eradication of fluorosis":

> Though we started, we were not happy; we wanted it to be a mass movement for water. Article 21 of the constitution says it is a fundamental right of all Indians. It means, every person has right to live and water is part of it. So, we started 'right to water' campaign. That's the reason it was named, 'Fluorosis Vimukti Porata Samiti'. It is not fluoride "*vimukti*". Fluoride is a natural resource and fluorosis is a disease. So, it was named, 'Fluorosis Vimukti Porata Samiti' which means we are fighting against the disease. People think that they committed sin and are born like this but I say, it is the sin of politicians, which gave "*shapam*" (curse) to people in this area. At the same time it became vote bank issue. The state has no interest in solving this problem. Netherland government sanctioned nearly 374 crores to solve this issue but our government does not have interest in it. They spent all these money in building 'Nalgonda technique' water plants. They wasted all 374 crores. They ate it all. They could have built a pipeline from Nagarjuna sagar with that money and they could have given safe water to all villages but they don't have interest.

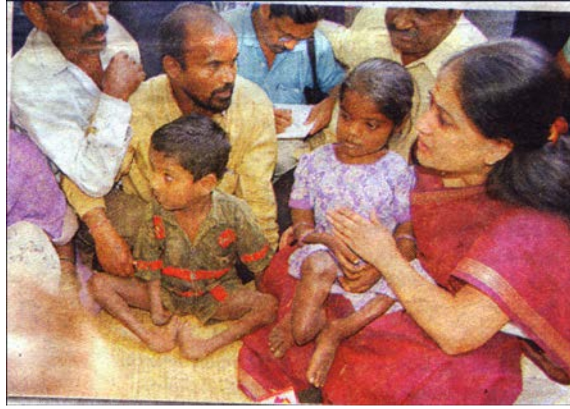
The NGOs in the region, especially FVPS and JSS will pass on the messages about meetings to its cadres in the villages and the cadres take the responsibility of passing information, and mobilize people from the villages.

But only a few people are happy with this activism. There is criticism that these organizations and activists work for their personal interest and concentrate only on those people who are educated and articulate. It appears that only people like Swamy and Tirupatamma are helped because they can participate in activism and articulate their views to the media. There are thousands of people suffering from fluorosis and their position is worse than Swamy and Tirupatamma but only these two people are known to the outside world. It could be because of the exposure given by the organizations. These organizations arrange vehicles to take them to public meetings to speak on fluoride contamination issue. They ask them to share their problems and experiences of being disabled and suffering due to fluorosis to gather attention of the government and aid agencies towards fluorosis issue. Some people said that Subhash never meets anyone except Swamy, Tirupatamma and few other well-known fluorosis patients. There is no fluorosis related meeting conducted by Subhash without Swamy's presence. Swamy has been active in JSS movement for the past twenty years and his father supports him in attending the meetings. Though Swamy is illiterate, his sharpness and more importantly, being male is an advantage. On the other hand, Tirupatamma is literate, has studied upto tenth standard and is intelligent but has not succeeded in getting as much attention because she is a single woman without a supporting family. She can't go far away from home, unaccompanied. Swamy's father is very supportive and ready to take him to the meetings at any place and time. He has been very active in the movement form the time JSS started. There are so many patients who do not have this kind of family support to attend the meetings and get exposure to the world.

Subhash with Swamy serving memorandum (left), serving contaminated water and safe drinking water bottles to compare (right).

Subhash says that he called political leaders like Chiranjeevi (actor/politician), Chandra Babu Naidu, Vijayasanthi, Y.S.Rajasekhar Reddy and others to visit the areas in order to highlight the fluorosis issue. He and others in the NGO know that these political visits alone will not solve the issue but at the same time they don’t want the leaders to forget about fluoride problem in the region. So they periodically call celebrities and politicians. Subash believes that, politicians do not want to solve the issue because if they do, there will be no other strong election agenda to go with to the people. Subhash encouraged fluorosis patients to participate in elections the last time (2006)[16], he gathered funds form Non Residents of India (NRI’s) of Nalgonda district and got Swamy and Tirupatamma to participate in the general body elections as (Mandal Parishad Territorial Constituency (M.P.T.C)) and Zilla Parishad Territorial Constituency (Z.P.T.C). But they did not win.

[16] See Appendix- II.III



Source: FVPS: Picture showing Vijaya Shanti with fluorosis victims.

Jala Sadhana Samithi:

Jala Sadhana Samithi is a non-profit organization founded by Dusharla Satyanarayana in the year 1980. Satyanarayana is well known for his activism in water rights in the region. He is fighting for safe irrigation and drinking water for Nalgonda people. He was working in Union Bank of India. In 1978, he was transferred to Shivannagudem branch as rural development officer. During that time, he came to know about fluoride problems in the village and became determined to fight for people in the region.

His fight is against the unjust water allocation in Nalgonda district and for completion of Srisailam Left Bank Canal (SLBC) project. Former chief minister Tangatoori Anjaiah inaugurated SLBC project in 1978 to supply safe drinking water and irrigation facilities to fluorosis villages. The estimated amount for completion of this project was Rs.1, 975 crores. It was believed that this project could provide water to 516 villages and three lakh fifty thousand acres of land but there was very little progress. Later in 1983, N.T. Ramarao inaugurated the same project and promised that it will be completed in three years but no progress. In 2007 Y.S. Rajasekher Reddy sanctioned Rs.1.3 crores to conduct survey on the same project and till 2010, Rs.900 crores were spent on this project.

Satyanarayana organized protests in various parts of the country. He motivated people from villages to go to Delhi and met prime ministers and presidents of India. He submitted memorandum to Chandra Shekhar, H.D. Deve Gawda, I.K. Gujral, Attal Bihari Vajpayee, Shankar Dayal Sharma and A.P.J Abdul Kalam during their term.

Source: TNF: Picture showing D.Satyanarayana, Swamy and other JSS members with A.B. Vajpayee and Bandaru Dattatreya in 2003.

He conducted a number of "*padayatra*" (walking tours) to religious places like Trupati, YadagiriGgutta, Varanasi and number of pilgrimage towns on riverbanks in the country, to give memorandum to the gods. He says, "when the political leaders who have powers to provide water do not help, we are left with only one option, to seek help from god." During these walking trips and protests, the participants have to bring their own food items and utensils to cook. Satyanarayana claims that JSS is a peoples' organization and all the participants are coming on their own volition to attend the protests and to fight for themselves and their future generations.

Satyanarayana’s groundwork for motivating people is quite different from other organizations. He stays in Nalgonda town and these villages are about 200 km from Nalgonda. It was very difficult to pass on the information about protests and dharnas during the 1980’s, when the organization was started. There were no mobile phones then. He would send messages through bus drivers. The villagers collected messages from the bus driver and sent a reply back to Satyanarayana. This went on for months. After that, when all the participants were ready with their beddings and food items, they started the protest. They would get travel in trains to Delhi and various parts of the country, without purchasing tickets, to display their protest against fluorosis. I was told that they were never questioned by the railway employees and ticket collectors for travelling without tickets because the numbers of protesters were huge.

There are certain instances, where the protesters gave memorandum to statues, gods, politicians, buffaloes and donkeys. They say that by doing so, they hoped that the political leaders might look at the issue more carefully and provide a solution. But until now, they have received no help from the leaders.

Source: TNF: Picture showing Dushyarla Sathyanarayana serving memorandum to Telugu Talli Satue (Left) and Kattamaisamma (Right)

Disability groups:

There are self-help groups for disabled people in the villages since last five years. There are no special groups for fluorosis patients but majority of the group members are fluorosis patients. All the group members have to deposit Rs.100 per month. A group leader collects money from the members and deposits the same amount with the bank every month. Since the group members are disabled, Indira Kranti Patham (IKP) staff in the mandal assists them in depositing money in the bank and applying loans etc. Society for Elimination of Rural Poverty (SERP) is implementing IKP. SERP is a government organization helping rural poor in managing their self-help groups (SHGs). The members of disabled self-help groups can avail loans from the bank on behalf of the group. The loan amount depends on the regular function of the group and their deposits in the bank. The loan is given to the group as a whole and depending on the needs of the members they can divide the amount among the members or can give it to a single member after considering members' opinions. These are not active because some of the members in each group, who took the loan, failed to repay loan amount to the bank. In almost all the groups, only the group leader or a few members of the group made use of the amount and they didn't repay so other members of the group felt insecure and stopped paying monthly installments. As a result all the groups are closed now.

Other Aid-agencies:

Swamy and Tirupatamma benefitted from a social organization called 'Sri Ram Charitable Trust'. This trust helped them to start a public telephone booth. Both Swamy and Tirupatamma earned their livelihood from this booth but it didn't last for long. The increased use of mobile phones in the villages has resulted in decreased use of public telephones so they had to close the telephone booths. They set up a petty

shop with cool drinks, cigarettes, chocolates and biscuits, along with other small goods. Later they closed it because of maintenance issues. Now Swamy helps his father at barbershop and Tirupatamma managing her household expenses from disability pension and donations from charities.

Amsala Swamy and Tirupatamma are very active participants in the fight against fluorosis. Both Swamy and Tirupatamma claim that they are fighting for the future generations. Since they know how difficult it is to live with disability, they don't want any other child in the region to suffer like them. Both of them became state committee members in 'Fluorosis Vimikti Porata Samiti' in the year 2001. From then onwards, they are actively participating in the movement. They also have membership in JSS. Swamy proudly talks about his experience as a member of JSS for twenty-five years and his trips to Delhi at a number of times along with Sathyanarayana to give representation to political leaders to solve this issue. But he also thinks that leaders at the centre did not respond properly.

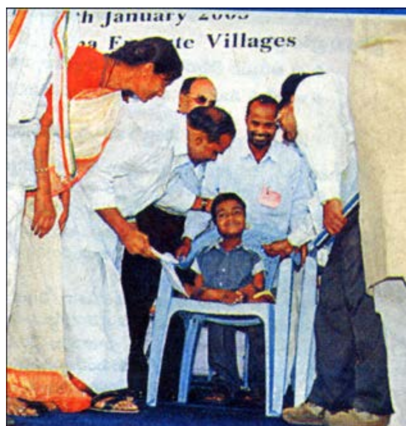
Apart from this, as part of both FVPS and JSS, Swamy and Tirupatamma gave so many representations to the state and central governments to solve the issue. They felt very disappointed when they lost the elections. They claim that money and liquor play important roles in winning the election. It has been almost seven decades since fluorosis problem in this region first came into limelight. Fluorosis problem in Nalgonda district continues to be part of the election agenda still even though parties, political alliances and leaders change often.

Telangana Issue:

From local newspapers, media and NGO's representations it is evident that the agitation for a separate Telangana state is also linked to the ways in which the issue of fluorosis has been dealt with in recent years. In a meeting held by Telangana

Netigen's Forum in collaboration with Jala Sadhana Samithi, Mr. K. Chandra Sekhar Rao, the leader of the Telangana Rashtriya Samiti (TRS), a prominent political party which championed the cause of Telangana state, said, "Every problem in Telanagana region is associated with the separation of Telangana State from Andhra Pradesh". (Namaste Telanaga, March14, 2013). There are many such instances where this issue is linked with the Telangana issue which confuses general public and influences them to view it as a Telangana problem and therefore can be solved only after the new state is formed. When it is represented as a safe drinking water problem, the state comes up with temporary arrangements like de-fluoridation units or supplying water through tankers. If the people approach the state representing it as a health problem, the state responds with health camps and tries to silence the critics temporarily. There are a number of other issues like environment, safe drinking water, health issues, economic problems, irrigation problems etc.

Dr. Govardhan Reddy, a resident of Nalgonda district, made a documentary on fluoride victims and presented it to the state government during 1980's. That time there were about 75000 fluorosis patients in the region and now it has increased to one lakh people. FVPS gave 25 memorandums to former chief minister Y.S. Rajashekar Reddy, when he was in power. But there has been no significant action till now, feel the residents.



Source: FVPS. Amsala Swamy with former chief minister Y.S.R. Reddy

Information gathered from NGOs and news articles published about the region give interesting figures about the allocation of funds for fluorosis by various governments and aid agencies. It is often mentioned that The Royal Embassy of Netherlands allocated Rs. 375 crores in the 1970's, which was used in Nalgonda technique project to filter contaminated waters and supply to the villages (WHO report 2001)[17]. I was told that the Housing and Urban Development Corporation (HUDCO), a public sector undertaking, allocated Rs.150 crores and the National Bank for Agriculture and Rural Development (NABARD) allocated Rs.150 crores in 2002. These amounts were used to provide safe drinking water to 450 villages in Nalgonda district from Nagarjuna Ssagar reservoir. But there is significant gap in the amount of water supply between urban and rural areas. The government is supplying 120 liters per person a day in Hyderabad city whereas in the contaminated villages it is only 40 liters per person a day. One can conclude that the negotiating capacity of the people in rural areas is very less compared to those in the cities.

Government Schemes:

The NGOs in the region argue that, article 14, 21, 39(B), (E), (F), 41, 43, and 47 of the Indian constitution guarantees safe drinking water to its citizens.

> "It is the state's duty to provide safe drinking water to all its citizens and the state is violating the rights of people in Nalgonda district. It's been more than six decades we got independence and the state is still failing to provide safe drinking water to the people of Nalgonda. It is an utter failure of the politicians and the government. It is sin to be born in this region." - Convenor, FVPS

At present there are two active schemes from the government addressed to the fluorosis patients. One is the disability pension, which is five hundred rupees per

[17] http://apps.who.int/iris/bitstream/10665/43514/1/9241563192_eng.pdf

month. The other is Anthyodaya Anna Yojana Scheme (AAY), which gives thirty-five kilos of rice per month to the family of disabled persons. These schemes are applicable to all disabled persons, and not just for fluorosis victims or their families.

The disability certificate is important to apply for disability pension and AAY cards. The certificates are sanctioned at the district headquarters after computerized testing. The machines used for testing cannot be carried around. The government sends special buses and conducts health camps in Nalgonda district to distribute these certificates. Prior to this in 1990's, there was no computerized testing for sanctioning disability certificates and most of the villagers had disability certificates. These certificates got cancelled after computerization of procedures. Most of the certificate holders were scrutinized and removed from the disabled list, and their pension was stopped. Due to practical problems involved in carrying some of the disabled people by bus to health camps, some of them were denied disability certificates. The condition of some of the fluoride victims was really bad. Some urinated and defecated in the bus. The villagers scolded the parents and asked them to get down from the bus. People who failed to go for tests are thus without any disability pension at present.

The AAY scheme was started on 25th December 2000 by the Indian government. The main intention of the scheme was to provide food security to the poorest families in the country. Under this scheme the poorest of the poor families were supplied with 35 kilos of rice every month through the public distribution system. Some families selected under 'below poverty line' and holding white-coloured ration card are eligible to apply for the AAY card. AAY cards are sanctioned based on the economic condition of the family. These selected families are supplied with thirty five kilos of food grains at a subsidized rate of three rupees per kilo rice

and two rupees per kilo of wheat a month throughout the country. In Andhra Pradesh state it is one rupee per kilo of rice.

Table 4.1: Total Number of disabled people who are sanctioned AAY cards.

S.no	Village name with No. of Disable Persons	Male	Female
1	Marriguda (19)	11	08
2	Vattipally(6)	4	2
3	Shivannagudem(35)	18	17
4	Sarampeta(12)	7	5
5	Kudashpally(11)	3	8
Total	**83**	**43**	**40**

This scheme looks useful to people but in reality it is not reaching those who are really in need. There are hundreds of people in the Marriguda mandal who are suffering from fluorosis but only eighty three people in the mandal are getting benefit from the scheme. There are no official records on the exact number of fluorosis patients in the mandal because there is no special department which looks at the problems of fluorosis patients in the region. NGOs like FVPS maintain some records regarding the fluorosis victims but the information is not updated. As per FVPS, there are 1050 fluorosis victims in the mandal in 2012 but one cannot be sure that this number is accurate. I could not find any alternate source. Out of 1050 only eighty three people in the mandal have AAY cards.

Social Security Pensions:

The government of Andhra Pradesh provides social security pension to all eligible persons. The intention of this scheme is to provide security for people below poverty line (BPL). Under the social security pension scheme there are five major types of pension namely, old age pension, weavers' pension, widow pension, toddy tappers'

pension and disabled pensions. Only fluorosis patients who have disability certificates are included under the scheme. As I mentioned earlier, there are about 1050 fluorosis patients according to FVPS in the mandal out of which only about 900 people are getting benefit. 286 people in the study villages are accessing this scheme.

The following table shows the village/caste wise Social Security Pension cardholders.

Table 4.2: Total number of Disabled people who are getting Social Security pensions.

		Disabled		**Category**				
S.no	**Village name with No. of Disable Persons**	**Male**	**female**	**minority**	**SC**	**ST**	**BC**	**OC**
1	Marriguda (69)	37	32	04	11	04	47	03
2	Vattipally(49)	26	23	Nil	05	Nil	41	03
3	Shivannagudem(65)	32	33	01	10	Nil	47	7
4	Sarampeta(37)	21	16	Nil	17	05	12	03
5	Kudashpally(66)	39	27	Nil	06	16	41	03
Total	**286**	**155**	**131**	**05**	**49**	**25**	**188**	**19**

All these people are eligible and are using the scheme. The financial support of five hundred rupees per month from the government is not helpful because of inflation. A major portion of the pension amount is spent on painkillers and other medicines they need to get relief from fluorosis. Fluorosis patients demand increase in pension amount and they want the government to take measures to distribute pension amount as well as rice to be delivered to their homes because they cannot go to the panchayat or ration dealer to collect them. Other people who are still waiting for this help know it is not enough but still look for some amount that will help them.

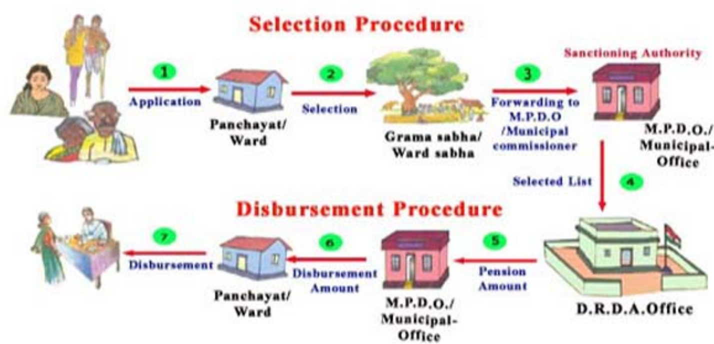


Diagram showing selection procedure for social security pensions[18].

Medical Camps:

The government and political representatives claim that regular health camps are being conducted to provide monthly medical kits and medicines to fluorosis patients. But in reality these health camps are not conducted every month. They are conducted only once or twice in a year during a visit by a political leader in the region. According to Dr. Dasya Nayak, Chief medical officer, Marrigud, during these health camps severe fluorosis cases are identified and affected persons are sent to Nalgonda district hospital for further examination. There is a separate ward in district headquarters for fluorosis patients. After medical examinations, they are given treatment according to their need. Accommodation and food is provided to the patients and their attendants during the treatment period.

Health care practitioners in the region agree that there is no cure for fluorosis and prevention is the only possibility. . So the question arises as to why health camps are being held in the area frequently and what medicines and treatments are given to the diseased people. The data I have gathered provides some answers. As I mentioned earlier, health camps are being conducted in the area as a temporary measure when people represent the fluorosis problem as a health issue. Through these health camps

[18] http://www.ssp.ap.gov.in/Info_Rural.aspx date of access: 14 March, 2014

people are supplied with health kits and medicines to get relief from body pain resulting from fluorosis. According to the health professionals, the ‘health camps’ were conducted in various parts of the region to distribute certificate of disability.

Conclusion

This chapter looked into the role of political leaders, government schemes and NGOs in alleviating or hindering those suffering from disability due to fluorosis in Nalgonda district. The state policies, members of civil society and the political leaders seem to play limited role in the fight against fluorosis and for the welfare of the fluorosis patients. Though the state is responding with the temporary measures from time to time, the implementation and success of these policies are dependent on active involvement of the leaders. The negligence of political leaders and lack of leadership from the local people could be the reason behind continuing presence of fluorosis in this region. On the other hand, though the NGOs seem more active, they also seem to be worried about their own identity than the problems of the fluorosis patients. Only a few people are taken care of by the NGOs in the region because people like Swamy and Tirupatamma are articulate, and the NGOs are interested in getting benefit from their ability to represent the problems of fluorosis patients. Though Tirupatamma and Swamy are active members in FVPS, the crucial decisions are made by the leader of the NGO, Subhash. But during public meetings and political gatherings, they will be in the forefront. So there is great need for political consciousness among the people.

Chapter-V

Conclusion

This thesis looks at social and cultural perceptions of fluorosis, and how people affected by fluorosis experience disabilities caused by the disease. This study is the result of empirical research among people affected by fluorosis in five select villages of Marriguda mandal, in Nalgonda district of Telangana region. Fluorosis in Nalgonda district is a well-known issue within the region and even in the larger Andhra Pradesh state (*The Hindu*, 21st April, 2014). In this study, I have highlighted some of the social, cultural, and political factors that play a major role in the lives of fluorosis patients and their family members. A common assumption is that disabled people are provided for by the state through welfare programs such as disability pension, reservations for education and employment in state and central government organizations. But in reality, these welfare measures have a very marginal role in the lives of fluorosis patients. For example, they do not have enough strength in their bodies to go through the lengthy procedure for applying for disability certificates. Though they have reservation for jobs, they do not have the required education to get good jobs. That is why a number of fluorosis victims have taken to begging in the city of Hyderabad as a permanent occupation. Informants, who I interviewed, who had fluorosis, felt that they do not have any qualification other than "*Angavaikalyam*" (being disabled).

There are various forms of activities taking place in Nalgonda district to solve the fluorosis issue. But participation and involvement of the fluorosis patients is not very high. Some social activists are seen to be exploiting the disabled persons to gain visibility for their own organizations. There is some value to the disabled persons in the case of fluorosis (Friedner 2013). These persons seem to be valued depending

upon their ability to talk and participating in public meetings and political gatherings. Most of the social activism is visible at these meetings but not in the villages. During my three months of filed work, no meeting was organized in the villages. But they gathered people from the villages and took them to the meetings at a far off place. For example, Swamy attended a number of meetings conducted by Telangana Netizens Forum in Hyderabad. The local activists and his family members helped him. He says:

> People in my village do not respect me. They think I am going to these meetings to get personal benefits but in reality I am fighting for them. My father is helping me because he knows how difficult it is to take care of a disabled person like me. People don't understand this; they accuse my father of benefiting from the social organizations and political leaders. But other villages respect me and value me.

This view was disputed by residents like Satheesh who says:

> It is Subhash, who is profiting from this activism. He is using fluorosis patients for his personal benefits. He never comes to people like us. We are also suffering from the disease and residents of the village but why does he only goes to them? Because, they are pretty famous.

The above two quotes suggest that people in the villages where disability caused by fluorosis is a daily and real experience look at NGOs and social activists very differently. There is lack of leadership among fluorosis patients. Though there is an organization for discussing about fluorosis, there is no effort made to mobilize already disabled people to come together and fight for their rights. They do not have a proper platform to come together and discuss their problems as patients of fluorosis. Political meetings do not address issues faced by disabled persons or their personal issues such as problems in getting married and care giving.

As elaborated in chapter four regarding government schemes for disabled persons, there are some temporary measures in place to provide relief to the people but there is no permanent solution yet. All the political parties and social activists know that improving surface water supply for both drinking and irrigation purposes are the only solution to the problem but no government is interested in providing river water because of huge costs involved in the projects. The local political parties blame each other for the continuation of the problem but have never come together to work for a solution. Supply of water from Krishna river is helpful to the study villages but the supply in not regular due to technical problems involved. Since the employer is not paying salaries on time, contract laborers of the water department often go for strike. As a result the villagers were not supplied SW (Sagar Water) for ten to fifteen days and sometimes there will be damage in the pipelines, which stops the supply for three to four days. Villagers struggling for safe drinking water have become a common scene. There was a protest through the display of empty pots during the Legislative Assembly speaker's Nadendla Manohar's visit to Nalgonda on July 7, 2012.

People in the villages cannot afford to buy filtered water every day. It is also a costly affair for the government to install reverse osmosis plants in all the villages. One suggestion is for the government on transport water from Nagarjuna Sagar to the villages to increase surface water sources in the region. Increasing surface water bodies are indirectly helpful in increasing ground water table. Filling up of lakes and ponds in the region with surface water seems to be the only possible solution for fluoride problem at present and complete eradication of fluorosis in the future. Though social activists and political leaders think that, safe drinking water and irrigation policies will solve the issue of excess fluoride in water bodies. This leaves

out those who are already suffering from the disease. People have been given an impression that the creation of Telangana State would solve all the problems related to fluorosis but it is hard to speculate when and how that will happen.

Most of the fluorosis victims, general public, social activists and the political leaders in the region agree that the Telangana state formation would solve the fluorosis problem. They believe that there is regional discrimination in allocation of river waters to Telangana and that has resulted in increase of fluoride contamination in the region.

Opinion differs on whether the creation of Telangana state will be helpful or not. Some people argue that if Telangana state is formed, the resources can be restricted to the area and safe drinking water provided to all the fluoride villages. But others are more cautious. NGOs also talk about the caste dynamics in the region and how that might work against finding a solution to this issue, since a majority of those affected are not from the dominant caste. Even in allocation of rainwater harvesting and de-fluoridation plants, the people from castes considered higher in the village possess most of them and other people are denied. They also argue that the state is violating a human's right to water and a child's right to nutritious food.

Most of the fluorosis victims are not in a position to earn their own livelihood. They are dependent on their family members. Socio-cultural ideologies about causation of the disease and disability, and makes it possible to give care to fluorosis victims but the quality of care when compared to other family members is always questionable, unless the person happens to the only child of his/her parents. In case of Ramya, who has three sisters and one brother, she is not given the same care as Swamy and Tirupatamma. Ramya has only two pairs of clothes with which she has been managing for two years. The economic status of the family also determines care-

giving for disabled persons. Sometimes their own relatives stigmatize, tease and make fun of the fluorosis victims and their families. It could be due to jealousy, greed and desire to get fluorosis victim's properties or any other familial rivalry.

The families of these disabled persons face various problems, which was elaborated in chapter three. There has to be one caretaker all the time with the disabled person. Washing their clothes, giving bath and cleaning the area where they sleep are tasks which require lot of patience. The disabled people also regret that they are making their family members suffer. There are cases where disabled people get married to disabled people and sometimes to those who are not affected by this condition. In case of Suresh, a T.V mechanic who got married to a woman who is not disabled, they are happily married, and she passed intermediate and studying for graduation. Another informant, Gopi married a disabled woman affected with polio. They have two children. There are a number of people who do not wish to get married. People say that those who hail from villages which do not face the problem of fluorosis do not want to marry persons living in villages where fluorosis is a problem. Now the effect of fluorosis is reducing and more marriage alliances are taking place amongst various villages. At the time of marriage, the family of a disabled woman has to give more dowries also.

Relationship amongst kins is one important focus of this study. It is found that, the relatives from the maternal side are kinder to disabled people compared to paternal relatives. The role of grandparents is important. In some cases, there is a difference in the care they give to their daughter's disabled children compared to their son's disabled children. In the case of son's children who are disabled, the grandparents blame their daughters-in-law for giving birth to a disabled child. Their own daughters join them in taunting the mothers of disabled children. But this is not

the case always. There are certain instances where the grand parents take care of their disabled grandchildren, in the absence of their parents.

There are different ways in which fluorosis affects an individual. There is a chance of treating the disease in the initial stages. There are some instances where some people underwent surgery and are now able to walk. The early detection of the disease is very important. Therefore, there is an immediate need for conducting periodical health camps in Nalgonda district to identify the fluorosis victims as early as possible. Children below five years of age should be given nutritious food. I referred to one case in chapter, of a mother who took her child to the hospital for injection for fever immediately after the child had been given polio vaccine. This resulted in the child suffering from disability. This is because of lack of awareness about the polio vaccine and its side effects. There is a need for creating awareness about various forms of fluorosis also and how it affects an individual physically and emotionally at various stages of his/her life.

Local understandings about the cause of disability like '*Grahanam Morri'* and '*Shapam'* show that some people strongly believe that it is the fault of the parents of the disabled children. This also results in tensions within the families, and the mental wellbeing of family members. In case of Swamy, he and his sister were both born with fluorosis. His grandmother conducted the deliveries and she argues that it is the result of affliction. She always victimizes Swamy's mother for this fault and fights with her often. Now, Swamy's mother is suffering from mental illness and Swamy argues that it is because of his grandmother's constant taunting. In the case of Kamala, people believe that it's her mother's religious conversion which resulted in her disability.

Marriages of disabled persons are not always successful. Balayya's mother

blamed her neighbors for poisoning her son's wife's mind which made her return to her natal family. Gopi's wife said that her sisters and family members did not tell her about her husband's profession and education before marriage and they cheated her. He is not educated and does begging for a living while she has studied till intermediate. In the case of Aruna, she got married to a physical disabled van driver last year and her family reportedly gave a dowry of four lakh rupees.

There are various temporary measures taken up by the government at various stages such as health camps and de-fluoridation plants and rainwater harvesting etc. This was helpful to people to some extent. People would argue that they can't represent all the issues at a time and it is not the best way of fighting for it. Breaking the issue into various sections and solving one by one is the best method. The dominant castes in the village are seen as making best use of the temporary measures but to some extent these are helpful to other people also.

NGOs like JSS and Fluorosis FVPS are active in the struggle for safe drinking water and were successful in getting water to the study villages. They also represented the problem to the state in different manners at different stages. There are other organizations like Sri Ram Charitable trust and Sai foundation that help the victims by providing wheel chairs and free surgeries to the people.

Regarding stigma only few people stigmatize disabled persons because of lack of awareness about the disease. Those who do not have good relations blame and stigmatize disabled people but those who know the cause do not stigmatize. The marriages also depend on this kind of stigma, there is village called 'Batlapally', this village is rated high for fluoride content in the water. Even today, these villagers do not allow outsiders in to the village to take photos and videos because they believe that people from media take photos and publish them in the newspapers and television

and as a result their village name is spoiled, being associated only with fluorosis.

The economic condition of the family prevents them from taking highly nutritious foods such as leafy vegetables, milk, and egg along with calcium and magnesium tablets. The government is providing nutritious foods through Aanganwadi centres to pregnant ladies and new mothers in the villages. To some extent this can help to prevent new cases of fluorosis.

Fluorosis victims in the villages are getting Rs.500 as disabled pension and some are getting 35 kilograms of rice every month through public distribution system. Those who do not have the disability certificate do not get this rice. There are some people whose bones are brittle. If they do not take care of themselves while moving from place to place, there is a chance of getting fractures. So it is better if the government conducts medical camps and issues these certificates in the villages directly to the concerned people.

People in the area say that provision of safe drinking water and irrigation through surface water to the fields is the permanent solution to the problem. Though the government provides various temporary measures, these will not help the people unless there is surface water to cultivate lands. They also say that it costs only thousand crores to give waters to all these villages but the amount has not been sanctioned. The government can also look into allocating appropriate funds for irrigations projects in the region such as 'Dindi', which is proposed by Telangana Retired Engineer's Forum. If this project gets completed, it can provide safe irrigation to three lakh acres of land and safe drinking water to nearly fourteen fluoride effected mandals of the district.

There are cases where fluorosis patients attempted to commit suicide. They took the extreme step because they did not want to burden the family. They are

worried about their future after the death of caretakers. They don’t know what happens to them and who will take care of them in the future. They can’t work and earn their livelihood in most cases so obviously they feel they are burden to the family as well as to themselves. These are serious issues which need to be dealt with both at the familial level and also at the level of the village community, and at the state level.

Limitation of this research and future topics for study

1. This brief ethnographic study has some limitations. For instance, due to time constraints, I could only look at five villages, even though fluorosis is an issue prevalent in the entire Nalgonda district. I also confined the focus of the study to only those affected by fluorosis and their families. I did not focus on other kinds of disability that people suffer from. But there is a lot of scope for further studies on this topic, both in this region and in other parts of India. Some future research topics could be
2. New schemes implemented in the last five years such as ‘Krishna water supply’ to these villages
3. Impact of major irrigation projects in the region.
4. Other health problems faced by fluorosis patients, and their diagnosis and treatment
5. Strong attachments that people in these villages have, to the place.
6. The place of fluorosis in the discourse about disability rights and ‘Right to health’.

Appendix- I: HOUSEHOLD CENSUS SCHEDULE

Indian Institute of Technology Hyderabad
Department of Liberal Arts

Name of the Investigator : Venkatesh Boddu

Place (Name of the village) : ______________________________

Mandal and District : Marriguda/ Nalgonda

Name of the Household Head : ______________________________

Caste/Clan : ______________________________

1). Demographic Particulars:

S.no	Name	Relation with head of HH	Age & sex	Marital Status	Profession/ Occupation	Education
1						
2						
3						
4						
5						
6						
7						

2). Is your wife, daughter or daughter-in-law married to a cross cousin or mother's brother? If yes, give details.

3). Which type of economic activity do you pursue mainly?

(Note down about crops grown, items collected in food gathering/ forest produce collection, service or wage labor).

a). Agriculture b). Wage-labor

c). Service d). Animal Husbandry

4). By which type of economic activities do you supplement your income?

(note down about the regularity, seasonality and duration).

a). Agricultural Land:

Category	Wet	Dry	Total
Own			
Leased-in			
Leased-out			
Share cropping			
Podu			
Total			

b). Source of irrigation for wet land:

1). Well 2). Stream/Canal

3). Bore-well 4). Other

5). Live Stock:

a). Oxen: b). Buffaloes: c). Sheep:

d). Goat: e). Pigs: f). Poultry:

g). Others:

6). Agricultural equipment (give details)

7). House:

a). Kacca/ Pucca b). Material Used (Mud/Thatched/Concrete)

c). Electrified/ Not electrified d). Number of rooms:

8). Do you have any of the following:

a). Television: b). Radio c). Motorcycle

d). Refrigerator e). Furniture: f). Bicycle

g). bullock cart h). Others:

9). Have you benefited from any of the development programs undertaken by the government in the last five years?

S.no.	Benefit	When	Value	Remarks
1				
2				
3				
4				
5				

10). Morbidity and Mortality

a). Details of the members who have suffered from any illness during last three months:

S. no	Name	Age/ Sex	Duration of suffering	Nature of Disease	Source of treatment	
					First contact	Subsequent contacts

b). Has anyone died in the family during last one year?

S. no	Name	Age/Sex	Cause of death

Give reasons for death:

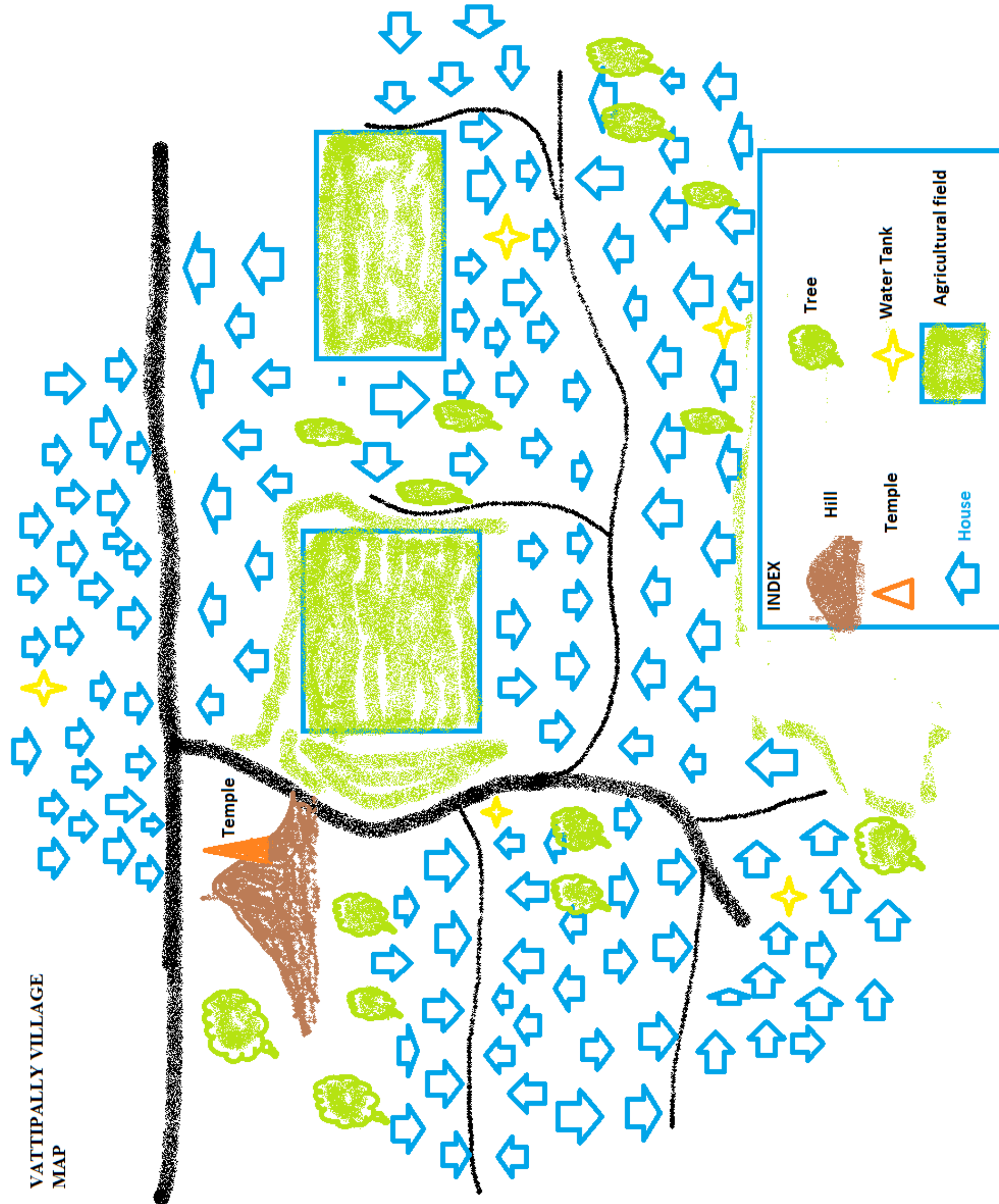
Appendix- II: Maps

II.I.I. Nalgonda District Map

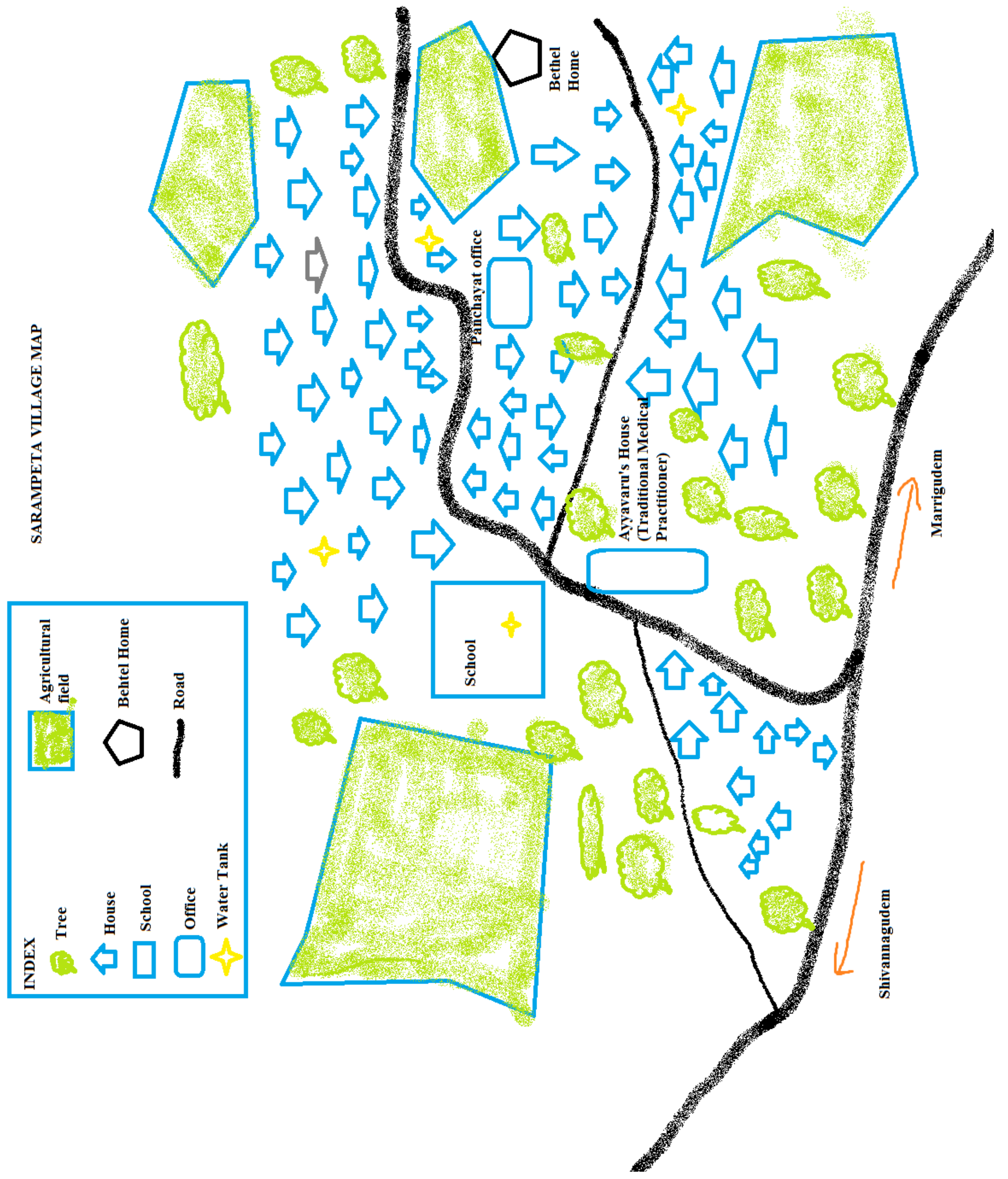
II.I.II. Marriguda Mandal Map

II.I.II. Marriguda Village Map

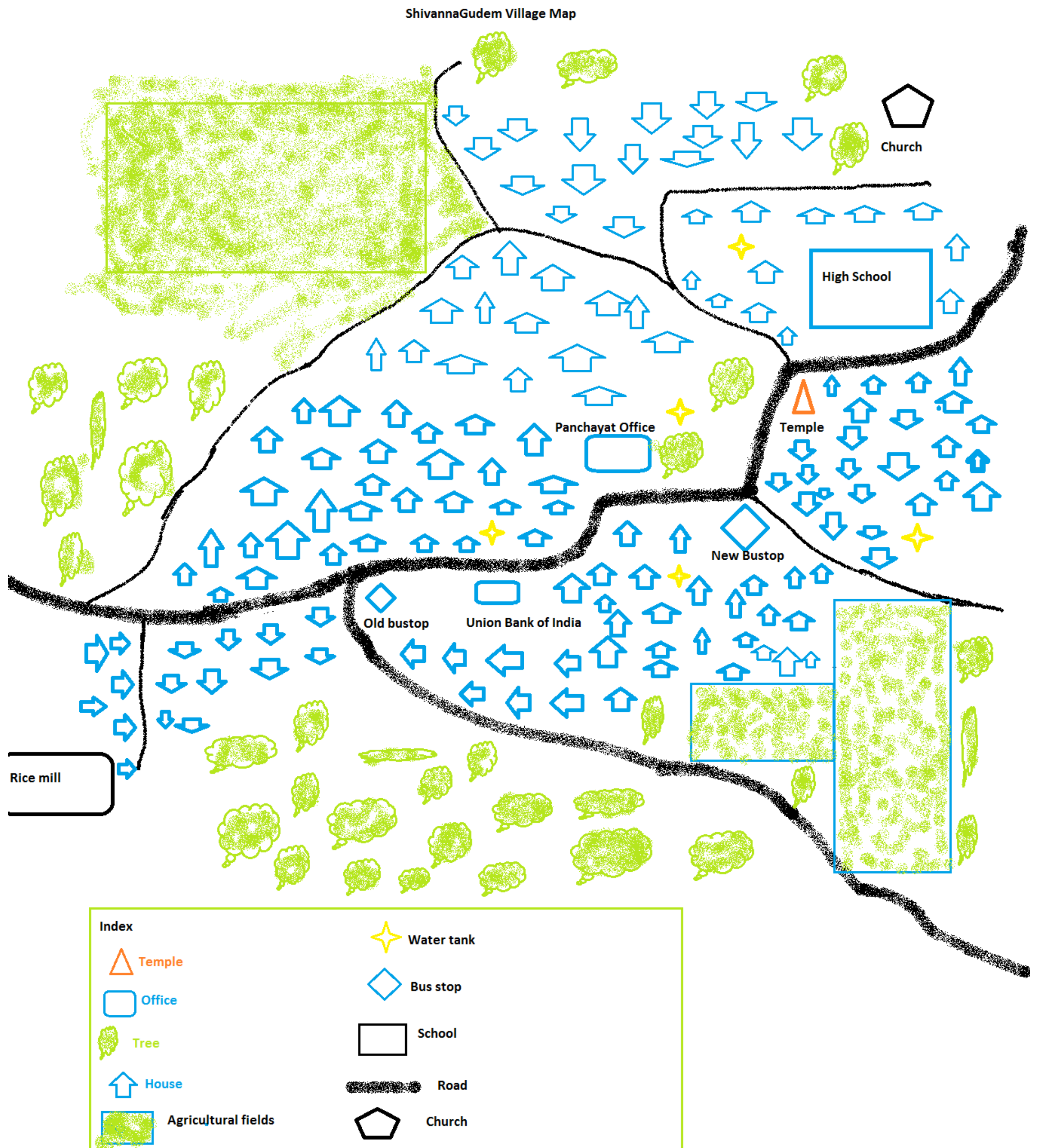
II.I.III. Vattipally Village Map



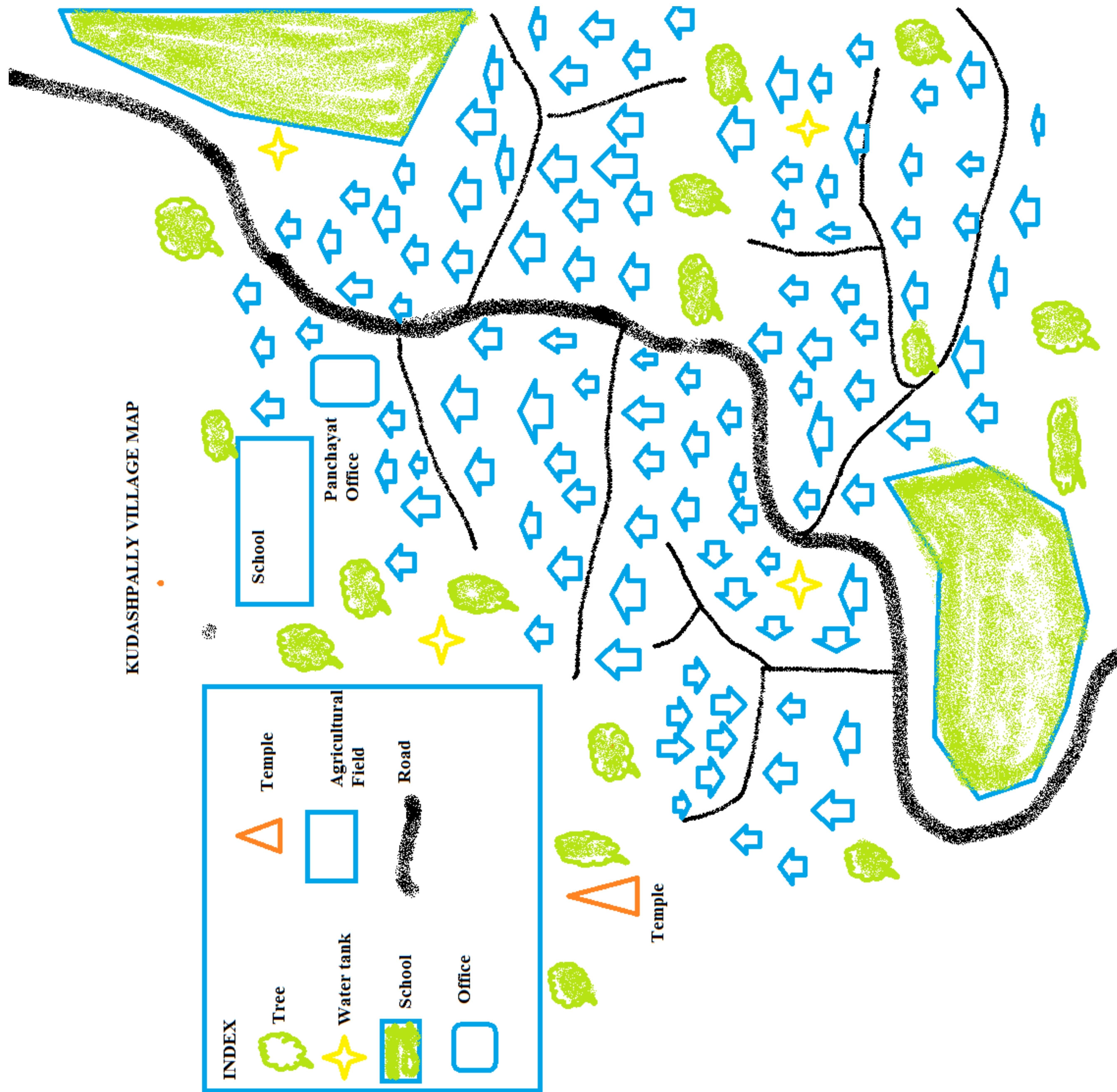
II.I.IV. Sarampeta Village Map



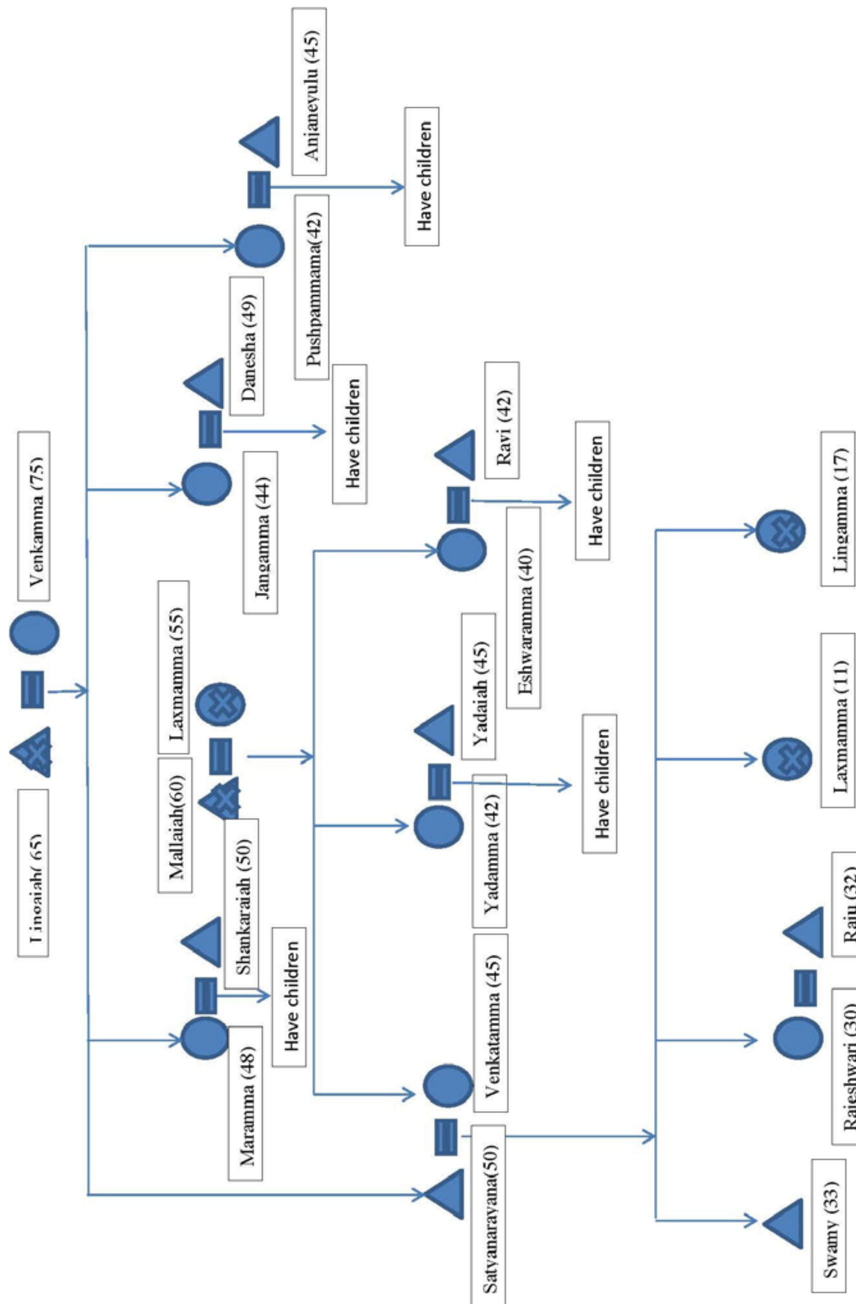
II.I.V. Shivannagudem Map

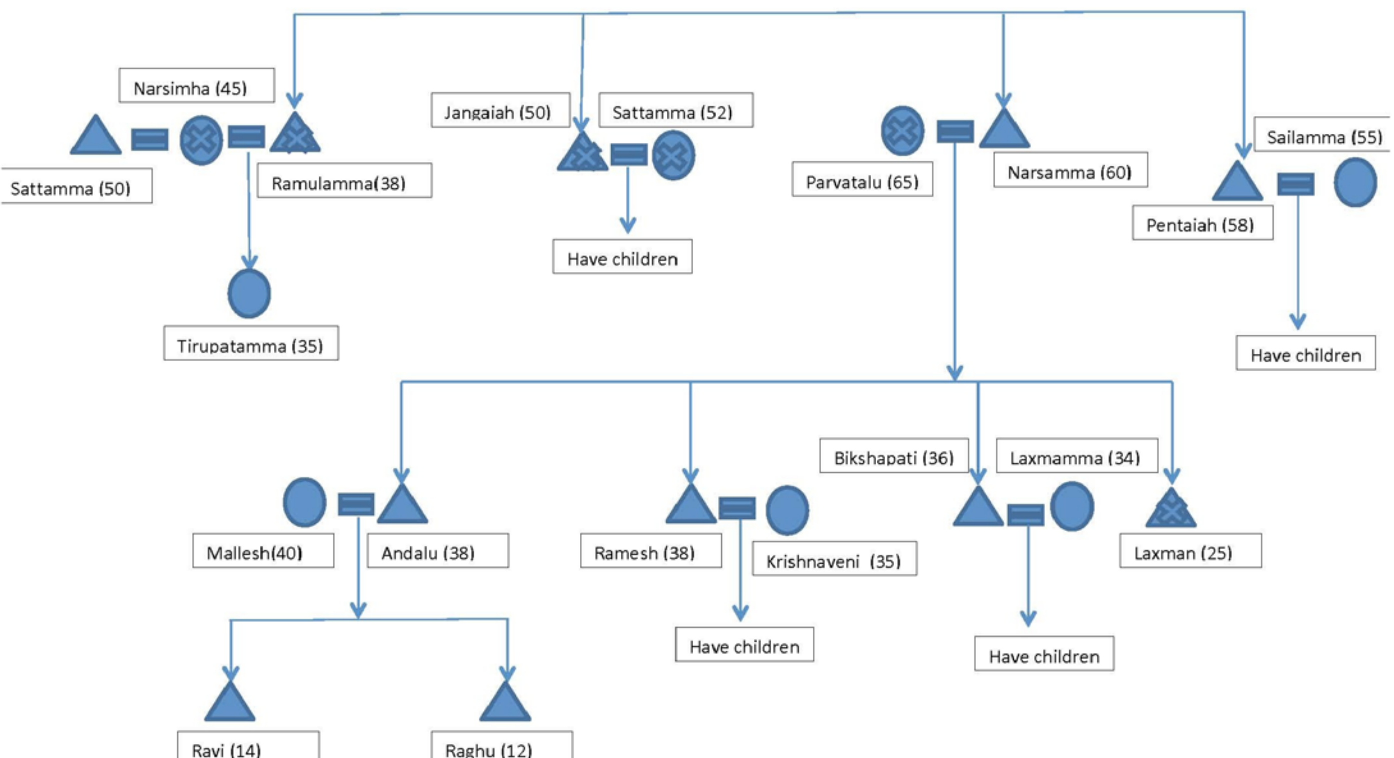


II.I.VI. Khudashpally Village Map



II.II: Kinship Diagrams.





Appendix : II.II.II Geneology of Panaganti Tirupatamma of Vattipally village

II.III: Photographs:

Picture on the left showing weights put on informant and on the right, a resident suffering from renal failure.

Picture on the left showing a specialist doing physiotherapy to a fluorosis victim and on the right, school children displaying rally against fluorosis.

Picture on the left showing model house with thatched roof and on the right, Tirupatamma preparing food in her house.

II.III: News Paper clippings:

Pamphlet circulated during 2006 Panchayat raj elections by FVPS.

Poster on Fluorosis Awareness

కరపత్రం

ఫ్లోరోసిస్ మహమ్మారిని తరుముదాం

మనిషి దుర్వినియోగం, నిర్లక్ష్యం వల్ల వచ్చిన అనేక ముప్పుల్లో ఫ్లోరోసిస్ ఒకటి. ప్రాణాలను నిలబెట్టాల్సిన నీరే ప్రాణాంతకంగా మారితే ఇక చెప్పవలసిందేముంది? నల్లగొండ జిల్లాలోని భట్లపల్లి, వట్టుపల్లి,శివన్నగూడెం లాంటి దాదాపు వెయ్యి గ్రామాల ప్రజల బతుకు శాపంగా మారడానికి కారణం ఆ పల్లెల్లో ప్రజలు త్రాగే నీటిలో ఫ్లోరిన్ ఉండవలసిన మోతాదు కంటే ఎక్కువ ఉండటమే. మనం తాగే నీటిలో దంతాలు, ఎముకలు పటిష్టంగా ఉండటానికి 0.2 ppm (Part per million) నుంచి 0 .8 ppm ఉంటే మంచిది. దీనికి మించితే ప్రమాదమే. పరిమితికి మించి నీటిలో ఎంతఎక్కువ ఫ్లోరిన్ ఉంటే దానివల్ల ఒనగూరే ప్రమాదం అంతఎక్కువగా ఉంటుంది. నీటిలో ఫ్లోరిన్ 2 పీపీఎం ఉంటే డెంటల్ ఫ్లోరోసిస్ వస్తుంది. ఫ్లోరిన్ 2 నుంచి- 5 పీపీఎం మధ్య ఉంటే ఎముకలు, కీళ్లు, నరాలు ఇతర అవయవాలు దెబ్బతింటాయి. ఇక ఫ్లోరిన్ 5 పీపీఎం దాటితే దారుణంగా ఉంటుంది. ఎముకలపై ఫ్లోరిన్ పేరుకుపోవడం వల్ల ఎముకల ఎదుగుదల క్రమంగా ఉండదు. మనిషి శ్వాస సంబంధమైన రోగాలు, న్యూమోనియా, క్షయ లాంటి వ్యాధులు కూడా వస్తాయి. పక్షవాతం, నపుంసకత్వం సంభవించడం, వెన్నెముక దెబ్బతిని నడవలేని స్థితికి రావడం లాంటి అనేక రోగాలకు గురి కావాల్సి వస్తుంది. ఈ ఫ్లోరోసిస్ వ్యాధికి చికిత్స ఏ వైద్య విధానంలో లేదు. నివారణ ఒక్కటేమార్గం.

25 సంవత్సరాల వయసులో ఉన్న యువకులకు ఈ వ్యాధి సోకితే 60–70 సంవత్సరాల ముసలి వారిలాగ కనపడుతారు. నవయవ్వన వయసులో 30–35 సంవత్సరాల వయసులోనే చేతకాక, చేతులు, కాళ్ళు చచ్చుబడిపోయి నడువలేని స్థితికి చేరుతారు. అందుకు నిదర్శనమే భట్లపల్లి గ్రామానికి చెందిన నూకల రాములు, గిరిముత్యాలు, కృష్ణయ్య. ఫ్లోరోసిస్ వ్యాధి తల్లి కడుపులో నుంచి ఉన్నట్లయితే వారిలో ఎదుగుదల లేక 20 –30 సంవత్సరాలు దాటినా ఐదేళ్ల పిల్లల లాగ కనిపిస్తారు. అందుకు నిదర్శనమే అంశాల స్వామి, తిరుపతమ్మ, రజిత, సుకన్య. ఫ్లోరోసిస్ సమస్య ఎక్కువగా పేద ప్రజలపై ప్రభావం చూపుతుంది, పేద ప్రజల్లో ముఖ్యంగా మహిళలు, పిల్లలపై ఎక్కువగా ఉంది. 1000 గ్రామాల్లో 7 లక్షల 70 వేల మందిపై ఈ ప్రభావం ఉన్నది.

నల్లగొండ జిల్లాలోని ఫ్లోరైడ్ ప్రభావిత గ్రామాలకు 2004 – 2011 మధ్య 718 .08 కోట్ల రూపాయలతో 45 పథకాలు కల్పించామని సర్కారు లెక్కలు చూపిస్తోంది. జిల్లా వ్యాప్తంగా 1031 ఆవాస గ్రామాలకు రక్షిత మంచి నీరు ఇచ్చామని చెబుతున్నది. ఇంకా 77 గ్రామాలలో పనులు జరుగుతున్నాయని ఇవి పూర్తి అయితే జిల్లాకు ఫ్లోరోసిస్ రహిత తాగునీరు ఇచ్చినట్టు అవుతుందని గొప్పలు చెప్పుకుంటున్నది. నిజానికి ప్రభుత్వం చెప్తున్నట్టు ట్యాంకులు, పైపులైన్ల నిర్మాణం జరగలేదు. ఫ్లోరోసిస్ సమస్య పరిష్కారం చేయాలని తెలంగాణ నెటిజన్స్ ఫోరం ప్రభుత్వంపై ఒత్తిడి పెంచడానికి ఉద్యమిస్తున్నది. ఫ్లోరోసిస్ పరిష్కారానికి జరుగుతున్న పోరాటంలో అందరూ కలిసి రావాలని విజ్ఞప్తి చేస్తున్నాం.

-తెలంగాణ నెటిజన్స్ ఫోరం

Telangana Netizens Forum Pamphlet on Fluorosis

నమస్తే తెలంగాణ

మంగళవారం, 10 జూలై 2012 — పేజీలు 16

ఇదేమైనా పర్యాటక ప్రాంతమా?

1980 నాటికే 75వేల మంది ఫ్లోరోసిస్ వ్యాధికి గురయ్యారు. వారి శరీరం అస్థిపంజరంగా మారింది. ఇప్పటికి సంఖ్య లక్షకు చేరింది. అలాగే 1-18 సంవత్సరాల మధ్య వయస్సు కలిగిన వారు 6.25 లక్షల మంది ఫ్లోరైడ్ నీటినే తాగడం వల్ల నవ్వే అదృష్టాన్ని కోల్పోతున్నారు.

–శిరందాస్ ప్రవీణ్‌కుమార్

News article publish in Local newspaper says, ‘It is not a tourist place’ (fluoride affected area)

A PRADESH

THE HINDU • FRIDAY, JULY 27, 2012

Rs. 68 cr. relief for fluoride-hit in Nalgonda

Speaker holds meeting with legislators, Collector; package to cover 690 habitations in the district

Special Correspondent

HYDERABAD: There was some forward movement in providing relief to the fluoride-hit people of Nalgonda district after a high-level meeting chaired by Speaker Nadendla Manohar on Thursday proposed a short term package of Rs. 68 crore.

The development comes a fortnight after the Speaker led an all-party delegation of legislators to the affected areas in Nalgonda district. On Thursday, Nalgonda Collector N. Mukteshwara Rao along with his team of officials attended a high-level meeting of legislators at the Assembly to work out a strategy to mitigate the sufferings of the affected people.

At the end of five-hour long meeting, the Speaker and others decided that as short term strategy, relief package for 690 habitations in 17 severely affected mandals would be taken up.

According to sources, the immediate priority was to provide fluoride-free drinking water to these habitations through the Rural Water Supply wing of Panchayat Raj Department by spending Rs. 68 crore. Though, provision for drinking water to schools was assured, its maintenance was entrusted to Rajiv Vidya Mission and Anganwadis to the affected villages.

- Speaker had led an all-party team to the affected areas in the district a fortnight ago
- Priority is to provide fluoride-free drinking water to habitations through the RWS wing

It was also decided to change the utensils in the schools from aluminium to stainless steel.

Health card

A major decision was to provide access to health facilities.

By August 15, all the affected persons would be provided with a health card, which would enable them to get monthly medical kit.

A separate ward to treat the fluoride affected people would be set up in district headquarters hospital in Nalgonda.

The elected representatives from the district were asked to attend programme during the distribution of Antyodaya Anna Yojana (AAY) cards on Independence Day.

Two categories

Special health camps were being conducted in the 17 mandals to identify the affected persons so that follow up action and relief was provided to them. The entire district was divided into two categories with 17 mandals being identified in category ‘A’ where the water level was above 2.5 parts per million (PPM) while in another 31 mandals in category ‘B’ it was below 2.5 PPM.

Telangana Rashtra Samiti MLA K. Tarakarama Rao thanked the initiative of the Speaker. TDP MLAs – Balli Durga Prasad and Kandula Narayana Reddy wanted the Speaker to visit affected areas in Prakasam district also.

News article on Speaker’s visit to Nalgonda district

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