Addressing the hidden burden of mental illness in a rural community

A journey in the setting up of an Adivasi Community Mental Health program



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#### FOREWORD

"The eye does not see what the mind does not know"

Mental illness is one of the most under-diagnosed conditions in medical practice in India. Psychiatrists report that up to 30% of out-patients attending referral centres have an underlying psychiatric problem. These have mostly been missed by general practitioners. The undergraduate medical curriculum teaches very little psychiatry. Most doctors are therefore at a loss to understand or treat diseases of the mind.

Studies report that 1% of the general population has severely incapacitating mental illness while 10% have minor mental illnesses. For a country as vast as India, there are only about 3000 psychiatrists, and even they are concentrated in the cities. What then happens to the thousands of patients living in rural India? They suffer silently and are often locked away in rooms or homes for the mentally ill.

In practice, India cannot hope to solve this problem in a short time by training more specialists in the field. The only solution would be to integrate mental health care with primary care. Primary care physicians could be trained in the basic principles of detection and treatment of mental illness. Grass roots health personnel, like village health workers, who have mastered basic health care in areas like infectious diseases and maternal care, could also be sensitised to the detection and care of mental illness.

ASHWINI, which has been implementing a comprehensive health care programme with adivasi communities in the Gudalur valley of the Nilgiris, Tamilnadu, implemented a community based mental health program in 2005 with the financial support of Sir Ratan Tata Trust, Mumbai.

This document records the remarkable results of this intervention, some important highlights and lessons learnt.

#### **INTRODUCTION**

ASHWINI (Association for Health Welfare in the Nilgiris), which started in 1990, is an NGO working for the health welfare of the tribals of the Gudalur Valley in the Nilgiri District of Tamil Nadu. Although the Nilgiris and its tribes (*Adivasis*, meaning original inhabitants) are one of the most researched and written about areas in the world, the five tribes of the Gudalur Valley have been consistently exploited and marginalized, becoming progressively worse off as more and more immigrants invaded the hills and deforested this once isolated Valley.

The *Adivasis* were forest dwellers and hunter-gatherers, till some of them became slaves and later bonded labourers. Slavery ended in the 19<sup>th</sup> century and the abolition of bonded labour was announced in the 1970's. But the exploitation of these unsophisticated people continued systematically from the early '60's when the government encouraged non tribal people under a 'Grow More Food Policy', to clear forests and stake their claims like pioneers of the Wild West. This felling of forests together with a National Forest Policy that pushed adivasis out of their homelands, led to a once self sufficient people becoming impoverished and helplessly inadequate. Bomman, a Bettakurumba elder put it in a nutshell when he said, "Our ancestors needed only a knife to survive in the forest. With it, they cut bamboo and grass for their homes and provided food for their families. It was a different world. A self dependent one."

In 1986, Stan and Mari, two social activists, along with a group of young tribals, set up ACCORD, to help the adivasi people fight for their rights. They were vulnerable and exploited, and working as unskilled seasonal agricultural labourers in lands they once called their own. ACCORD's objective was to help the *adivasis* fight for their land, stop their exploitation and help them become self-sufficient again. This was done by mobilizing people to form village level organizations, called *sangams*. In 1988, these sangams federated to form a registered society, the Adivasi Munnetra Sangam (AMS), a peoples' movement bringing all the five tribes together. Today the AMS covers close to 16000 adivasis in over 200 hamlets. The interventions helped many families to reclaim land and today nearly a 1000 families own small plots ranging from half an acre to two acres.

At another level, the health of the people was alarming. Malnutrition was rampant; many women died in childbirth; children as well as adults died of preventable diseases like dysentery and

tuberculosis. People preferred to stoically await death at home, rather than go to an unfriendly, alien hospital far away.

In 1987, two young doctors, Deva and Roopa, joined ACCORD to fight the health battle. With patience and perspicacity, they trained a cadre of *adivasi* village women as "health workers". The focus of the work in the villages was the health of the most vulnerable group – namely pregnant women and under five children. A weekly mobile clinic would visit the villages covered by the health worker to cater to more serious patients and also to upgrade the skills and knowledge of the health worker. An important step had been taken towards the objective of encouraging people to access health services.

After almost three years of gruelling, often frustrating effort, the tide slowly turned. Infant and maternal deaths were no longer accepted as commonplace and inevitable. And patients seeking curative care began pouring in. The problem now was that there seemed nowhere to treat the more serious cases. The government hospital was overcrowded and impersonal, private hospitals prohibitively expensive. Fortunately, in 1990, another doctor couple joined the team. Nandakumar, a surgeon, and his wife Shyla, a gynaecologist had just returned after 10 years in the United States, wanting to start a hospital for the poor in rural India!

So, ASHWINI, another Society, was started to cater to the health needs of the community. The 20-bedded *Gudalur Adivasi Hospital* was set up to complement the community health work. Youngsters from the different adivasi tribes with some schooling were trained as nurses, accountants and other support staff. Today the busy secondary care hospital is efficiently managed by this team with the help of a few professionals.

Soon afterwards, a process of active decentralization was set up, with the establishment of 8 area centres each covering between 20 and 60 adivasi villages, so as to bring health care to the door step of the villagers. Today, the area centres are run by trained adivasi nurses called "Health Animators", who are more skilled in curative care than the health workers were. People come to the sub-centre for all their basic health needs. What the Health Animators could not handle at the area-centre is referred to the Gudalur Adivasi Hospital. The health animators also visit each village on a regular basis. They treat minor illnesses, take health education classes, and continue,

in collaboration with the old health workers, to monitor pregnant women, children under five years of age, and persons with chronic diseases like TB, asthma, etc

An analysis of the causes of death in 2004, revealed some totally unexpected findings. Suicide was the second commonest cause of death, being surpassed only by cancers. The nearly two decades of preventive work in the villages had been paying off and avoidable deaths from diarrhoea, anaemia and tuberculosis had become a rarity. Maternal deaths were practically non existent in the villages covered.

Suicides too *should* be preventable. We analysed the reasons for the high suicide rates, and discovered that in many cases, abnormal behaviour had been noted prior to the event. Our doctors team consisted of Dr Nandakumar, a surgeon, Dr Shylaja, an Obstetrician and two junior doctors. Our knowledge of psychiatry was rudimentary. Dr.Seetha, a psychiatrist from St Johns Medical College, Bangalore visited us every 3-4 months and provided support with treatment planning and evaluation.

K who is about 35 years of age, lives in a remote village with his wife, five children and his old parents. Our health team along with Dr Nandakumar went to see him as he had not been coming out of his hut for almost two months. He was angry and muttering to himself. They tried to coax him to come out as the inside was pitch dark. K refused and held on to the posts of his hut with such force that the hut almost collapsed. The team went back, unable to come to any conclusion.

A month later we took Dr Seetha to see him. By then the old father had died of starvation. In tribal culture, old people stop eating if there is not enough food at home. The family was in a precarious state. Dr Seetha listened to the story, took one look at the patient and said "This is Psychosis. Start Risperidone". Sure enough, two months later, K was back at work and life was back to normal.

In Mental illness, it is not just the patient, the entire family suffers. The sense of helplessness is overwhelming.

We started detecting more and more patients with mental illness. We were unable to follow them up regularly, since few people – not even the health team – believed that mental illness was treatable with medicines like any other illness. At a staff meeting where about 20 of the tribal staff participated, the reasons for mental illness were discussed. All those who believed that mental illness was an illness like any other and could be treated with medicines, were asked to raise their hands. Only one did so. And these were people who had been working in health care for over 15 years.

We *had* to do something- to change the attitude of the community as a whole, as well as to improve the health teams' understanding of mental illness and its treatment. It was at this juncture that, as if by serendipity, the Sir Ratan Tata Trust (SRTT) suggested the setting up of a Community Mental Health Programme and offered to fund it!

This was all very well, but we had no idea how to go about doing it. We used the approach that we had used earlier to solve our problems...one that we knew *would* work...one that was based on the belief that people, irrespective of their educational and social status, know what is best for themselves. Our role would be to provide the knowledge, options and support that they needed. This also meant involving the community in all aspects of the programme.

#### The beginning

#### The issue was first discussed with the team....

There are a large number of patients with mental illness in the community. This was causing a lot of suffering both for the patient and for the families that cared for them. When patients resorted to suicide, it was the last straw. When the breadwinner of the family was ill, the impact on the family, especially the children, was catastrophic.

A baseline survey was conducted. This was done to assess the burden of the disease in the community and to start discussions about the topic. Village leaders, health workers and youth groups were involved in the discussions. 184 villages were covered in the survey. Meetings were held in each of these villages and a survey form was used to collect data regarding number of people with abnormal behaviour, mental retardation, alcoholism, substance abuse and suicides. Peoples' attitude to the causation and treatment of mental illness was also studied. The survey report is given in *Annexure 1*.

Mental illness was not being recognised as a treatable disease, and people were still using priests, sorcerers and black magic to cast out the evil spirits that they believed were causing the abnormal behaviour.

#### A plan was made....

The health team comprising of the doctors and health animators would first gain more understanding about mental illness and its treatment. This would be followed by discussions in the villages, to get a better understanding of the burden of the disease, and to create awareness of the program to be implemented.

In keeping with our ideology, the focus of the work would be on building the capacity of people at the village level. The community would be encouraged to take responsibility for the detection and treatment of the mentally ill patients in their village.

Health volunteers would be encouraged to come forward to learn more about mental illness and its implications. They would be primarily responsible for the detection and follow up of patients. Being in the village, they would also counsel and support the families in need. These volunteers were to be the crucial link for the success of the program.

Health education sessions would be held in the villages and schools. The support of the villagers would be taken in the treatment of the patients, this being implemented at the village level, to whatever extent possible. Hospitalisation would be a last resort. The Health Animators who are first trained would be in charge of the health volunteer training and health education.

SRTT was central in putting us in touch with experts in the field and with other organisations implementing related programs.

# The plan in action....

An intensive workshop was conducted by Dr Kishore, Chief of Community Psychiatry at NIMHANS, Bangalore. He taught the doctors, health animators and hospital staff the basic principles of detection and treatment of mental illness.



Learning symptoms of mental illness at the workshop

The workshops were lively with teaching, play acting sessions and analysis. With his vast experience, Dr Kishore simplified the main principles of psychiatry. Once everyone was familiar with the basic diagnosis and treatment, he moved on to other issues like counselling, rehabilitation and side effects of drugs.

Patients came to these workshops and the symptoms were analysed. These sessions were used to illustrate how psychiatric history taking should be done, how suggestions should be avoided etc. Treatment plans were analysed, corrections if any made and long term strategies were discussed. He illustrated side effects of some of the drugs on some of the patients. These were extremely useful sessions both for learning and for the treatment planning. Workshops were conducted every 3-6 months during this 3 year period.

Dr Jacob John for CMC, Vellore and Drs Mirza Hussain and Sudeshni from Kings College, London were other psychiatrists who visited us and supported us with training and treatment planning.

Two simple booklets published by NIMHANS - "Mental Health Care by Primary Care doctors" and "Manual of Mental Health Care for Health Workers" - gave all the medical information necessary for a program of this type. We translated this into Tamil and used it for all our training.

40 health volunteers were identified each year and trained using a definite curriculum. The training manual used is given in *Annexure 2*.

In the first year the training was done by Doctors and Mr Ranan, a medical Social worker. The health animators were also involved. From the second year on, most of the training was done by the health animators. Health volunteers also attended some of the workshops held by Dr Kishore. Over a three year period, 120 volunteers have been trained.

The health volunteers had a very definite advantage of being able to detect patients with abnormal behaviour as they knew all the people at a personal level. The main responsibility of the health volunteer is to report any patient that is suspected to have mental illness to the health animator or the hospital, follow up to make sure that he/ she is regular with medication, counsel the family about the need for continued medication, encourage the patient to go to work etc.

When needed, they would also ensure that the medicines reach the patient on time. With villages being small and spread out, the health volunteers have been the key to the success of the program.

#### Records and Systems...

Simple records of all patients are kept at the hospital. Follow up cards with standardised monitoring indicators are maintained by the health animators. Doctors follow up the patients regularly with the help of the health animators and volunteers. Sample records and follow up cards are given in *Annexure 3 and 4* respectively.

#### Medicine Inventory ...

The medicine inventory for use in mentally ill patients was very limited. Two basic drugs, Risperidone and Injection Fluphenazine were used to treat psychosis, the latter, a depot preperation, being used for less cooperative patients. Depression was treated with Imipramine and Amytryptilline in most cases. A few patients needed the more expensive Fluoxetine and Sertraline. Lithium and Carbamazepine were used effectively for bipolar disease. Phenytoin, Phenobarbitone, carbamazepine and clonazepam were used for Epilepsy. Only a handful of patients needed other, more expensive drugs. Most drugs were procured in bulk at very nominal costs.

Numerous health awareness sessions have been held in villages, schools etc. The "Area Team" consisting of health animators, animators and education workers have been involved in these sessions as mental illness impacts all aspects of the life of the family. This multi-sectoral approach has helped in rehabilitating the patient and the family.

Chandran has been walking the streets of Gudalur with a gunny bag filled with petitions for more than a decade. He had worked as a peon in a bank prior to being inflicted with mental illness. Prior to the program starting, we had tried several times to treat him. There was no success. Today with regular treatment, incredible support from the health volunteer in his village and the area team, he leads a near normal life.

The education team put him in charge of the village library and he teaches children in the evenings. He volunteers to come for health volunteer training sessions in other areas to impress upon them the need for treatment.



Counselling at the village



A team approach- Health staff along with staff from other sectors and health volunteer visiting a patient at home

# The patient profile....

214 patients have been identified and started on treatment. Out of this 36 patients needed admission to hospital for various periods for control of symptoms. All others were managed at the village level. Of the 182 that continue on treatment, 136 patients are functioning normally,

going to work and earning a livelihood. Only 10 are not yet functional while 36 are partially functional.

There has been only one suicide in this group of patients. Details of the patient profile is given in *Annexure 5* in the impact assessment study.

# INTERESTING ASPECTS OF THE INTERVENTION

The uniqueness of the patients has been the openness with which they presented their complaints. There is *no trace of taboo*.

V must be about 30-35 years of age. She is married and has 4 children. She came to the hospital in a very agitated state. She was not feeling normal. They had tried temples and calling the gods to get rid of her problem. It had not worked.

Her complaint "I always feel like having sex with my husband, even when we are not alone. I try to tell myself that this is not good but- she points to her pubic areathis will not listen!"

The simple and straightforward answers make diagnosis and treatment so much easier.

The *support provided by the family*, most importantly the spouse, even in patients that have been unwell for long periods of time, is another unique factor. Difficult as the relationship must be, they remain faithful to their partner and tend to them. There are many such instances.

A and B are a couple in their late thirties. They have been married for over 15 years now. A has severe mental illness with inability for even self care. She sits in a corner of her house silently and does nothing all day long. She has been suffering for over 10 years now and has not been willing to take treatment all these years. They have no children.

B takes care of all her needs before he goes to work in the morning. He comes home and cooks and fetches water. After the Mental health program commenced, our team convinced B to bring his wife for treatment. After two years treatment, with incredible support for the husband, she is better, and is able to take care of herself.

The support provided by the spouse in this long drawn out illness is commendable.

The *sensitivity of patients to medical treatment* has been another notable feature.

C of about 40 years of age is a widower with 4 children living in a remote village. When we first saw him during a village visit, he had not been talking to anyone for six months. He sat quietly in his house with no self care. His old mother fed him. We practically carried him to the jeep and brought him to the hospital. 3 days after treatment was started, he started speaking and eating on his own. Soon after, he became fully functional and went back to doing manual labour.

The response of many patients to chemotherapy has been as dramatic.

The main impact has been the change in the attitude of the community towards mental illness in such a short period of time. We did a survey to assess this. The objective was to understand the attitude of people to mental illness and to see whether the health education had made an impact at the community level.



Health worker Lalitha, hailing from a village deep in the forest, says, "We never thought that this was an illness. Now when we hear others talk about it being a curse, it sounds so absurd. We are convinced that it is treatable disease like many others.".

Using the standard questionnaire which was used at the beginning of the program with some modifications, 510 people from various villages selected randomly were interviewed. A report of the impact assessment is given in *Annexure 5*.

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A family that got their father back

The 210 tribal villages served by ASHWINI are scattered small hamlets with 10-40 families in each. Many are inside forests and you have to walk through elephant country for 4-7 miles to reach some of them. The health volunteers are mainly women with little or no formal education. Most cannot read or write. In spite of all these obstacles, we have been able to bring about a dramatic improvement in the quality of the life of over 200 families. The attitude of a major part of the community towards mental illness has changed for the better. The dedication of health volunteers, health animators, nurses and other staff, the support given by SRTT and the visiting psychiatrists, has made this possible.

For us at ASHWINI, the medical treatment of mental illness has been as magical as oral rehydration solutions for diarrhoea. While we wait for the Government to implement The National Mental Health Program, we can ease a lot of suffering by creating more awareness about mental illness and its treatment in the community.

It would not be an exaggeration to say that no other single intervention appears to have changed the lives of so many people in such a short time.

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# ANNEXURES

# Annexure - 1

# Mental illness among adivasis of Gudalur valley, Nilgiris – Base line study on Prevalence and Perceptions

# **Objectives of the Study**

The study on mental health was organised with a view to get a clear picture of the prevalence of mental illness, perceptions of the people, potential problems in tackling mental illness and to estimate the resources available at the field level.

Specifically, the main objectives of this study were -

- To assess the burden of mental illness with special focus on suicides in the community.
- To asses the magnitude of other related issues like mental retardation, epilepsy, drug abuse (Ganja) and alcoholism.
- To understand popular perceptions about mental illness, its causes and treatment
- To generate discussions and raise awareness on mental illnesses.
- To reinforce the role of the Health volunteers in the community.
- To use the results of this study as bench mark to evaluate the effectiveness of Ashwini's intervention at the end of the project period.

# Methodology

A structured questionnaire was designed to collect the information required for the study. Since most of the adult members of the adivasi community are not literate enough to fill in the questionnaire themselves, the health animators of Ashwini administered the process with active help from the health volunteers of the respective villages.

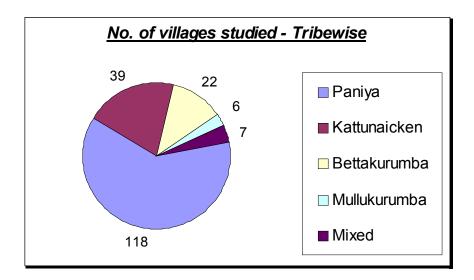
The English version of the study form is given in the Appendix of this report. After conducting the pilot study in a few villages, some changes were made in the design / format of the questionnaire. Training was given to the health animators on the study by the coordinator, a qualified social worker.

Focus Group Discussion was the chosen methodology to conduct the study. Since one of the main objective of the study was to raise awareness about mental health among the community and to initiate discussions, this mode of organising informal meetings at the village level and collecting data was found to be most useful and effective. Key members of the village were informed before hand and assembled in a common place for the focus group discussion.

#### <u>Sample Size</u>

Since Ashwini's area of operation has been divided into eight geographical zones called "Areas", the sample size was also chosen from all the eight Areas. Totally, the study was conducted in 184 sangam villages covering almost the entire area of operation of Ashwini.

Since Paniyas were the most populous tribe in this region, the study was also conducted in more Paniya villages. Moreover, the incidence of suicides in different tribes during the last few years was also taken into account while deciding the villages to be studied.



The table given below gives the distribution of villages in the eight Areas where this study was conducted.

Area	Paniya	Kattu Naicken	Betta Kur- umba	Mullu Kur- umba	Mixed	Total
Gudalur	15	1	5	0	5	26
Devala	12	4	2	0	0	18
Devarshola	18	6	5	0	0	29
Ponnani	13	1	1	0	0	15
Pattavayal	9	4	4	0	0	17
Srimadurai	11	5	1	0	1	18
Erumadu	22	3	1	2	1	29
Ayyankolli	18	7	3	4	0	32
Total	118	31	22	6	7	184

# No. of surveyed Villages

The total number of families that were covered in this study through the focus group discussion held in 184 villages was 2759. The areawise break-up is given in the table below.

Area	No. of Famil- ies
Gudalur	740
Devala	210
Devarshola	404
Ponnani	170
Pattavayal	264
Srimadurai	231
Erumadu	279
Ayyankolli	461
Total	2759

# Prevalence of Mental Illnesses

In this section, the results of the study with respect to the prevalence of mental illnesses in the adivasi community are being tabulated and analysed.

# i. Mentally Ill Patients under treatment

During the Focus Group Discussions, the members were requested to identify the patients in their village who are undergoing treatment at that point in time. This was to find out the extent of prevalence of any sort of mental illness in the community. The Areawise list of mentally ill patients under treatment is given in the table below.

Area	Number of Patients under Treatment
Gudalur	12
Devala	6
Devarshola	20
Ponnani	4
Pattavayal	8
Srimadurai	10
Erumadu	9
Ayyankolli	17
Total	86

# ii. New Mentally Ill Patients identified during the survey

One of the important gains of this study was the fact that we were able to identify more mentally ill patients. When we discussed the symptoms of mental illness and elicited the response of the village members, it was found that there were more people with symptoms of mental illness, but who were not taking any treatment. The statistics of such new patients identified is given below.

Area	Number of New Patients identified	
Gudalur	15	
Devala	13	

Devarshola	1
Ponnani	8
Pattavayal	3
Srimadurai	13
Erumadu	8
Ayyankolli	6
Total	67

These patients were also included along with the patients undergoing treatment for future followup by the field of ASHWINI. Detailed follow-up plans were drawn up and responsibility shared between the health volunteers and sangam members for this.

# iii. Profile of the Mentally Ill Patients

During the study, we tried to draw a profile of mental illness in the adivasi community. We analysed the symptoms of the mentally ill patients identified by the respondents and classified them into two broad categories of Psychosis and Neurosis. Some patients had both the symptoms and they have been included in the Psychosis category. This was more an impressionistic opinion of the respondents, rather than diagnosis by doctors or other psychiatric professionals.

Area	Psychosis	Neurosis
Gudalur	10	6
Devala	13	5
Devarshola	8	4
Ponnani	5	7
Pattavayal	9	2
Srimadurai	7	6
Erumadu	10	1
Ayyankolli	12	4
Total	74	35

Later, we shared this data with the psychiatrists and got their expert advice. This also helped in designing our treatment protocol and training programmes of the health volunteers.

# iv. Status of Suicidal Tendencies

In a sense, the germ of this intervention started when we noticed an alarming increase in the reported cases of suicides and attempts. So, we had a separate section to find out the extent of suicidal tendencies. The respondents could clearly report cases of suicides and attempts to commit suicides during the last five years. This data is presented in the following table.

Area	No. of Attempted Suicides	No. of Suicides
Gudalur	5	6
Devala	0	4
Devarshola	1	6
Ponnani	2	10
Pattavayal	2	4
Srimadurai	10	3
Erumadu	4	1
Ayyankolli	2	9
Total	26	43

# v. Epilepsy & Mental Retardataion

Though our focus was mainly on mental illness, we used this opportunity also to estimate the prevalence of epilepsy and mental retardation. Even though we were not planning to include mental retardation in our programme, this data was collected in the base line study. The figures are given in the following table.

Area	Epilepsy	Mental Retardation
Gudalur	5	1
Devala	1	2
Devarshola	3	2
Ponnani	1	0
Pattavayal	5	2
Srimadurai	1	1
Erumadu	1	0
Ayyankolli	0	3
Total	17	11

# vi. Other contributory factors and Addictions

We were also concerned at the prevalence of addictions to alcohol and ganja, especially among the younger generation. In fact, most of the people who had committed suicide, were alcoholic. Almost as a rule, all the suicides were committed in an inebriated condition. So, special effort was taken to find out the extent of addiction to alcohol, ganja and other substance abuse among the adivasi community.

Area	Alcohol	Ganja
Gudalur	3	1
Devala	1	0
Devarshola	1	23
Ponnani	3	3
Pattavayal	1	0
Srimadurai	10	27
Erumadu	2	0
Ayyankolli	4	0
Total	25	54

The result of this is given in the following table.

# Perception and Awareness about Mental Illness

As part of the survey, an open ended section was included to understand the perception and general awareness of the adivasi community about mental health. The objective of this section was to understand the issues of concern for the adivasi community with respect to mental health and the popular belief systems existing in the adivasi community. A clear understanding of the perception of the community will help us articulate the focus of future intervention, to design our communication materials and awareness programmes.

The following four questions were asked and a focus group discussion was organised around these issues :

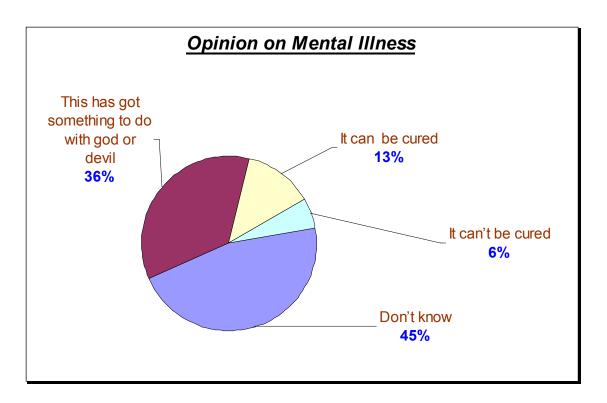
- What is your general opinion about mental illness ?
- What are the main reasons for mental illness ?
- What does one do if one gets mental illness ?
- Where can we get treatment ?

Since these questions were open ended, the views expressed in the Focus Group Discussion were captured by the health animators and were later tabulated into a few categories. For the above 4 questions, the response was as follows –

#### • General Opinion about Mental Illness

This question elicited a wide range of views from 'it is due to sorcery' to 'it is a disease of the mind'. However, a vast majority of 45% of people did not know anything about this illness or what causes it. A significant 36% of the respondents felt that it is something to do with God or devil, can be caused by sorcery, people use black magic to make others become mad, this is very much prevalent among adivasis etc.

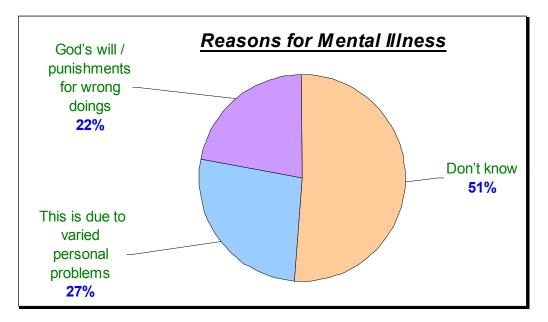
Many people also felt that it can be cured using 'spiritual powers' and by countering the effects of black magic. 6% of the respondents felt that it cannot be cured at all. A very small percentage of people felt that it is actually a disease and can be cured with medication and treatment. Results of the responses to this question are given in the chart in the next page.



# • Main Reasons for Mental Illness

Responses to this question showed that the community is quite ignorant about the reasons or causes of mental illness. More than half of the respondents did not know the reasons why some people become mentally ill. However, many people felt that it is caused by god or evil spirits. Some sample responses falling in this category were :

- God's will
- Lack of faith in God
- Wrong deeds done by people
- Sorcery
- Curse of God
- Must have got scared of evil spirits



A significant 27% of the respondents felt that it is caused due to family and social problems like alcoholism, unemployment etc. Some responses under this category were :

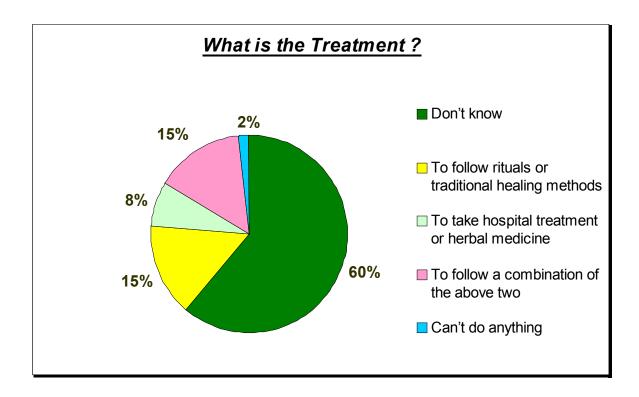
- Alcoholism
- Indebtedness
- Family disputes
- Fights with other villagers

- Too much of thinking
- Suspicion
- Sadness
- Inferiority Complex
- Love Failure

On the whole, the understanding among the adivasi community on the causes of mental illnesses was quite limited.

# • What does one do if one gets a mental illness ?

Along the lines of the responses to the first two questions, here too the majority of the respondents did not know anything about possible treatment for patients. About 38% of the respondents felt that some action can be taken. 15% of the people mentioned the possibility of praying, performing pooja and other such rituals and getting in touch with people like astrologers, *panikkar*, village elders etc. 8% of the people thought some kind of medication will help heal the patients. Though few people mentioned the need to go to allopathic doctors / hospitals, many felt that herbal medicines will help.



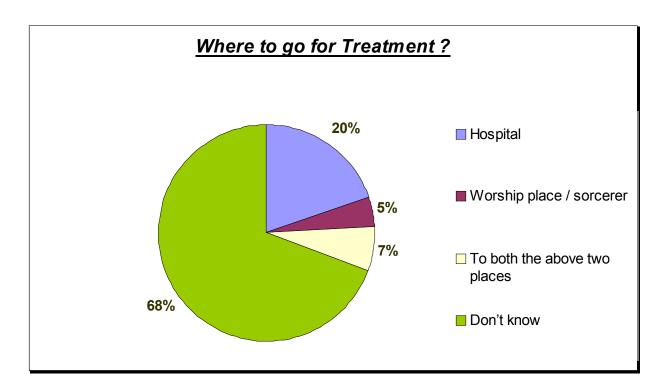
An important issue is that 15% of them said they would follow a combination of both rituals / pooja and medication (either allopathic or herbal). A small 2% said that we cannot do anything and the illness cannot be cured by anything.

# • <u>Where do you go for treatment ?</u>

This question was asked more to cross check the responses to the previous questions. In fact, the second and third questions were phrased in a different manner here. The responses to this question also confirm the general perception as given in the previous sections. A majority of the respondents did not know where to access any sort of treatment for the mentally ill patients.

Most of the people who mentioned Hospital, had actually referred to the Gudalur Adivasi Hospital. This could probably due to the fact that the interview was conducted by health animators and volunteers who were associated with this hospital. One respondent had mentioned Calicut Mental Hospital.

The place of worship also differed quite a bit in these responses. Some people felt that they can perform the pooja at their village itself, many people felt that they need to take the patients to some temple or other.



#### **Conclusions**

To summarise, the majority of the people (more than 60%) surveyed were completely or partially ignorant about issues concerning the mental health of the community, be it the reasons or the possible treatment. About 12% of the people had strong misconceptions and wrong beliefs about mental illness. This fact is more striking, when we consider that the survey was conducted only in sangam villages. Adivasi members in sangam villages are expected to have comparatively more exposure to health issues than the non-sangam villages, due to continuous interaction of Ashwini's health team with them. The level of awareness about mental health would be poorer in other non-sangam villages which were not surveyed. This underlined an urgent need to create awareness in the society and Ashwini has made plans for this.

The most important result of this base line study was that it triggered lots of discussions in the villages on mental health. This was an issue, as mentioned before, not tackled or discussed in any forum till then and no organised attempt had been made by Ashwini or any other agency among the adivasi community. This was the first time, people came together to discuss various new issues like mental health, suicides, depression, alcoholism, epilepsy etc. In fact, 67 new patients had been identified during the course of this base line study and people felt that they need to be followed up or some sort of treatment should be started.

Moreover, we could also highlight the spread of addition to alcohol and ganja during the course of this study. Because of this, separate Health Education programmes were conducted in such villages and that is making impact in those villages.

In short, this base line study on mental health among the adivasis of Gudalur valley, the prevalence and perception about it, was an ideal first step in the intervention being planned by Ashwini with the support of Sir Ratan Tata Trust, Mumbai. It has thrown up the areas which need attention and has highlighted the issues that should be covered in the health education programmes.

We thank Sir Ratan Tata Trust, Mumbai for having funded this study. And, we would like to specially acknowledge the contributions all the sangam members and health volunteers of Adivasi Munnetra Sangam who participated in this study.

# Village Mental Health Survey

# A. Profile of the village and people

- 1. Area
- 2. Village :
- 3. Sangam :
- 4. Tribe

# 5. Key Informants / Respondents :

:

:

No	Name	Sex	Age	Responsibility	Opinion about mental illness	What is the cause of mental illness	What possible treatment	Where
1.								
2.								
3.								
4.								
5.								
6.								
7.								
8.								
9.								
10.								

6. Total number of families in the village sangam :

# B. Prevalence of Mentally illness in the village

Sex	No. of Patients
Male	
Female	
Total	

# 7. Number of psychiatric patients undergoing treatment

# 8. Suicides / Attempted suicides during the last 5 years

Nature	Male	Female	Total
Attempte d			
Died			

# 9. Are there any new patients in the village Yes / No

# 10. If yes, please give details of the patients

No.	Name	Father / Husbands name	Sex	Age	Major complaints – according to the informants (specify suicidal tendency if any)
1.					
2.					
3.					
4.					
5.					
6.					
7.					
8.					
9.					
10.					

# 11. Other complaints

	Problem	Name	Father /	Sex	Age	Remarks
--	---------	------	----------	-----	-----	---------

	Husband's name		
Alcoholism			Since when :
Ganja			Since when :
Epilepsy			
Mental Retardation			

# C. <u>Perception / Awareness about Mental health in the village</u>

12. What is your general opinion about mental illness ?

13. In your view, what are the main reasons for mental illness ?

14. Is there any treatment available for mental illness?

:

:

:

15. Where do you think we can get treated for mental illness?

Thank you.

Survey conducted by

Date

Signature

# Annexure - 2

# Training Manual for Health Volunteers in the ASHWINI's Community Mental Health Programme

# Introduction

Ashwini (Association for Health Welfare in the Nilgiris) launched a special health intervention targeting mental health issues of the adivasi community living in the Gudalur and Pandalur taluks of the Nilgiri district, Tamilnadu in 2005. The mental health programme was implemented at the community level. The field health staff and the health volunteers from the adivasi community played an important role in detecting , ensuring treatment and continuous follow-up of the patients.

Lot of effort was spent in training the health volunteers, young girls and women from the adivasi community, on various issues involved in mental health. A structured training programme was designed and a broad curriculum was developed. Since literacy levels among the adults of the adivasi community here are not very high, we used audio visual aids, presentations and lectures to a large extent.

This training manual captures the important stages involved in this training programme and covers the contents of the training programme. We hope that this may help other such community based interventions on mental health among some other communities.

# Background

Ashwini has been running a comprehensive health programme providing both curative and preventive health care services to over 15000 adivasis in the Gudalur valley, primarily to those organised under the banner of '*Adivasi Munnetra Sangam*'. Health intervention among the adivasis here started in 1987, with the training of adivasi women as health workers to provide ante natal care and under-5 children care.

In 1990, The Gudalur Adivasi Hospital was started.. Adivasi youth were trained to work as nurses in the hospital and as health animators to coordinate the community health programme in the villages. From 1994, health sub-centres were organised so as to decentralise the health care programme. An innovative health insurance programme was also started to stress the

concept of mutual help, to make the health programme accountable to the adivasi community and to mobilise resources from the community.

After about two decades of health intervention, the health status of the community improved significantly in many fronts. Antenatal care went up, and more than 90% of children were immunized. Preventable illnesses were effectively tackled at the village level itself. Maternal mortality was almost eliminated in the sangam villages, while infant mortality rate was below the national average. Importantly, the health seeking behaviour of the adivasis improved significantly.

The intervention in mental health till the launch of this programme was limited to treatment of serious patients by a visiting psychiatrist and Ashwini's doctors. Hospitalisation when necessary at the Gudalur Adivasi Hospital was provided, with follow up by the health animators.

# Mental Health Programme

Although much progress has taken place in other areas, Ashwini's intervention did not tackle the major problem of mental health. Suicide was a common cause of death. Many of those who committed suicide had a history of mental illness.

In April 2005, a comprehensive intervention was set in motion to tackle mental health issues. As a first step, a base line study was conducted to understand the perceptions of the community about mental health, the extent of prevalence of mental illness and the profile of patients. This was followed by intensive health education at the villages with the help of health volunteers. The health animators and the health volunteers, with the help of the doctors and a qualified social worker interacted with the community quite intensively for more than 2 years.

This manual summarises the issues discussed in the training programmes for health volunteers and the highlights of each of the modules. Training sessions were conducted in the eight health sub-centres on a monthly basis. In these one day sessions, between 10 to 15 health volunteers participated. Besides, once in two months, two-day camps were organised in which about 50 volunteers in almost as many villages participated.

As mentioned before, these sessions were instrumental in breaking the stereotypes about mental illness, in bringing the important issues to the fore for discussion and in motivating the health volunteers to address the problems faced by mentally ill patients. Though these sessions were quite interactive and free-flowing, inputs were provided around a framework. In this manual, the structure for the training programme has been articulated.

This can be easily adapted by other community based interventions, after taking into account the local conditions, profile of mental illness prevalent and the extent of awareness about the problems in the community.

# Lesson 1

# Mental Health & Your role

#### What do we mean by 'being healthy' ?

• Being healthy means having a sound body, a sound mind and social well being.

#### Issues on which we concentrated in our community health program in the beginning:

- Maternal deaths
- ✤ Tuberculosis
- Anaemia
- \* Diarrhoea

After 15 years there is an awareness and development in these matters.

# Important problems we are facing now

In our community diseases like cancer, mental illness, suicides have increased in number. The awareness about these diseases is very less. So, we need to address them – like we worked on preventive health, ante natal care, under-5 children care and the insurance programme for so many years.

# Suicides – A big problem in our community

• If the society is not united and everyone is separate, the number of suicides will increase.

• In the past 4 years an average of 15 persons per year have attempted suicide in our society.

# **Mental illness**

Causes a lot of difficulties to

- $\Rightarrow$  the patient
- $\Rightarrow$  the family
- $\Rightarrow$  the society

If proper care is not given, this will lead to great danger. This is why we have started the Mental Health Program.

# What are the problems in treating mental illness?

- •There is very limited knowledge about this in the society.
- •People do not know that it is actually a disease.
- •Many do not know that there is treatment for this disease.
- Mentally ill patients do not volunteer to take treatment and they do not take treatment regularly.

#### What can we do for this?

- For treatment of mental illness, it is necessary for everyone to join together and work as a team.
- In this each one of you has an important part to play.

#### Why is your part very important?

- Since you have a good relation with everyone in the community, you can easily identify the mentally ill patients.
- Since everyone here knows you and trusts you, they will listen to what you say.
- Since you are in the village, you can always know the condition of the patients.

#### Points to remember

- There are many mentally ill patients in our society. Since there is no proper awareness about this, many are not taking treatment for this.
- Everyone has wrong notions about mental illness, its causes and treatement methods like black magic and evil spirits. These views are quite strong and will be difficult to change.
- If this illness is identified in the beginning, good treatment can be given and the patient can be completely cured.
- If not treated, mental illness will not only affect the patient but also his / her family and the community.
- It is the responsibility of each one of us to take care of a mentally ill person.

# Lesson 2

# **The Mentally Ill Patient**

# How do we approach mentally ill patients ?

Without proper knowledge and skills, it is difficult to protect mentally ill patients.

- How should we talk to them ?
- How to make them accept medicines and other treatment methods ?
- How to help them ?
- Will they cause harm ?

Many similar questions may worry you. Let us see how to approach such patients.

# General reaction to a mentally ill

When someone happens to meet a mentally ill patient, s/he may react in any of these following ways. They will directly or indirectly express their reactions.

- Fear and suspicion that the patient will cause harm .
- Hate and dislike because they are not neat and clean.
- We may get angry and avoid them because they are disturbing us.
- We feel pity and are sorry for them because they are suffering.

- We may laugh at them because they behave childishly.
- No trust / faith in them because their behaviour is not predictable.

General approach towards such patients is to avoid them. If we get thoughts like 'Why should I care for him ? He is mad', it means that we see these patients as very 'low'. We may not respect them or may not treat them as human beings.

If we treat them like this, they will not believe us and will not accept our help.

# Approaching a mentally ill patient

First of all, you should be quite aware of the reason for mental illness. If you trust them and treat them with love and affection, they will reciprocate.. If you are helpful, they will cooperate.

Mentally ill patients have their own feelings, likes and dislikes and self esteem. They should be treated as a responsible person and with respect.

# Give importance to the patient

- When you are with the patient you should give importance to them. If you don't treat him / her as an important person, it is being disloyal to the patient.
- First ask them what their problem is. Do not give opinion, argue, criticise or laugh at them. Listen patiently.
- Try to understand what they are saying. It is not necessary that you should agree to everything they say. Accept it as a mediator or take it as a real happening. Ask about their experience and beliefs. Assure them that you will do your maximum to help them. This will help you to gain their trust.
- After the patient has told you about his / her problems, get information about their problems from relatives. If there is difference between the two, do not argue. Bring this to their notice and ask for clarification.
- When you are communicating with the patient or his relatives ask only what is needed. Due to your curiosity, do not interfere in unnecessary matters. When others are there, you should not ask about very personal or sexual matters. Ask such questions when they are alone. Assure the patient that you will not discuss about his / her problems with others.

ashwini

#### Points to remember

- You must develop a desire to help the patient, in spite of their physical condition.
- Give priority to the care of the patients.
- You should have the confidence that you can help the patient and his family.
- Your help will lead the patient and his family helping themselves.

Lesson 3

# **Symptoms of Mental Illness**

#### Kullan's story

Kullan is a 22 year old youth. In his village, he is the only person who had studied till tenth standard. When he stopped studies he started working in the nearby tea estates. He got lot of money. His mother also liked him very much, because after work he brought rice, vegetables, fish and beetle and nuts.

But, it did not last for many days. For the last one year he is not going for workand is not doing anything on his own land . On enquiring, his friends said that he was talking abnormally for some days. He was trying to avoid them and talked very little. After few months, he stopped going to work completely and also lost interest in doing anything at home.

Later if somebody came to see him, he stopped coming out of the house. He completely lost interest in meeting others. His mother had to remind him many times even to eat. When he was alone, he talked and laughed as if somebody was talking to him. Some days he went to the nearby forest and sat there alone. He came back after one or two days.

If someone asked. "Where did you go ?", he did not answer.

### Who is mentally ill?

How we can identify a mentally ill patients ? Are there any symptoms that help us identify ? The mentally ill patients will have one or more of the following symptoms :

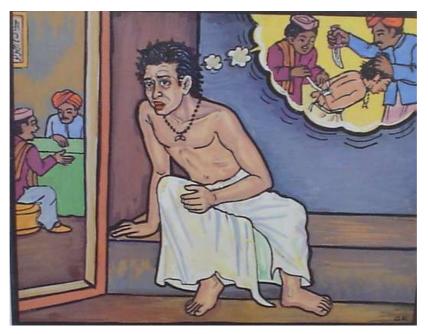
• They talk meaningless things and behave in a different, abnormal manner.



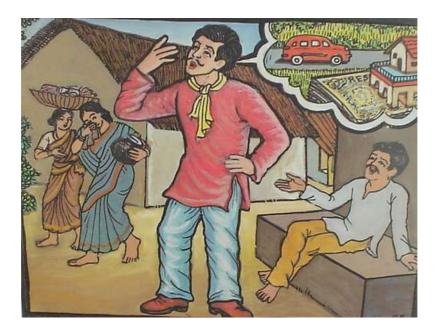
- They are very silent and do not talk or mix socially with anyone.
- They say that they can see and hear things which others cannot see or hear.



• They may suspect very much that some people are trying to cause harm to them.



• They may be unusually happy and tell jokes. They may boast that they are very rich and superior to others when really they are not.





• They may be very sad and keep crying without reason.

• They keep talking about committing suicides or have attempted suicide.



• They may claim that they are possessed by black magic or evil spirit.

### Lesson 4

### **Depression, Mania and Neurosis**

Both the extreme emotions – sadness and happiness – can be symptoms of mental illness. These two conditions are differentiated as Depression and Mania. We must understand the symptoms of these two conditions clearly.

### **<u>DEPRESSION</u>**

### **Symptoms**

Patients with depression usually have the following symptoms :

- Low or sad mood
- Loss of interest
- Disturbed sleep
- Guilt or loss of self confidence
- Fatigue or loss of energy
- Irritability
- Disturbed appetite
- Suicidal thoughts or actions

#### **Problems with these patients**

- People believe that they are lazy and good for nothing when actually they are trying hard to cope.
- There is a high risk of suicide.
- Symptoms are not easily recognised

### What can I do?

- Explain to the families that this is an illness that has effective treatment.
- Ask about risk of suicide. If patients have plans for suicide, close supervision by family and friends is needed.
- Talk to the patient.

- Identify social stress factors and try to resolve these issues.
- Report to health team as patients often need medications.

### <u>MANIA</u>

#### **Symptoms**

Patients with mania usually have the following symptoms :

- have excessive happiness
- Laughing loudly without reason
- Over confidence
- Will do more work. But that work won't be proper.
- Will speak highly of themselves.
- Will get angry soon.

### **Problems with such patients**

- They will have more energy
- Will spend lavishly. Sometimes will sell their land also
- They will get irritated by people very easily
- Patients with mania will most often go on to have periods of depression when they become unduly sad and quiet.
- We have to watch out for this

### What can I do?

- Should make their family and others understand that this is also a mental illness
- Should not ask any questions or argue with the patient.
- See that money and costly things are not left under their control
- Inform the health animator.
- There is good medication for this disease (mania)
- Should take treatment for 6 months

- Somebody should monitor intake of medicines
- Watch for symptoms of depression

#### Difference between Depression and Mania

Sl. No.	Depression	Mania
1	Sadness	Happiness
2	Cries when alone	Laughs excessively
3	Lack of self confidence	Over confidence
4	Will not do any work	Will do more work

### <u>NEUROSIS</u>

Sometimes, the patients may complain that they have continuous pains in their legs and arms or some other symptoms of disease for which medicines are not effective.

- If people are hurt, they cry or get angry and scream.
- But some people keep it in their mind.
- Often these people present with problems like pain in arms and legs, headache, giddiness, and feeling tired.
- They often take medicines from doctor or drug stores. But the pain will not reduce.
- It may not get cured at all, even after taking all kinds of medicines
- Such people basically want somebody to attend to them or counsel them.
- Should rule out other illnesses in these patients.
- If there are no symptoms of such diseases, the patient may be having depression.
- The important thing in this is to talk to them
- Many patients may be having this problem. If we talk to them they will tell us openly.
- Sometimes these problems can be caused by other concerns like unemployment, abusive husband etc.
- If we talk to these patients early, we can get good result.
- Sometimes small dose of medicines may also be needed for some days

### Lesson 5

### **Psychosis**

Psychosis is a major mental illness.

- Patients with psychosis live in their own world.
- They do not take care of their daily routines

### **Symptoms**

- They have hallucinations they see things and hear voices that others do not see or hear.
- They have delusions strong beliefs that are wrong and are not accepted by others.
- They act on these beliefs.
- They show abnormal emotions.
- Their thoughts and speech are abnormal.
- They cannot perform responsible duties at home or at work.

### Problems with such patients

- Because of all this they are a major problem for themselves, their relatives and neighbours.
- Most people believe that psychosis is due to evil spirits, God's curse, supernatural powers etc. Instead of giving medication patients are taken to temples, faith healers etc.
- Because of their violent behavior they can do harm to the people around them and to themselves.
- They can also destroy things.

### What can I do?

- Psychosis can be treated effectively with medicines like any other disease.
- We must make the people aware of the importance of proper treatment.
- It is important to detect psychosis early and get treatment.
- Inform the health animator as soon as you know about a patient with symptoms of psychosis.
- Treatment should be given for as long as is advised by the doctor.
- A patient with psychosis is a big burden on the family and the community. We must take every action to make them useful members of the community.

### **Points to remember**

- Abnormal speech, behaviour, no involvement in usual things, hearing and seeing things which are not there and strong wrong beliefs are important signs of psychosis
- Psychological and chemical changes or damages in brain can cause psychosis.
- There are medicines which help psychosis treatment. Continuous medication, proper care, bringing the patient quickly to the old condition, help and guidance from family / relatives help the patient get well soon.

### Lesson 6

### **Treatment and side effects of medicines**

While on treatment, mentally ill patients are required to take the medicines continuously for long period. Psychiatric medicines may have side effects on some patients. It is important for the health volunteers to understand the effects of these side effects and possible actions that can be taken. This is important, otherwise the patient or his family may discontinue the intake of medicines.

Sl. No.	Side Effect	Action to be taken
1	Dryness of mouth	<ul><li>Reassurance.</li><li>Advice the patient to take more liquids</li></ul>
2	Drowsy / excess sleep	<ul> <li>Reassurance.</li> <li>Let the patient take medicines before going to sleep.</li> <li>Get advice from doctor for correct measures.</li> </ul>
3	Rigidity of hands and legs, light movement of the limbs or light shivering	<ul><li>Refer to doctor.</li><li>Doctor will give him the correct medicines.</li></ul>
4	Neck / limbs moving to one side. Suddenly, eye spot going up	<ul><li>Inform doctor immediately.</li><li>Doctor may give an injection to treat him</li></ul>
5	Giddiness while moving from one place to another.	<ul><li>Check BP.</li><li>Inform doctor.</li></ul>

### Side Effects of Imipramine / Amitriptyline

Sl. No.	Side Effect	Action to be taken
1	Dryness of mouth	<ul><li>Reassurance.</li><li>Advice the patient to take more liquid food</li></ul>
2	Constipation	<ul> <li>Reassurance.</li> <li>Advice to take lot of greens / fibrous vegetables and fruits.</li> <li>Drink plenty of water.</li> </ul>
3	Blurred vision	<ul> <li>Reassurance.</li> <li>Advice to avoid reading for some days.</li> </ul>
4	Retention of urine	<ul><li>Stop medicines.</li><li>Inform doctor immediately.</li></ul>

### Lesson 7

### **Epilepsy**

Ravindran is a 10 year old boy. When he was five years old, he started getting fits.

During fits, he suddenly cries and falls to the ground. For sometime his body becomes rigid and he pulls his hands and legs. During fits, he is completely unconscious. Also he holds his teeth tight. Sometimes froth comes out of his mouth. Sometimes unknowingly, he passes urine and wets his clothes. This attack lasts for 2 to 4 minutes. After that he becomes conscious. These

attacks come at an interval of few days. His parents say that he has become very irritable.

All of us have seen people with fits. They become unconscious and fall where they are. They may get hurt, when they fall. Their hands and legs become rigid and start to pull. These movements are continuous and normally last for 1-2 minutes. During this time normally they have froth in their mouth. They may bite their tongue or lips and may bleed. They may wet their clothes. It may take few minutes to few hours for them to become normal. Following fits patients may have headache, vomiting, body pain and other pains, increased tiredness, unclear speech, weakness, or weakness of hands and legs, or increased sleep. Due to the tiredness after fits, patient may wish to sit and take rest. Some patients may show confused or abnormal behaviour after fits.

- Epilepsy can come at any age in males and females.
- It will affect people of every caste and community. But, it is mostly seen in children and youth (below 15 years of age).
- In the whole population, for every 1000 people, 10 are affected with epilepsy.
- This is called by different names in different parts of the country.

Before the attack, some may get warning symptoms. These symptoms are giddiness, fear, seeing stars or dreams, disturbance in the stomach. In some patients fits may start in one part of the body and spread to other parts.

Patients with following symptoms are suspected to have epilepsy:

- $\Rightarrow$  Reccurent burns or wounds.
- $\Rightarrow$  Mentally retarded children are more prone to epilepsy
- $\Rightarrow$  Showing abnormal behaviour for only few minutes with fits or after fits
- $\Rightarrow$  Reduced activity in school.
- You may hear about a person getting treatment from traditional practitioners for being possessed by evil spirit. These people may have epilepsy.

### **Causes for epilepsy**

Epilepsy is a symptom of brain disorder. There is abnormal electrical discharge in some nerve cells leading to fits. If brain is damaged at birth or after birth, epilepsy may occur.

If epilepsy occurs for the first time after 20 years there will be identifiable brain damages in the person like wound scar, bleeding inside the brain, tissue growth, use of alcohol or other drugs for long days. Brain fever and other damages of brain also may cause epilepsy.

Sometimes, children (below 5 years) with high fever can get epilepsy. This is called febrile fits. Some children get fits even while bathing in hot water.

Whatever the reasons may be, any epileptic seizures should be informed to the doctor. Every attack may cause brain damage. Epilepsy of long duration may cause mental illness for the patient or may damage their mental skills. Seizures which occur near water, fire or running machines may cause wounds or even kill the patient. So every epileptic patient should be taken care of properly and need correct treatment at correct time.

### **Treatment of epilepsy**

Epilepsy is treatable. Continuous treatment can control and cure it. During treatment, patient can do his ordinary work. Children can go to school. There is no diet restriction. In the beginning, when fits cannot be controlled completely, patient should not work alone near fire, water or heavy machines, should not drive, should not climb trees or work on tall buildings. If these warnings are remembered an epileptic patient can live normal life.

### First Aid : If a person gets fits ...

### What you should do

- $\sqrt{}$  Empty the place around the patient
- $\sqrt{}$  Remove hard things or furniture so that they don't hurt themselves.
- $\sqrt{}$  Lie them on their side so that the secretions from their mouth will not block their breath.

### Things NOT to be done

- Do not keep any hard object between their teeth (you may unexpectedly break their teeth or damage their gums)
- During fits do not hold their hands or legs.
- During fits do not give them anything to drink. If you compel him to do so, you may cause them suffocate.
- Do not keep key or any other iron things in their hands. Fits stops by itself.

#### **Points to remember**

- Epilepsy is the symptom of brain dysfunction.
- Epilepsy can be controlled and cured by taking proper medicines for long days
- During fits, patient should be turned to a side and left alone. When the movements have stopped, he should be taken care of. It is not necessary to take more medicines before or after fits
- Epilepsy patients on treatment can go to school or do their day to day works and live normal life.
- Epilepsy patients should be careful that they do not work alone near fire, water or running machines.
- Every epileptic patient should be visited monthly to see if they are taking medicines regularly. Remind them to take medicines regularly.
- If a patient gets fits for the first time and recur after one or two minutes get medical help immediately.

### Lesson 8

### Substance Abuse

#### Alcohol and drug abuse

In human history, man has used drugs or things that change human mind in one way or another. These drugs changes human thoughts, feelings, sleep, appetite, sexual function, social habits, pain, stress and other behaviour.

Today, the use of drugs, amount of use and the number of consumers have reached alarming proportions. In many countries, including India, alcohol and drug abuse have become an important health problem.

#### Drug abuse

We say a person is a drug addict, when he is dependent on any drug. They are not able to stop the use of these drugs. Commonly this condition occurs only after continuous use of drugs for long days. This abuse can be a desire (psychological) or a physical need.

In the case of physical need if a person stops taking drugs, he will have withdrawal symptoms. For example, if a person addicted to alcohol stops taking it, he will get severe muscular pain, stomach ache, vomiting, diarrhoea, sweating and loss of sleep. The reason why an alcoholic continues to drink is that he is not able to bare its painful withdrawal symptoms.

Every person starts using drugs to give company, as an enjoyment, to avoid pains or as an adventurous act. But gradually they become addicted to that.

### Problems caused by drugs

Long term use of drugs and alcohol cause problems to health, behaviour, and family life. Addicts may lose their job and suffer financially and legally.

The amount of food intake will be less for these addicts. This causes vitamin and other nutritional deficiencies. Other common problems include diseases in their lungs, liver, stomach, heart and kidney. Those who are addicted to alcohol, often meet with road accidents, falls, fire accidents and accidents at working place.

Use of drugs often causes emotional and psychological problems. Memory may reduce, personal qualities may change, and in some, this may cause psychosis.

Health and psychological problems affect the family. In such families there will be more stress, quarrels and problems in marriages (divorce, living alone), problems between parents and children, and criminal thoughts in children.

Use of alcohol and drugs also cause problems in the society. There are many legal problems in this group. Problems related to alcohol and drugs are mostly difficult to solve. Health volunteers are ideal and capable to handle such problems and to help them. With the help of health animators, health volunteers can give education, advice, prescription and follow up.

### Lesson 9

### Mental Retardation

Kempi is a 10 year old female child. She cannot talk clearly. She cannot bath or dress herself. When others talk to her, she cannot understand completely. Other children don't like to play with her. Sometimes they make fun of her. Her mother also says that she is different from her other kids. Her growth, mainly her mental growth is slower. They say that she behaves like a 4 year old child.

Her sisters and brother should help her in doing her daily routine. Her family is worried because she is not able to read or keep in mind even very simple matters. They have taken her to many temples and priests. She has been given many medicines by different doctors. But nothing has helped to change Kempi into a normal 10 year old child.

It is clear that Kempi is not like her sisters or brothers or like other children of her age. She is one of the children having lower intelligence. Such children are called 'mentally retarded'.

#### What is mental retardation?

Now see your hands. All your fingers are not of same length and same shape. Some are long, some are short. Similarly capacity to do a job differs from one person to another. They can be categorised under different levels of intelligence. Mentally retarded means having lower or

subnormal intelligence than ordinary level. This is not a disease but it is a state obtained due to the lower development of brain.

In common population 3% of the people are mentally retarded. Mental retardation can be seen in every caste, community, rich and the poor.

We expect a child to grow physically according to its age. Similarly, the child's mental growth is also expected. A child's measure of growth of mental skills is called the mental age. For a normal child, its age and its mental age coincide. A particular child's mental skills should coincide with the mental skills of most of the children of the same age.

However, in a mentally retarded child, there will be a delay / slowness in the development of the mental skills. Hence, that child's mental age will be lower than its physical age. For example, a child will be 10 years old, but its mental skills will be that of a 3 year old child only.

Health volunteers should be able to distinguish between mentally retarded patients and mentally ill patients. Care of these two categories of patients will be different and hence health volunteers should be able to understand the symptoms clearly.

### Lesson 10

### **Frequently Asked Questions**

Let us see some of the common questions asked by the public regarding mental illness. You can use these questions to develop your health volunteer's skills in responding to doubts / concerns of the community and the affected family.

Most important thing is to communicate the answers in a proper way. Remind them to be patient. And, request them to spend enough time to clear doubts, suspicion, their concerns and fear.

### • Is mental illness hereditary?

Children of mentally ill patients do not suffer from mental illness. Most of such children are healthy and lead a normal life.

# • Will mental illness spread to others? Will others get the disease by living with the patient?

Mental illness will not spread to others. It is not a communicable disease. By living with a patient, we will not get mental disease.

### • Will ghosts, black magic, evil forces or curse of god cause mental illness?

In olden days, people did not know that the changes in brain caused mental illness. Also they thought that diseases like Cholera, malaria and small pox were caused by such supernatural forces.

Today we know that there are other reasons for these diseases. Changes in our life, diseases in brain, stress and difficulty in family or official life, social atmosphere etc. can cause mental illness.

Chemical changes in our brain is the primary reason for mental illness.

### • Will masturbation, night discharge, loss of semen cause mental illness?

Masturbation and night discharge are common matters in our sexual life. They will not cause any harm. Loss of semen will not cause any weakness or harmful affects.

### • Will drinking of alcohol cause mental illness?

Alcohol is harmful to the brain cells. Continuous use of alcohol for many days will cause serious mental illness.

### • Is mental illness treatable? Will medicines help?

Mental illness is treatable. Medication is an important way in the treatment of mental illness.

Medicines set right the instability of brain and reduce the symptoms. Like other diseases of the body, mental illness also responds to treatment.

### • Is it always necessary to send mentally ill patients to mental hospitals?

Not necessary. Mentally ill can take medicines at home and get well soon with the help of their family. In some cases, in fact, sending to mental hospitals delays the

healing. So it is better to see the patient in his own house or village. In some cases, if the patient has physical problems or if special treatment is needed, treating them in mental hospitals may help.

### • Will marriage cure mental illness?

When a mentally ill patient marries when they have not been completely cured, their condition may become worse. Marriage will increase the stress.

But, after the patient is cured, he or she can marry and live a normal life like others.

### **Conclusion**

One of the important objectives of our community mental health programme is to improve the awareness and knowledge about issues involved in mental health care in the adivasi community. The focus is more on investing on the community in terms of information, knowledge and technical inputs, as much as possible. The health volunteers are the key people and crucial links in the design of our intervention.

Early identification of mentally ill patients, ensuring continuous treatment and follow up of the patients, motivating the entire village to help the affected families etc. are possible only with the active involvement of the health volunteers at the village level. For example, when one of the patients got totally cured, the village came forward to utilise his services by giving him the responsibility of taking the children to the school every day. When a village library was opened in that village, the villagers requested him to inaugurate the library. Such support and care by everyone around is as crucial as the treatment he received in terms of medicines.

In view of their crucial role, training programmes to provide inputs to the health volunteers were designed meticulously and lot of effort was spent in organising them. We hope that this manual will help and motivate other such initiatives also to take care of the mentally ill patients in their community.

Annexure - 3	
<u>MENT</u>	<u>'AL HEALTH CARD</u>
Name:	Age:
Sex:	Village:
Tribe:	Sangam / Non-Sangam :
	Insurance no
Diagnosis:	
Presenting complaints:	
Treatment history:	
Treatment started on:	
Medicines to be given:	
Treatment responsibility:	
Remarks:	

### **Treatment summary**

Date	Medicines / Remarks

Annexure - 4

### Mental Health Follow-up Card

<u>Note</u>: Use the following codes. Normal - 3 Decreased – 2 Poor – 1 \* Enter Yes or No

Month/ Year			
Sleep			
Appetite			
Hygiene			
Work			
Social norms			
Cooperation			
Hallucination / * Delusion			
Depression			
Elation *			
Alcohol intake *			
Drug abuse *			
Suicidal tendency *			
Violence *			
Fits			
Medicine intake *			
Side effects *			

### Annexure - 5

### Impact Assessment Study of the Community Mental Health Program

### Background

ASHWINI (Association for Health Welfare in the Nilgiris) has been implementing a comprehensive health care programme among the adivasis in the Gudalur valley for the last two decades. After addressing the critical areas of Maternal and child care, the focus shifted to other health problems of the adivasi community. In 2005, ASHWINI launched a community based mental health programme with the financial assistance of Sir Ratan Tata Trust, Mumbai.

The vision of this project was to establish a mental health care system that is rooted in the community to ensure a long term impact. The objectives were to:

- Create awareness about mental illness so it is seen as another illness and not as a possession by spirits.
- Help the community take responsibility for its mentally ill patients.
- Ensure early detection and treatment.
- Provide continuity of care.
- Provide treatment close to home.
- Provide social support and ensure a multidisciplinary approach.
- Give economic support during hospitalization.
- Avoid unnecessary hospitalization.
- Rehabilitation where applicable.

The main activities undertaken were:

- Training of the health staff
- Training of village health volunteers
- Early detection, treatment and rehabilitation for patients
- Health education
- Documentation and research
- Interacting with Government

This report evaluates the impact that the program has had on the awareness about mental illness in the general community and the specific impact on the patients with mental illness and health volunteers who played a pivotal role in the implementation of the program.

### **Methodology**

When the programme was launched in 2005, a baseline study was conducted in the adivasi villages to document the level of understanding about mental illness in the community, the level of incidence of mental illness, the perceptions of the community regarding symptoms and the causes, and the treatment given to the mentally ill patients.

At the end of the project, a similar survey was conducted among the adivasi population and among the village health volunteers. The primary objective of the study was to understand the attitude of people to mental illness and to see whether the health education during the project period had made an impact at the community level.

The questionnaire used at the beginning of the project was modified a bit and was used to assess the changes in perceptions. This format is given in Appendix.

508 people from various villages were selected randomly and interviewed.

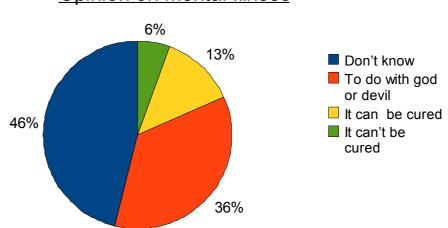
Total interviewed	508
Male	169
Female	339

The analysis of the responses from the community at the end of the project period in comparison with those expressed at the beginning of the program are follows:

#### **General Understanding of Mental Illness :**

#### In 2005

While we were asking their opinion about mental illness we were looking for broad, general response, without providing a framework or direction to it. Hence we got wide and varying response. A majority of respondents said they do not know anything about mental illness and 36 % responded that it has got some thing to do with god or devil. Only 13 % of the section had an opinion that it can be cured and a small fraction of 6 percent felt it is incurable.

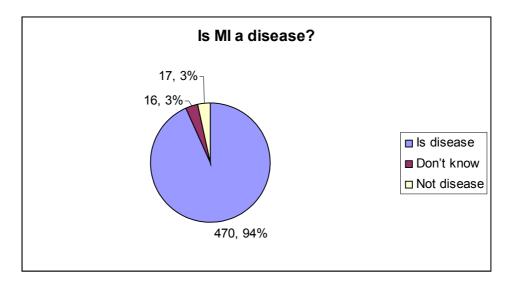


### **Opinion on Mental Illness**

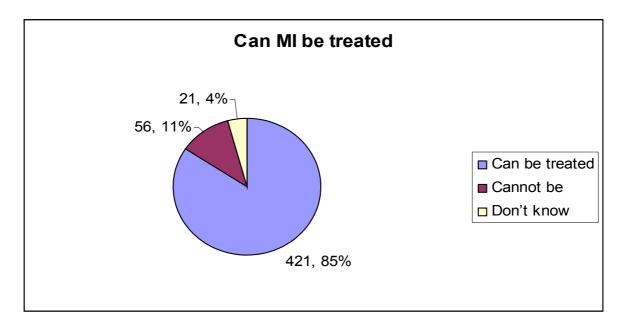
### In 2008

There is a very remarkable change in the understanding of mental illness in the community. It is becoming almost universally accepted as a disease like any other. This was one of the main objectives if the Mental Health Program.

94% of people today are able to accept this as a disease. Only 3% said they did not know and another 3% said it was not a disease.



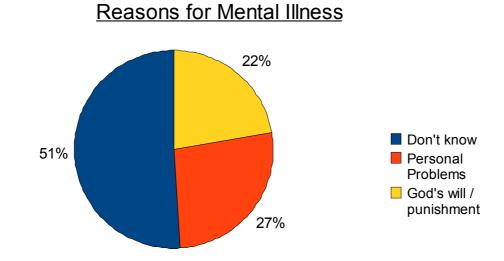
85% of people responded that this could be treated. This again is a fantastic achievement as this belief will help to bring patients forward for treatment. Only 11% still feel that it cannot be treated.



### Perceived Reasons for mental Illness :

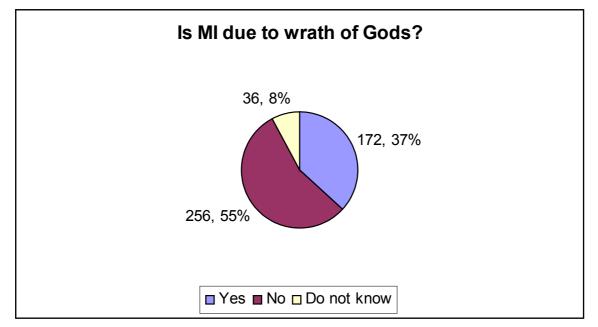
### In 2005

When asked about the reasons for mental illness more than half (51%) responded that they don't know anything about it. 27 % of the respondents felt that this is due to various personal problems such as Alcoholism, Family dispute, Death, Unemployment, Indebtedness, Love failure etc., Another 22 % believed that it is the god's will or punishment for wrong doings.

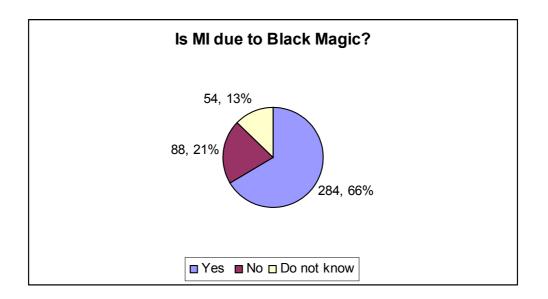


#### In 2008

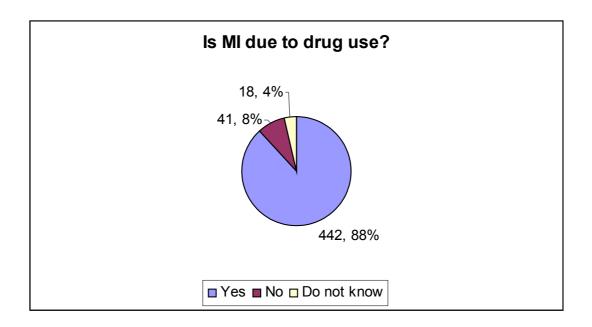
We asked more focused questions to see if people's perceptions had changed. Although 55% of the people felt that this had nothing to do with the wrath of gods, it is obvious that this deep rooted belief is still very much there and 37% of people believe this to be so.

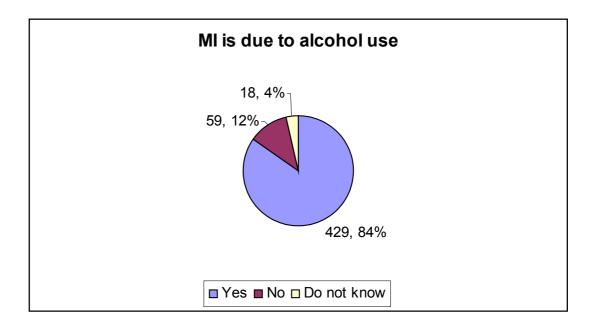


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Similarly 66% people feel that black magic still has a role in the causation of Mental Illness. And, 84% of responders believe that alcohol and drug abuse can lead to deranged mental function.

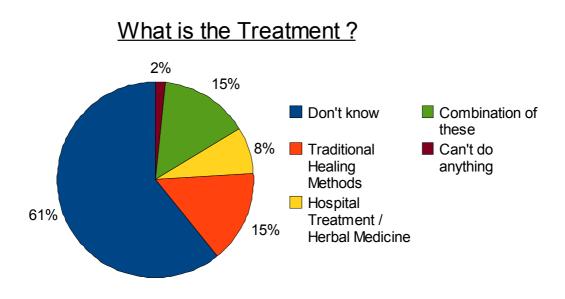




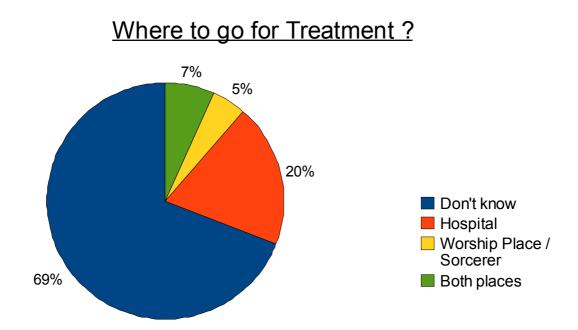
### What to do if one gets mental illness and where to take for treatment? :

### In 2005

It was clear that people did not know what to do with a Mentally III patient. Majority of the respondents said they do not know what to do or where to take the patient for treatment. A 15 % said they would follow rituals or traditional healing methods.

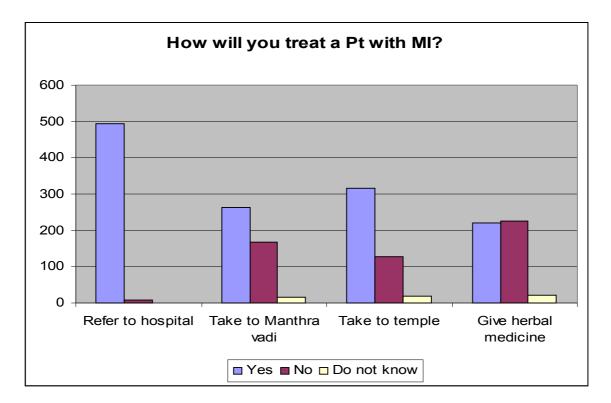


Regarding the question 'Where to take a MI patient for treatment ?', only 25% responded that they will go for either hospital medicine or herbal medicine and another 7% of them said they would follow a combination both. A vast majority of the respondents did not know where to take the patients.

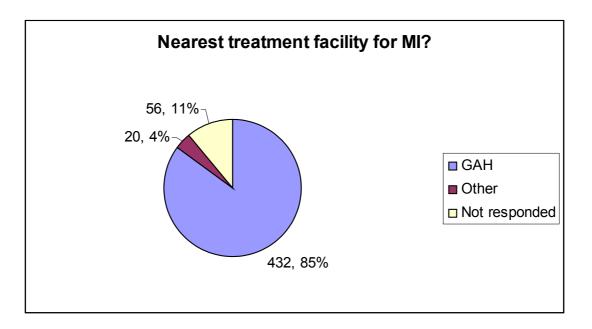


### In 2008:

There has been a major shift in the responses. Almost all of them said that the patient needs to be taken to hospital. It is most interesting to note that more than half of them still feel the need to take the patient to the temple, the black magic healer and the herbal medical practitioner.



This is interesting because ASHWINI has been careful in suggesting other means of treatment while not ridiculing the existing practices. They have accepted modern medicine without loosing faith in all the traditional healing methods.

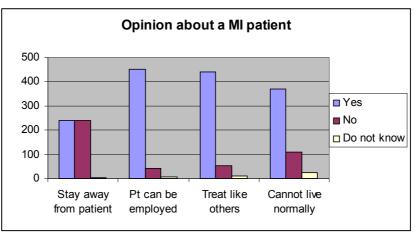


85% of people know that treatment is available at The Gudalur Adivasi hospital. This is very reassuring and is the result of the extensive health education and publicity given for this programme during the last three years.

### The community's perception about a Mentally III patient's Prognosis

This was an additional question that was asked at the end of the project period in 2008 to see what the perceptions were and what we need to do to change this. While it is good to find that almost all the respondents felt that the mentally ill patients can be employed and treated like others, a significant number of people also have apprehensions. Half the people feel that they should stay away for the patient and the majority feel that they cannot lead normal lives.

More exposure to patients with the disease and health education should change these misconceptions of the community as well.



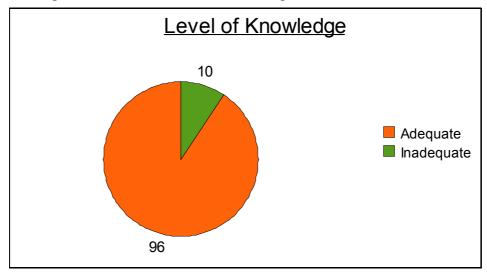
### **Evaluation of Village Health Volunteers**

Out of the total 121 health volunteers selected, 114 completed the training. Only 7 volunteers dropped out in between. This was a clear indication of a success of the programme, as our training methodology and the continuous interaction our health animators had with the health

volunteers could motivate these volunteers to continue the training during the entire programme.

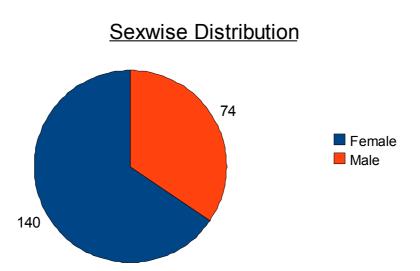


Out of the volunteers who completed training, 106 volunteers were evaluated at the end of the project period. A questionnaire was designed covering many aspects of Mental illness including detection, support and treatment. According to this evaluation, 96 of them had adequate knowledge while 10 were found to be inadequate.

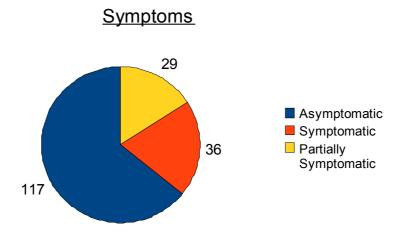


### Curative care

214 patients have been identified and started on treatment. About 65% of them were women.

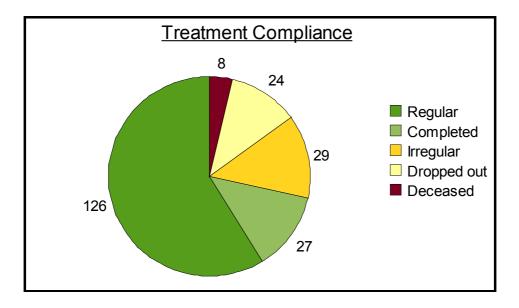


The distribution of patients seems to follow the pattern of population among different tribes. However, among the Kattunaicken community, there seems to be disproportionately high number of patients.



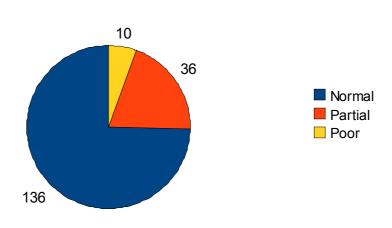
Out of this, 36 patients needed admission to hospital for various periods for control of symptoms. All others were managed at the village level.

More than 70% of the patients are quite regular in seeking treatment and taking medicines.



Of the 182 that continue on treatment, 136 patients are functioning normally, going to work and earning a livelihood. Only 10 are not yet functional while 36 are partially functional.

Level of Functioning



There has been only one suicide in this group of patients.

### **Conclusion**

The Impact of the Mental Health Program has been most remarkable. The change in the lives of the 214 families with affected members was unlike that made by any other intervention. The fact that hospitalisations were minimal and that most patients, even with major mental illness were managed at the village level is a giant step in proving that the community can take responsibility for its mentally ill patients.

There has been a remarkable change in the attitude of the community towards Mental Illness. The majority now believe that mental illness is just another disease and that patients can get benefited by treatment. This is a big step in the right direction. We thank SRTT for having been a partner with us in this unique intervention.

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## Village Mental Health Survey

Name Village	Age Tribe	Area		Sex:		
<ul> <li>Mental illness is a disease-</li> <li>It can be treated -</li> <li>Mental illness is due to the will of</li> <li>Mental illness results from the fol</li> <li>1. Alcoholism</li> <li>2. Ganja use</li> <li>3. Death of close person</li> <li>4. Family dispute</li> <li>5. Unemployment</li> <li>6. Indebtedness</li> <li>7. Failed love affairs</li> <li>8. No particular reason</li> <li>9. Black magic</li> <li>What can you do for a person witt</li> <li>1. Follow rituals/ call gods</li> <li>2. Go to hospital for treatment</li> <li>3. Take herbal medicines</li> <li>4. Go to temple</li> <li>5. Go to sorcerer</li> <li>6. Combination of the above</li> <li>7. Don't know</li> </ul>	llowing Yes Yes Yes Yes Yes h mental nt Yes Yes Yes	Yes No Don't Know Yes No Don't Know Yes No Don't Know No Don't Know No Don't Know No Don't Know Yes No Don't Know illness Yes No Don't Know illness Yes No Don't Know No Don't Know No Don't Know Yes No Don't Know Yes No Don't Know	Yes No Yes No ow now now now Don't Know now	Don't Know Don't Know Don't Know		
<ul> <li>7. Mentally ill person is very dangerous and it is best to keep away from him Yes No Don't Know</li> <li>8. Recovered mentally ill person can be employed</li> </ul>						
Yes No Don't Know 9. Family members should treat a mentally ill person like any other person Yes No Don't Know 10. Mentally ill person can never led a normal life after recovery Yes No Don't Know						
Survey conducted by :		Date:				