STATE HEALTH RESOURCE CENTRE

A PILOT STUDY

ON

DEPRESSION, SUICIDAL IDEATIONS AND ATTEMPTS AMONG SICKLE CELL DISEASE PATIENTS IN TWO VILLAGES OF MAHASAMUND DISTRICT IN CHHATTISGARH.

STATE HEALTH RESOURCE CENTRE

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ABSTRACT

Introduction: Sickle Cell Disease (SCD) is a chronic and potentially, quite a debilitating disease which may lead to severe complications and psychosocial problems. In Sickle cell disease the depression is associated with severe pain, low socio economic status, poor treatment compliance and low quality of life which may lead to suicidal ideations and attempts. The disease may result in significant morbidity, as well as a shortened life span in patients. This study was conducted to determine the prevalence of depression, suicidal thoughts and attempts among Sickle cell disease patience of two villages of Mahasamund District of Chhattisgarh.

Methodology: A community based cross sectional study was conducted in Narasinpur and Jagadhispur villages. A list 25 of Sickle cell disease patients was generated from the Seva Bhavan Hospital Jagadhispur. 5 interviewers from Seva Bhavan Hospital were trained on the interview schedules. Two interview schedules were used one for patients above 15 years and the other one to assess the parents of below 15 years of age. Data was analysed using Excel and SPSS software.

Results: Out of 22 patients 18 were 15 years and above and 4 were below 15 years. Most of them were educated up to middle school. Most of them belonged to three generation family and were below poverty line. Most of them were on regular treatment but were getting treatment from private hospitals most of them had extreme pain which had interference in their day to day activities and school attendance. Their mood was moderately frustrated and irritated often and they get full support from their family and neighbours. Suicidal thoughts were found to be among 13.6% of the patients.

Conclusions: As stated in the WHO definition, health is a state of physical, mental and social wellbeing; but the patients with Sickle cell disease are facing difficulties in life through all the aspects like physical pain, depression and psychosocial problems. The findings of this study indicate that there is a need to develop appropriate treatment interventions and policy. The aim should be providing free medications, blood transfusions, treatments under the packages of Rashtriya Swasthya Bima Yojana (RSBY) scheme since all the families have smart cards and counselling and guidance that depend on the accessibility to health care at different levels, and in different settings.

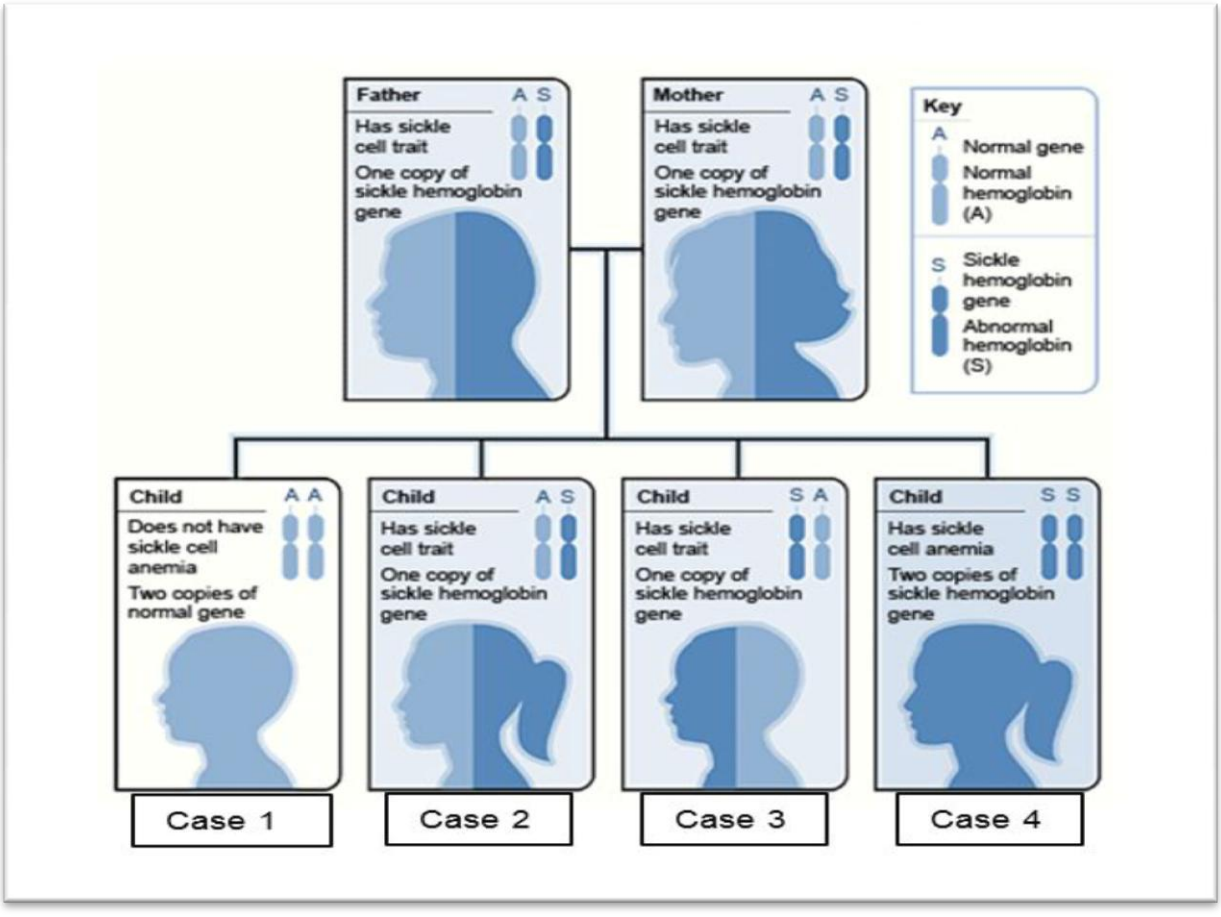
Key words: sickle cell disease, pain, depression, suicidal thoughts.

INTRODUCTION

Together we will break the sickle cycle and find a cure

Sickle cell disease (SCD) is a widespread genetic disorder characterized by red blood cells assuming an abnormal, rigid, sickle shape that results in a risk of serious complications[1]. Sickle Cell Disease (SCD) is a chronic and potentially, quite a debilitating disease. The disease is severe and may result in significant morbidity, as well as a shortened life span.[2]

The SCD gene causes an abnormality in the iron-rich protein haemoglobin that is responsible for carrying oxygen through the blood and giving blood its red colour. The abnormal haemoglobin causes cells to become "sickle shaped" resulting in irregular blood flow (National Heart, Lung, and Blood Institute ([NHLBI], 2010).[3]



Source: nhlbi.nih.gov

The RBCs are produced in bone marrow and average life of normal RBCs is about 120 days. Biconcave disc shape of RBCs changes to sickle shape under low oxygen tension due to polymerization of faulty haemoglobin called HbS arising out of a point mutation in beta globin gene.

The life span of RBCs in SCD patients is only about 10 to 20 days and the bone marrow can't replace them fast enough. As a result there is decrease in number of RBCs in the body and the RBCs don't contain sufficient amount of haemoglobin (hypochromia). In SCD the RBCs become sickle or crescent shaped which are stiff & sticky and tend to block the blood flow in small capillaries. Blocked blood flow causes ischemia leading to severe pain and gradual damage to organs.[4] The sickling occurs due to a mutation in the haemoglobin gene. Person with trait leads a normal life but the diseased person suffers from various complications throughout the life such as anaemia, bone & joint pain, joint swelling, recurrent infection, osteomyelitis, necrosis of bone, aplastic crises, abdominal pain, splenic sequestration crises, hepato-splenomegaly etc.[1] Worldwide, approximately 300,000 infants are born with SCD .[2] It occurs in high frequency in many tropical countries of the world.[1]

In India, sickle haemoglobin was first discovered by Lahmann and Cutbush about 50 years ago among the tribal's of Nilgiri Hills of Southern India. Later, subsequent studies conducted by various workers reported its high frequencies throughout Central India and parts of Southern India.[3] Clinically Indian sickle cell anaemia a moderate to severe anaemia with high HbF level that seems to be milder than SCA in Africa and Jamaica & similar to SCA in central Asia.[4] Initial screening for sickle cell disease across the state of Chhattisgarh has revealed that its prevalence as 10% in Chhattisgarh population. In some communities, the prevalence of the sickle cell disease is as high as 30%. [5]

Depression caused by chronic illness often aggravates the illness, especially if the condition causes pain, fatigue, or disruption of social life. The prevalence of depression in Sickle cell disease patients has been reported to be high. Previous studies have found elevated depressive symptoms in 43-56% of Sickle cell disease patients. Those who report more frequent painful sickle cell episodes are more likely to be depressed.[6]

Sickle cell disease can result in increased isolation, poor quality of life, financial insecurity, increased worry, family strain, maladaptive health behaviour. All these factors may increase the risk of depression which in turn can intensify the experience of physical symptoms, increased functional impairment, impede adherence to treatment, worsen overall prognosis, and shorten life expectancy.

The result is a vicious cycle of poor physical and mental health and poor functioning. Depression and suicidal ideations in the sickle cell patients may go undetected and untreated which stresses the importance of developing integrated services. Despite their impact, mental health problems remain a low priority in our country.

I could find no literature in India on depression, suicidal thoughts and ideations in Sickle cell disease patients. So the current study is aimed to know the depression and suicidal ideation among sickle cell disease patients in Chhattisgarh where the prevalence of the disease is highly prevalent.

This study will provide the base line data by showing the level of public health problem which in turn will guide the public health professionals and the government in generating and synthesising policy, relevant research findings, building capacity among policy makers and other health care providers to take appropriate action and provide counselling and guidance to the patients and their family members.

RATIONALE:

Sickle cell Disease is a chronic disease which causes severe complications if not treated promptly. People with sickle cell disease are facing struggles in all aspects like sever pain, socio economic burden, psychosocial disturbance and depression. This study will help in identifying the true burden of the patient's sufferings and help in generating policy for free treatment and social support like counselling and guidance.

OBJECTIVES

- To determine the prevalence of depression and suicidal ideations in the patients with sickle cell disease.
- To determine possible psychosocial factors associated with depression and suicidal ideation in the disease group.
- To find out the economic burden and social factors related to pain and treatment in patients with Sickle cell disease.

METHODOLOGY

1. Study design:

A Community based Cross Sectional Descriptive study.

2. Study setting:

The study was conducted among the sickle cell disease patients in the villages Jagadhispur and Narasingpur of Mahasamund District in Chhattisgarh.

3. Study unit:

Sickle cell disease positive patients.

4. Sampling and sampling frame:

In both the villages the list of identified sickle cell disease positive patients 5 years and above was generated at the local community health development programme team in the Seva Bhavan hospital Jagadhispur and those patients were the accessible population for the study. Totally 25 patients with positive sickle cell disease were in the sampling frame got from the hospital and 22 patients were present during the time of data collection and they were included in the study.

5. Study tools:

- **Tool 1**: A semi structured interview schedule was used for assessing the pain, depression, suicidal ideation and attempts in patients with sickle cell disease aged 15 years and above.
- **Tool 2:** A semi structured interview schedule was used for assessing the pain of the children and the Depression, suicidal ideations and attempts in parents of sickle cell disease children.

Before collecting data the tools were field tested and necessary correction was made in the tools.

6. Data collection:

Interviewers were 5 members of the Community Health development Programme Team of Seva Bhavan Hospital Jagadishpur. Before collecting the data from the patients, the interviewers were trained on the interview schedule. The data from individual patient was collected by interviewing the

patients 15 years and above and for patients below 15 years their parents were interviewed using a semi- structured schedule by the trained interviewers.

7. Study Variables:

The variables that were assessed in this study are socio demographic characteristics, pain, depression, suicidal ideations and suicidal attempts along with their socio-economic status.

8. Inclusion criteria:

Individuals included in the study were sickle cell disease positive patients aged 5 years and above. For patients less than 15 years their parents were interviewed to assess the pain of the child and depression, suicidal ideations and attempts in their parents.

9. Exclusion criteria:

- Those who were currently ill (needing admission) and patients who were not willing to participate in the study were excluded from the study.
- Those positive children below the age of 5 years.

10. Consent and ethical approval:

Institutional ethical approval was not taken but written informed consent was taken from the patients after explaining the purpose of the study. For patients below 18 years informed consent was taken from their parents. Assurance was given to the patients that the confidentiality of the data will be maintained throughout the study.

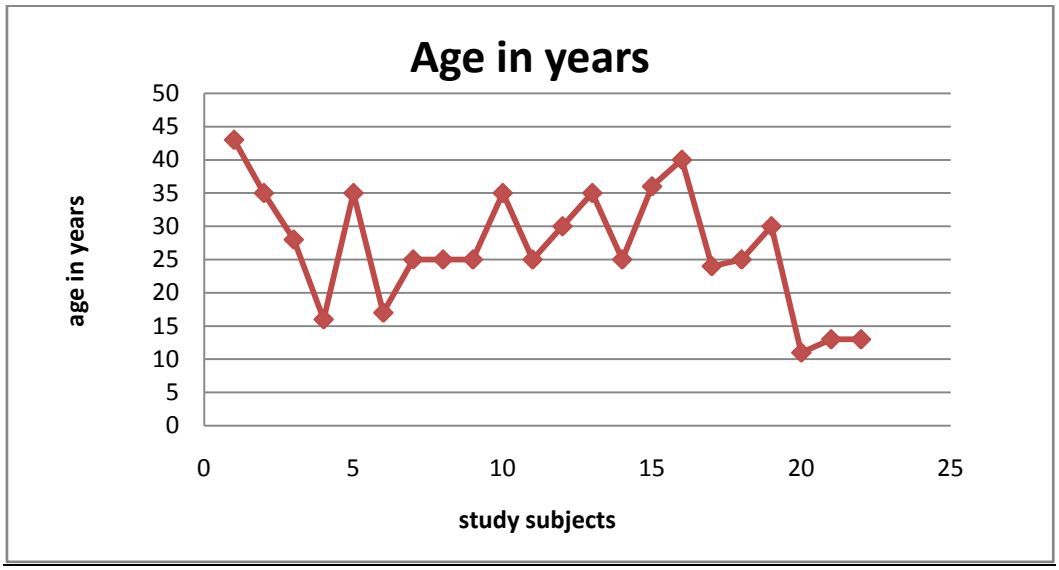
11. Data analysis:

The data analysis was done using excel and SPSS software. Data was represented in tables and graphs as relevant.

RESULTS

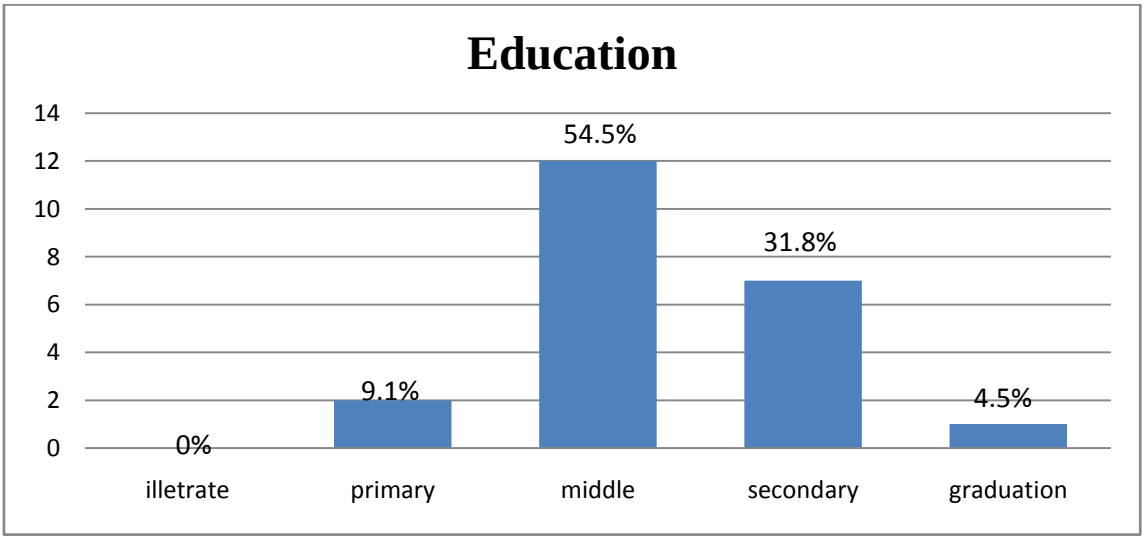
I. SOCIO DEMOGRAPHIC CHARACTERISTICS:

Table 1: Distribution of study subjects according to their age and sex (N=22)



From the above table 1 it was observed that out of 22 sickle cell disease patients most of them belonged to the productive age group of 20-40 years of age. The mean age of the study subjects was 26.86 years. There are more women (15) than men (7) among the adult population. No patient appears to be over the age of 50.

Figure 1: Distribution of study subjects according to education (N= 22).



From the above figure it was revealed that most 12(54.5%) were educated up to middle school. No illiterates were among the study group. The literacy rate in Jagadhispur is 78.61% and Narasingpur 74.94% (source -Census 2011).

Table 2: Distribution of study subjects and parents according to occupation (N= 22).

Occupation	Occupation of parents of the patients below 15 years		Occupation of patients above 15 years	
	Frequency	Percentage %	Frequency	Percentage %
Unemployed	0	0	6	33.3
House wife	0	0	6	33.3
Unskilled	2	50	2	11.1
Semi skilled	1	25	4	22.2
Semi profession	1	25	0	0
Profession	0	0	0	0
Total	**4**	**100**	**18**	**100**

The table 2 reveals that among the 4 patients below 15 years 2 of their parents were unskilled workers by occupation and among 15 years and above most of the study subjects 6 were unemployed.

Table 3: Distribution of study subjects according to their religion and group (N = 22).

Group	Frequency	Percentage
SC	1	4.5%
OBC	21	95.45%
Total	**22**	**100**

From table 3 it was observed that most of the study subjects belonged to group OBC 21(95.45%).only one patient belonged to Schedule caste.

Figure 2: Distribution of study subjects according to their type of family (N = 22).

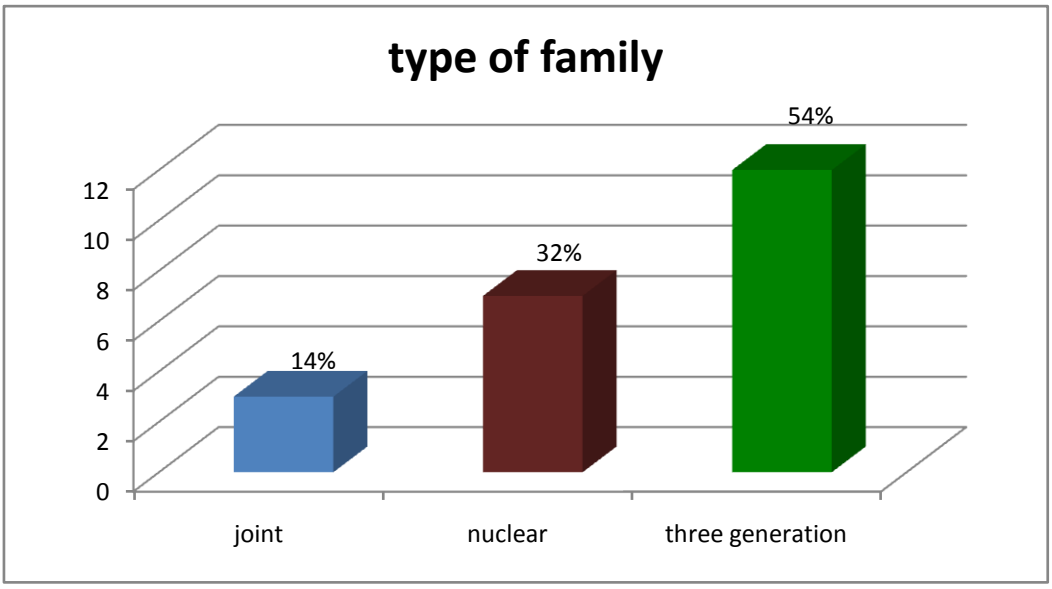
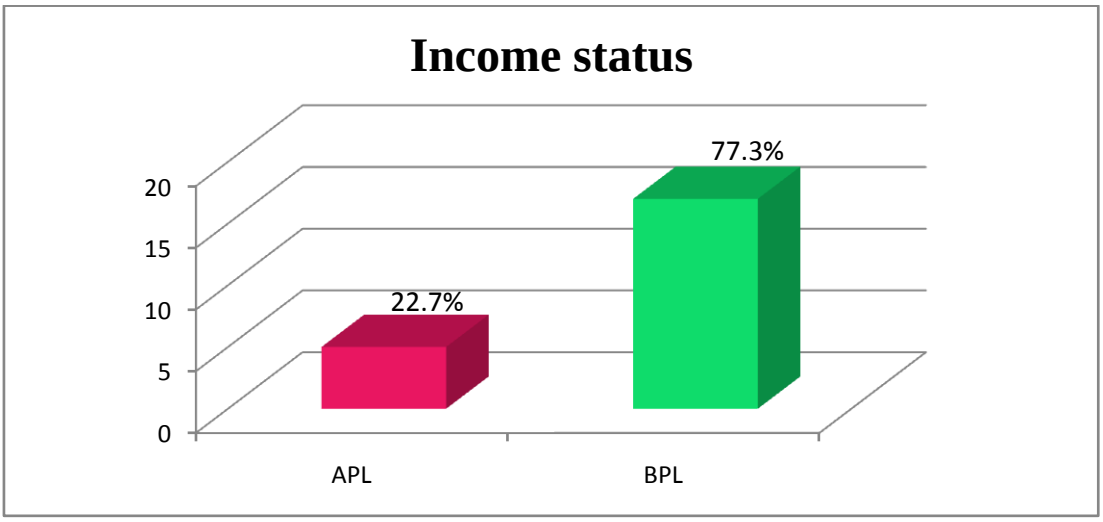


Figure 2 reveals that most of the families live in three generation families living together in a specified geographic area. Few families belonged to nuclear family.

Figure 3: Distribution of study subjects according to their family income status (N= 22).



From the figure 3 it was observed that most of the study subjects 17(77.3%) belonged to the Below Poverty Line families.

Table 4: Distribution of study subjects according to their history of sickle cell disease in their families (N= 22).

History of Sickle cell disease in family	Frequency	Percentage
Yes	14	68.6
No	8	36.4
Total	**22**	**100**

Table 4 reveals that most of the study subjects 14(68.6%) had history of sickle cell disease in their family and relatives and most of them told that they died because of the complications of the disease.

Figure 4: Distribution of the study subjects based on their treatment (N= 22).

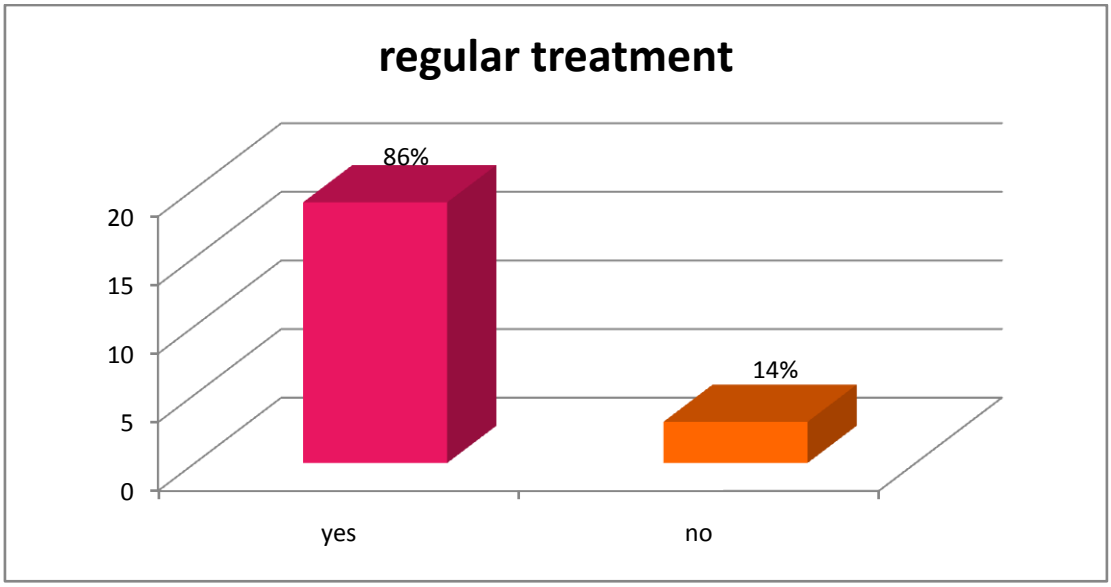


Figure 4 reveals that most of the study subjects 19(86%) were getting regular treatment but were receiving only folic acid and multivitamin tablets and some pain killers prescribed by the physician. Most of the subjects were in allopathic treatment and few were getting Ayurvedic treatment. None of the patient was receiving Hydoxyurea.

Table 5: Distribution of the study subjects according to the place of treatment (N= 22).

Place of treatment	Frequency	Percentage (%)
Government hospital	0	0
Private hospital	22	100
Total	**22**	**100**

From the above table 5 it was observed that all the study subjects 22(100%) go to the private set up for their treatment and none of the patient goes to Government hospital because of the non availability of the treatment.

Table 6: Distribution of study subjects according to the money spent on their treatment (N= 22)

Money spent	Frequency	Percentage (%)
No treatment	1	4.5
Free treatment	1	4.5
100-500	8	36.4
501-1000	2	9.1
1001-1500	4	18.2
1501-2000	2	9.1
2000 above	4	18.2
Total	**22**	**100**

Table 5 reveals that most of the patients10 (45.5%) spend more than 1000 rupees monthly for their treatment which shows they burden of their out of pocket expenses. Only one patient gets free treatment since she's working in the Seva Bhavan hospital in Jagadhispur.

II. PAIN INVENTORY:

Pain caused by sickle –cell disease can be acute, chronic or a mixture of the two. The acute pain of tissue infarction, in skeletal or soft tissue, tends to be sudden, unpredictable in onset and intense.

The participants describe experiencing unimaginable, agonising, continuous, inescapable and limitless pain which was almost impossible to describe.

Figure 5: Distribution of study subjects according to their interference of pain in their day-to-day activities (N=22).

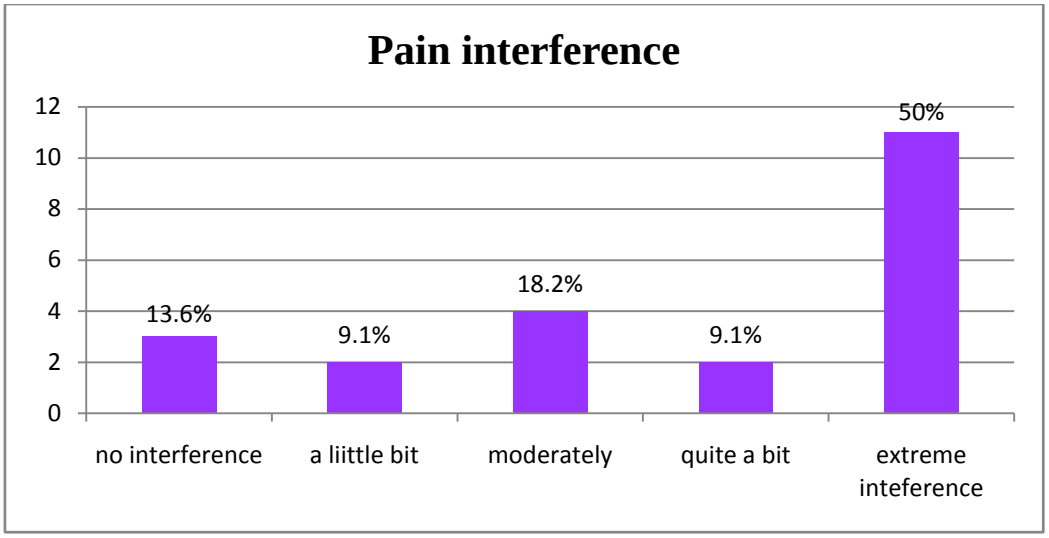
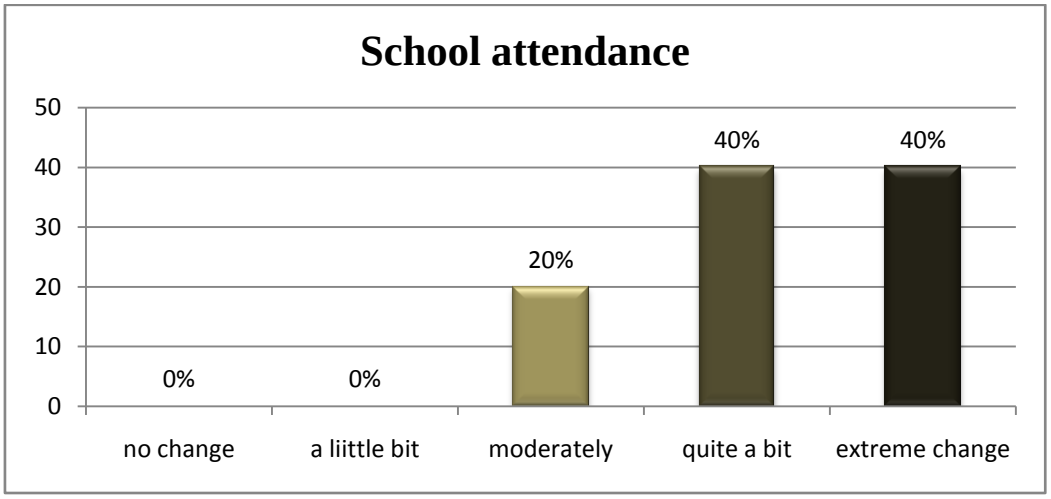


Figure 5 reveals that most of study subjects 11(50%) had severe pain that interferes in their day to day activities which in turn may affect their work, school attendance and economy of the family. They told that they were not even able to lift a glass of water when their pain starts.

Figure 6: Distribution of study subjects according to level of their pain and its influence on them in attending their school (N=5).



From figure 6 it was observed that 4 children had interference of pain in attending their school regularly. This may lead to poor performances in their academics.

Table 7: Distribution of study subjects according to the suffering they experience because of their pain (N= 22)

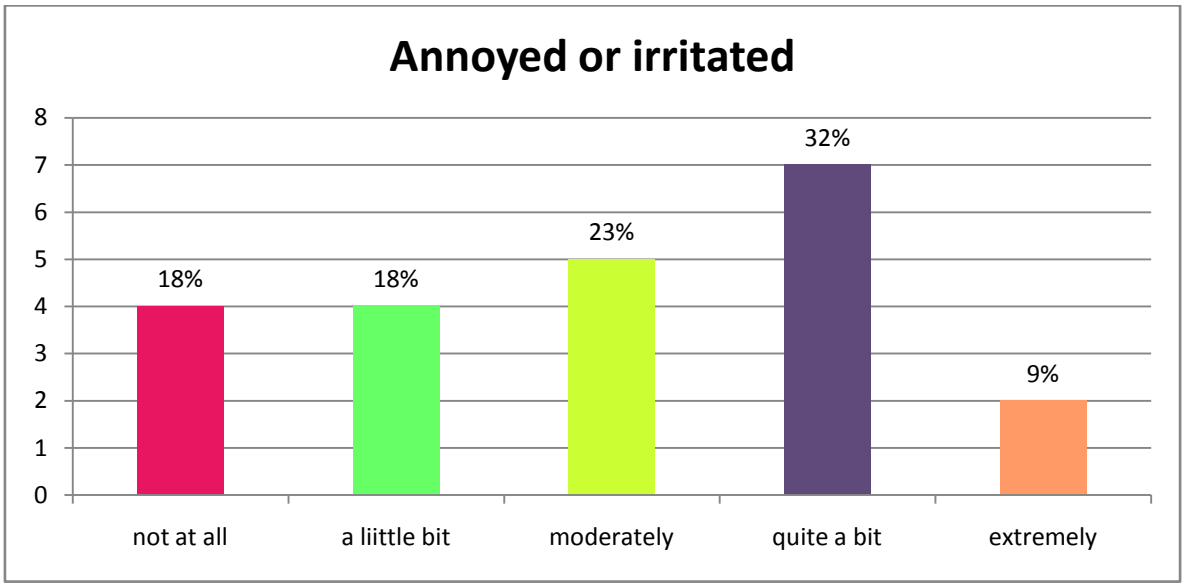
Suffering they experience	Frequency	Percentage (%)
No suffering	2	9.1
A little bit	1	4.5
Moderate suffering	3	13.6
Quite a bit	7	31.8
Extreme suffering	9	40.9
Total	**22**	**100**

From table 6 it was observed that most of the study subjects 9(40.9%) had extreme suffering because of their severe pain.

III. DEPRESSION INVENTORY

Depression and Anxiety in Sickle cell Disease is associated with greater daily pain, lower quality of life measures, and poor adherence to treatment regimens. Depression and Anxiety if not diagnosed in its early stages will lead to many psychiatric illnesses like psychosis, depressive disorders and even suicides.

Figure 7: Distribution of study subjects according to the feeling of getting easily annoyed or irritated (N= 22)



From the above figure 7 it was observed that most of the study subjects 7(32%) quite a bit get easily annoyed or irritated with family members and themselves.

Table 7: Distribution of study subjects according to feeling low in energy or slowed down (N=18).

Low in Energy	Frequency	Percentage
Not at all	3	16.7
A little bit	2	11.1
Moderately	2	11.1
Quite a bit	5	27.8
extremely	6	33.3
Total	**18**	**100**

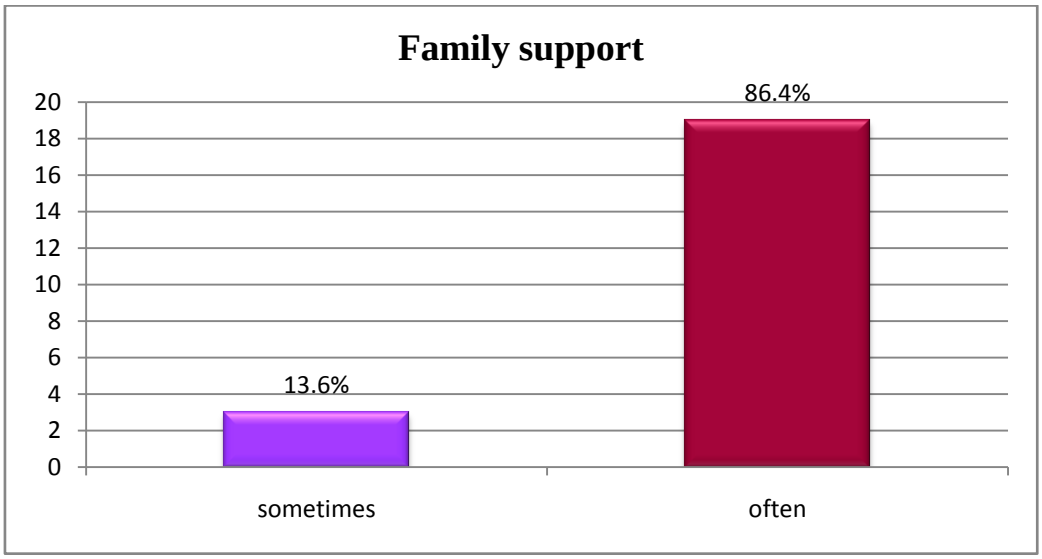
Table 7: reveals that most of the study subjects 6(33.3%) were feeling extremely low in energy or slow down in their activities and mood when they get their pain.

When asked the study subjects about blaming themselves for the things that they are suffering most of the study subjects 8(36.6%) answered that they blame themselves a little bit for the sufferings and when asked about feeling of no interest in things most of the study subjects 8(36.6%) answered that they were a little bit not interested in things.

IV. FAMILY AND SOCIAL SUPPORT

Sickle cell disease is a chronic disease which is associated with stigma and social factors which influence the patient's physical and psychological health. It is necessary to assess whether there is family and social support to the patients both economically and psychologically.

Figure 8: Distribution of study subjects according to their family support (N= 22).



From the figure 8 it was observed that most of the study subjects 19(86.4%) had their family supporting them in their suffering both economically and psychologically.

Figure 9: Distribution of study subjects according to their family members getting irritated or frustrated with them (N= 22).

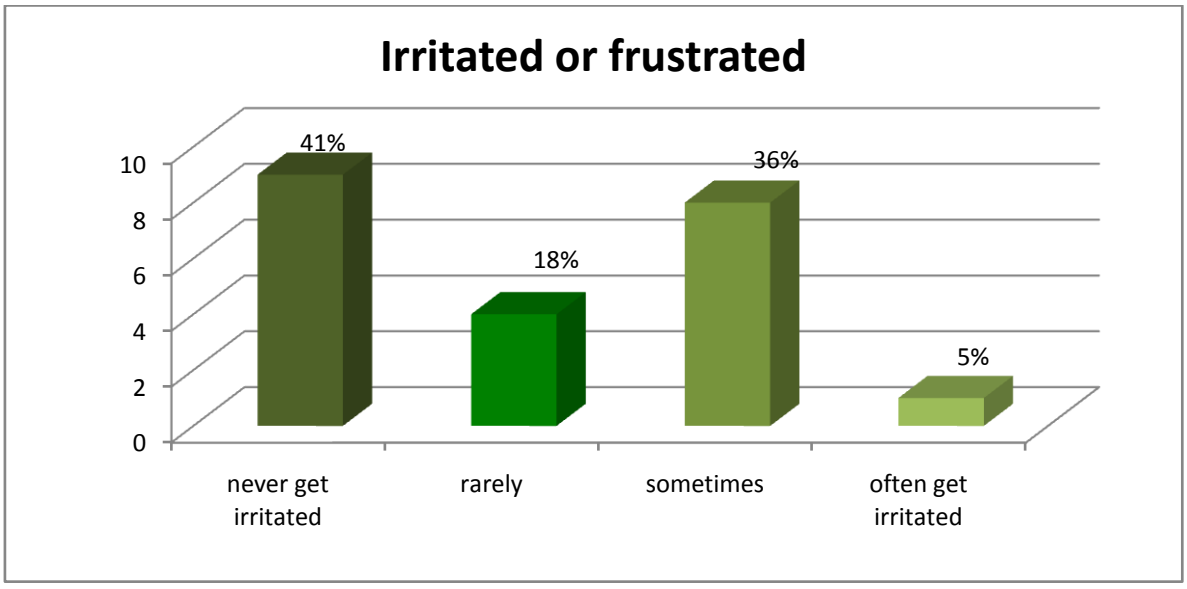


Figure 9 reveals that most of the study subjects 9(41%) were supported by their family members, but 8 (36%) were getting frustrated or irritated with them.

Table 8: Distribution of study subjects according to their family members trying to divert their mind from pain and suffering to make them comfortable (N= 22).

Divert mind	Frequency	Percentage (%)
Never divert	5	22.7
Rarely divert mind	2	9.1
Sometimes	6	27.3
Often	9	40.9
Total	**22**	**100**

Table 8 reveals that majority of the study subjects 9(40.9%) family members try to divert their mind from pain and suffering to make them comfortable.

V.SUICIDAL IDEATIONS, THOUGHTS AND ATTEMPTS:

Suicidal ideations and thoughts are very common among patients with depression, chronic illness and chronic severe pain. Studies have indicated that suicide is also one of the causes of death among sickle cell disease patients. This may be due to the severity of the pain they suffer, the economic burden on treatment and psychosocial factors.

Table 9: Distribution of study subjects according to their thoughts of killing themselves (N=22).

Thoughts of killing self	Frequency	Percentage
Never thought	19	86.4
Rarely thought	0	0
Sometimes thought	3	**13.6**
Often thought	0	0
Total	**22**	**100**

From table 9 it was observed that most of the study subjects 19(86.4%) had no thoughts of killing themselves but still 3(13.6%) had the thoughts of killing themselves because of the pain and economic burden on their family.

DISCUSSION

Sickle Cell Disease (SCD) is a chronic and potentially, quite a debilitating disease which may lead to severe complications and psychosocial problems. The disease may result in significant morbidity, as well as a shortened life span in patients. The patients with Sickle cell disease are facing problems in all the ways like physical pain, complications of the disease, psychosocial problems, and socio economic problems. This study helped in finding out the problems that the patients are facing in their day to day life.

The school going patients reported that the disease was affecting them in attending their schools regularly and so they could not perform well in academics. This was similar to the findings of a study conducted among African American adults which reported that the study participants were less educated and had lower incomes.[16]Another study also indicated that more than half of the participants (60%) reported that Sickle cell disease interfered with their performance in school.[19] Similar results were derived in a study conducted among forty adults with sickle cell disease which revealed that 27(68%)of patients reported missing at least one important exam each year and 34 (85%) patients reported missing school on average once per week .[20]

Majority of People live in below poverty line. People in a vulnerable socioeconomic situation are more exposed to the determining social factors of the disease, which can lead to an aggravation of the patients' general health. Therefore, these individuals deserve special attention with respect to free medical costs and psychosocial perspectives. The low education level and socioeconomic status of the patients were similar to the studies con-ducted in Brazil[23], Aljuburi et al in England[24], and USA[25].

Most of the subjects in this study were on allopathic treatment and few were in ayurvedic treatment. The patients were given folic acids and multivitamins by the physicians and no patients were in hydroxyura therapy. Despite studies suggesting that the use of Hydroxyurea improved morbidity (fewer acute painful episodes, less acute chest syndrome, decreased need for transfusion, decreased hospitalizations), mortality (improved survival), reduced health care cost, and strong recommendations for its use, the use of Hydroxyurea remains underutilized[26].

In the present study all the patients were getting treatments from private settings and none from Government. The families belonging to below poverty line are spending out of pocket expenses on their treatment which increases the economic burden not only on them but the whole family. The patients reported that there's a Primary Health Centre nearby and the medications was not available in the centre. So they had to travel to nearby town or to Raipur for their treatment and blood transfusion which puts them into more of a financial burden. Most of the patients (10) were spending more than 1000-2000 Rs monthly only for their treatment and travel alone. This should be taken into consideration by the Government and the policy makers to provide the patients with free treatment and blood transfusion and minimise their economic burden.

They had extreme suffering both physically and psychologically because of their sever pain which was affecting their day to day activities. This was similar to findings of the studies conducted by Coleman et al[10] and Ezenwa MO et al.[11].

Out of 22 study subjects 13.6% of patients were found to have suicidal thoughts because of the severity of pain and the economic burden they are facing. Out of 13.6 % one subject had the thoughts often and 2 subjects had the thought rarely. This is similar to the findings of a retrospective review of case notes in Nigerian Hospital where, among 50 adolescents 11 (22%) had the symptoms of attributable to depression, 4 (8%) had suicidal ideation while 1(2%) had a history of attempted suicide.[14]

CONCLUSION

This study was conducted to begin with the information that there is a lack of empirical evidence of the prevalence of depression and suicidal thoughts ideations and attempts in patients with

SCD, and how commonly the associated symptoms present in an adult sample. Previous studies provided the evidence that a significant number of people are having Sickle cell disease may not present as symptomatic manifestation prior to a successful suicide. This implies that they either suffer in silence, maintaining an asymptomatic social presentation, or they do not experience those symptoms.

Further the depression and suicidal thoughts are also due to the hardships they face through all the dimensions of life. As stated in the WHO definition, health is a state of physical, mental and social wellbeing; but the patients with Sickle cell disease are facing difficulties in life through all the aspects like physical pain, depression and psychosocial problems.

The findings of this study indicate that there is a need to develop appropriate treatment interventions and policy. The aim should be providing free medications, blood transfusions, treatments under the packages of Rashtriya Swasthya Bima Yojana (RSBY) scheme since all the families have smart cards and counselling and guidance that depend on the accessibility to health care at different levels, and in different settings.

RECOMMENDATIONS

The following recommendations are proposed based on the study results

- A large scale up study can be done in all the districts where the disease is highly prevalent so that the exact burden of the disease, economic burden and psychosocial aspects could be identified.
- A structured policy should be planned and implemented to provide treatment free of cost even at the basic level of care i.e. Primary health centre.
- Free medication and blood transfusions expenses could be incorporated in the packages of Rashtriya Swasthya Bima Yojana (RSBY) scheme since majority of the families belong to below poverty line families.

- Community mobilization and participation should be done to improve knowledge about the disease, adherence to treatment, prevent stigma, and counselling and guidance to prevent psychosocial illnesses.

LIMITATIONS

- The primary limitation to the current study is the sample size (N) within a limited sample of patients with SCD due to time constraint and less resource which cannot be generalized to whole of sickle cell disease patients.
- Even though pain episodes are among the most common sequelae of Sickle cell disease obtaining reliable information on the severity of the pain still is difficult and elusive. Due to its subjective nature, methods for assessing pain are at best imprecise, and this is a foundation of interpersonal difficulties among persons with Sickle cell disease, their families and medical providers in assessing the levels of pain.

ACKNOWLEDGEMENT

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ANNEXURES:

I. CONSENT FORM

INFORMED CONSENT FORM

Study Title: A study on the depression, suicidal ideations and attempts among sickle cell disease patients in two villages of Mahasamund district in Chhattisgarh.

Name of the investigator:

Subject's Name: **Age:**

Purpose of the study:

This study on the depression, suicidal ideations and attempts among sickle cell disease will help in providing the base line data by showing the level of physical and psychological health problem. This study helps the health care providers and the government in making policy, and to take

appropriate action to help the sickle cell disease patients in getting regular free treatment, counselling and guidance.

I..... (Name of the investigator) would like to interview you for 20 to 30 minutes to get information for this study. I need your valuable time and cooperation during the interview.

Consent:

- I confirm that I have been explained about the need for the study in a language known to me and understood the purpose of my participation for the above study and have had the opportunity to ask questions.
- I understand that my participation in the study is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.
- I understand that relevant data collected during the study would not be shared with other individuals /organizations. I was explained that the confidentiality of my data would be maintained.

Signature (or Thumb impression) of the Subject/Legally Acceptable:

Date:

II. ENGLISH QUESTIONNAIRE

a. Schedule 1

A STUDY ON THE DEPRESSION, SUICIDAL IDEATIONS AND ATTEMPTS AMONG SICKLE CELL DISEASE PATIENTS IN TWO VILLAGES OF MAHASAMUND DISTRICT IN CHHATTISGARH.

SOCIO DEMOGRAPHIC CHARACTERISTICS

1. Name: date:

2. Address:

3. Age in years:

4. Sex:

5. Relation with head of the family ……

6. Educational status: Illiterate / Primary /Middle /Secondary /Graduation / Drop out.

7. Occupation of the respondent…….

8. Marital status **:** Unmarried / Married / Separated /Widower

9. Family income status: APL / BPL.

10. Religion: Hindu / Muslim / Christian / Other Specify.

11. Which of the following group you belong to: OBC / SC / ST / Others

12. Type of family**:** Joint / Extended /Nuclear / Third generation.

13. History of sickle cell disease in family/relatives/friend/ neighbourhood : Yes/No

14. If yes specify:

15. Are you on regular treatment : yes/ no

16. Where do you go for your treatment: government/ private

17. How often you get your blood transfused.....

18. Have you ever opt for any government schemes: yes/ no

19. How much money do you spend monthly for your treatment.....?

PAIN INVENTORY

20. In general, how much does your pain interfere with your day-to-day activities?

0 1 2 3 4

No interference Extreme interference

21. Since the time your pain began, how much has your pain changed your ability to work? (If applicable)

0 1 2 3 4

No change Extreme change

22. How much your pain has disturbed you from attending your school? (If applicable)

0 1 2 3 4

No change Extreme change

23. Rate your overall mood during the <u>past week.</u>

0 1 2 3 4

Extremely low extremely high

24. How much do you limit your activities in order to keep your pain from getting worse?

0 1 2 3 4

Not at all Very much

25. How much suffering do you experience because of your pain?

0 1 2 3 4

No suffering Extreme suffering

26. During the <u>past week</u>, how well do you feel you've been able to deal with your problems?

0 1 2 3 4

Not at all Extremely well

DEPRESSION INVENTORY:

For the *past week,* how much were you bothered by?

27. Feeling easily annoyed or irritated

0	1	2	3	4
Not at all	a little bit	moderately	quite a bit	extremely

28. Feeling low in energy or slowed down

0	1	2	3	4
Not at all	a little bit	moderately	quite a bit	extremely

29. Blaming yourself for things

0	1	2	3	4
Not at all	a little bit	moderately	quite a bit	extremely

30. Feeling no interest in things

0	1	2	3	4
Not at all	a little bit	moderately	quite a bit	extremely

31. Feeling others do not understand your feelings

0	1	2	3	4
Not at all	a little bit	moderately	quite a bit	extremely

32. Feeling inferior of others

0	1	2	3	4
Not at all	a little bit	moderately	quite a bit	extremely

33. Feeling hopeless about future

0	1	2	3	4
Not at all	a little bit	moderately	quite a bit	extremely

34. The idea that something serious is wrong with your body

0	1	2	3	4
Not at all	a little bit	moderately	quite a bit	extremely

FAMILY AND SOCIETY RESPONSE/SUPPORT

35. How supportive or helpful is your family to you

1	2	3	4
Never support	rarely	sometimes	often

36. They get irritated/ frustrated with me

1	2	3	4
Never	rarely	sometimes	often

37. They try to divert my mind to make me comfortable

1	2	3	4
Never	rarely	sometimes	often

38. Do your family members neglect you because of your disease?

1	2	3	4
Never	rarely	sometimes	often

39. Do your friends neglect you because of your disease? (If applicable)

1	2	3	4
Never	rarely	sometimes	often

40. How much your disease affects your family economically?

1	2	3	4
Never	rarely	sometimes	often

SUICIDAL IDEATION AND ATTEMPTS:

41. Have you ever had thoughts of killing yourself?

1	2	3	4	
Never	rarely	sometimes	often	(If never skip the questions below)

42. How often have you had thoughts of killing yourself?

1	2	3	4
Never	rarely	sometimes	often

43. Have you ever told someone that you had the thoughts of killing yourself?

1	2	3	4
Never	rarely	sometimes	often

44. Have you ever tried to attempt suicide?

1	2	3	4
Never	rarely (1 time)	sometimes (2 times)	often (3-4 times)

45. Have you ever told someone that you were going to commit suicide?

1	2	3	4
Never	rarely	sometimes	often

46. How likely is it that you will attempt suicide someday?

1	2	3	4
Never	no chance at all	likely	very likely

47. Have you ever thought about how your family and friends will suffer after your death

1	2	3	4
Never	no chance at all	likely	very likely

****

Schedule 2

A STUDY ON THE DEPRESSION, SUICIDAL IDEATIONS AND ATTEMPTS AMONG SICKLE CELL DISEASE PATIENTS IN TWO VILLAGES OF MAHASAMUND DISTRICT IN CHHATTISGARH.

SOCIO DEMOGRAPHIC CHARACTERISTICS

1. Name of the child: date:
2. House no:
3. Name of the father:
4. Age in years:
5. Sex:
6. Relation with head of the family …….
7. Educational status: Illiterate / Primary /Middle /Secondary /Graduation.
8. Occupation of the father…….
9. Family income status: APL / BPL.
10. Religion: Hindu / Muslim / Christian / Other Specify.
11. Which of the following group you belong to: OBC / SC / ST / Others
12. Type of family**:** Joint / Extended /Nuclear / Third generation.
13. History of sickle cell disease in family/friend/ neighbourhood : Yes/No
14. If yes specify:
15. Is your child on regular treatment: yes / no
16. Where do you go for your child's treatment: government/ private
17. How often your child gets blood transfusion.....
18. Have you ever opt for any government schemes: yes/no
19. How much money do you speand monthly for your child's treatment.....?

PAIN INVENTORY

20. In general how much does your child's pain interfere with his activities

0	1	2	3	4

No interference Extreme interference

21. Since the time your child's pain begin, how much has the pain changed their ability to play

0 1 2 3 4

No change Extreme change

22. How much your child's pain has disturbed him/her from attending their school?

0 1 2 3 4

No change Extreme change

23. How much does your child limit his activities in order to keep his/her pain from getting worse?

0 1 2 3 4

Not at all Very much

24. How much suffering does your child experience because of his/her pain?

0 1 2 3 4

No suffering Extreme suffering

DEPRESSION INVENTORY:

For the *past week*, how much were you bothered by your child's condition?

25. Feeling easily annoyed or irritated by your child's suffering

0 1 2 3 4

Not at all a little bit moderately quite a bit extremely

26. Blaming yourself for your child's suffering

0 1 2 3 4

Not at all a little bit moderately quite a bit extremely

27. Feeling no interest in things

0 1 2 3 4

Not at all a little bit moderately quite a bit extremely

28. Feeling others do not understand you and your child's feelings

0 1 2 3 4

Not at all a little bit moderately quite a bit extremely

29. Feeling inferior of others because your of child's illness

0 1 2 3 4

Not at all a little bit moderately quite a bit extremely

30. Feeling hopeless about your child's future

0	1	2	3	4
Not at all	a little bit	moderately	quite a bit	extremely

31. The idea that something serious with your child's body

0	1	2	3	4
Not at all	a little bit	moderately	quite a bit	extremely

FAMILY AND SOCIETY RESPONSE/SUPPORT

32. How supportive or helpful are your relatives/ neighbour to you

1	2	3	4
Never support	rarely	sometimes	often

33. Do you get irritated/frustrated with your child

1	2	3	4
Never support	rarely	sometimes	often

34. Do you try to divert your child's mind to make him comfortable?

1	2	3	4
Never support	rarely	sometimes	often

35. Do your child's friends neglect him/her because of his/her disease

1	2	3	4
Never support	rarely	sometimes	often

48. How much your disease affects your family economically?

1	2	3	4
Never	rarely	sometimes	often

SUICIDAL IDEATIONS AND ATTEMPTS

36.Have you ever had thoughts of killing yourself?

1	2	3	4	
Never	rarely	sometimes	often	(If never skip the questions below)

37. How often have you had thoughts of killing yourself?

1	2	3	4
Never	rarely	sometimes	often

38. Have you ever told someone that you had the thoughts of killing yourself?

1	2	3	4
Never	rarely	sometimes	often

39. Have you ever tried to attempt suicide?

1	2	3	4
Never	rarely (1 time)	sometimes (2 times)	often (3-4 times)

40. Have you ever told someone that you were going to commit suicide?

1	2	3	4
Never	rarely	sometimes	often

41. How likely is it that you will attempt suicide someday?

1	2	3	4
Never	no chance at all	likely	very likely