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"A STUDY TO ASSESS KNOWLEDGE ON SICKLE CELL ANEMIA AND QUALITY OF LIFE AMONG SICKLE CELL ANEMIC PATIENT IN SELECTED AREAS OF DADRA AND NAGAR HAVELI."

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ABSTRACT

Background: Sickle Cell Anemia is characterized by a modification in the shape of the red blood cell from smooth, donut-shape into a crescent or half-moon shape. The misshapen cells lack plasticity and can block small blood vessels, impairing blood flow. This condition leads to shortened red blood cell survival, and subsequent anemia also known as sickle cell anemia. Poor blood oxygen levels and blood vessel blockages in people with sickle cell disease can lead to chronic acute pain syndromes, severe bacterial infections and necrosis (tissue death).

Aim: The aim of the study was to correlate the level of knowledge and quality of life among sickle cell anemic patients.

Objectives: 1. Assess the level of knowledge on sickle cell anemia and quality of life among sickle cell anemic patient. 2. Find correlation between the level of knowledge on sickle cell anemia and quality of life among sickle cell anemic patient. 3. Find the association between levels of Knowledge among sickle cell anemic patient and selected demographic variables. 4. To find the association between quality of life among sickle cell anemic patients and selected demographic variables.

Methodology: A descriptive correlational survey design through non probability purposive sampling 100 samples were selected from areas of Dadra and Nagar Haveli. The final study was conducted from 16/10/23 to 25/11/23. Demographic data and structure knowledge questionnaire was used to collect basic information and assess the knowledge level and standardize tool SF-36 was used to check the quality of life of sickle cell anemic patients. The data was analyzed and interpreted based on descriptive and inferential statistics.

Result: The result of the study shows that 9% were having inadequate knowledge, 68% of them were having moderate knowledge and 23% were having adequate knowledge on sickle cell anemia. 19% of the participants having poor Quality of Life, 64% had average Quality of Life and only 17% had good Quality of Life. The p-value is <0.001 which is highly significant. Thus, the level of knowledge and quality of life gives a significant correlation through average quality of life.

Conclusion: Thus, it can be concluded that knowledge is must to improve the health related quality of life among sickle cell anemic patients.

Key words: Assess, Knowledge, Quality of Life, Sickle Cell Anemic Patients.

INTRODUCTION

Sickle Cell Anemia is characterized by a modification in the shape of the red blood cell from smooth, donut-shape into a crescent or half-moon shape. The misshapen cells lack plasticity and can block small blood vessels, impairing blood flow. This condition leads to shortened red blood cell survival, and subsequent anemia also known as sickle cell anemia. Poor blood oxygen levels and blood vessel blockages in people with sickle cell disease can lead to chronic acute pain syndromes, severe bacterial infections and necrosis (tissue death).

Quality of life (QOL) is defined by the World Health Organization (WHO) as an "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns". Standard indicators of quality of life include wealth, employment, the environment, physical and mental health, education, recreation and leisure time, social belonging, religious beliefs, safety, security and freedom. Aspects of culture, values, and spirituality are also key domains of overall quality of life that add to the complexity 3 of its measurements. Health related QOL (HRQOL) is an evaluation of QOL and its relationship with health.

Dadra and Nagar Haveli is lain near the west coast and it has total population of 343709. Sickle cell anemia disease is most common in the tribal community like Dhodia, Kokana, Kolcha, Kothvadia, Vasava, Gamit, Tadavi, Koli, Kathodi, Naika abd Dubla etc. it is estimated that about 39.49% of population are screened for sickle cell anemia, 3.67% are having Sickle Cell Trait and 0.15% are suffering from Sickle Cell Disease.

STATEMENT OF THE PROBLEM

"A study to assess knowledge on sickle cell anemia and quality of life among sickle cell anemic patients of selected areas of Dadra and Nagar Haveli.**"**

OBJECTIVES OF THE STUDY:

The objectives of the study are:

1. To assess the level of knowledge on sickle cell anemia and quality of life among sickle cell anemic patient.
2. To find correlation between the level of knowledge on sickle cell anemia and quality of life among sickle cell anemic patient.
3. To find the association between level of Knowledge among sickle cell anemic patient and selected demographic variables.
4. To find the association between quality of life among sickle cell anemic patients and selected demographic variables.

ASSUMPTIONS

1. Sickle cell anemic patient may not have knowledge regarding sickle cell anemia.
2. Sickle cell anemic patient may have poor quality of life.
3. Knowledge regarding sickle cell anemia may influence quality of life among sickle cell anmeic patients.

HYPOTHESIS

The hypothesis were tested at 0.05 level of significance.

H1: There will be significant correlation between knowledge on sickle cell anemia with quality of life among sickle cell anemic patient.

H2: There will be significant association between knowledge and quality of life with selected demographic variables among sickle cell anemic patients.

DELIMITATION:

The study was delimited to:

- Sickle cell disease patients above 18 years of age.
- Those who could be able to read and write Gujarati and Marathi.
- Those who are willing to participate in the study.

OPERATIONAL DEFINITION

- **ASSESS:** In this study assess refers to evaluate the level of knowledge regarding sickle cell anemia.
- **KNOWLEDGE:** In this study Knowledge refers to awareness among patient regarding sickle cell anemia in terms of their ability to give correct response. It is assessed by structured knowledge questionnaire.
- **QUALITY OF LIFE:** In this study, quality of life is considered as absence of impairment, disease or symptoms; appropriate physical functioning associated with pain and discomfort, emotional functioning associated with feeling depressed or anxious, social functioning associated with interaction

with friends and relatives. It is assessed by Short Form Survey-36 Questionnaire (SF-36) standardized tool.

- **SICKLE CELL ANEMIC PATIENTS:** In this study, sickle cell anemic patients are those who are having Sickle cell disease (SCD) and having full yellow colour card.

RESEARCH METHODOLOGY

REASERCH APPROACH: Survey approach

RESEARCH DESIGN: Descriptive correlational survey design

VARIABLES:

- **Research variables: Knowledge and Quality of life**
- **Demographic Variables:** Age, Gender, Marital status, Caste, Occupation, Education status, source of information, family history of SCD, regular follow up and medication history.

RESEARCH SETTING: Selected areas of Dadra and Nagar Haveli.

POPULATION AND SAMPLE:

POPULATION: Patient with sickle cell disease above 18 years of age.

SAMPLE: Patient with sickle cell disease above 18 years of age.

SAMPLING TECHNIQUE: Non Probability Purposive Sampling Technique.

DESCRIPTION OF TOOL:

Final tool consisted of three parts:

PART 1: SOCIO- DEMOGRAPHIC DATA:

In this study Section I consists 11 items such as age, sex, caste, marital status, occupation, educational status, source of information, family history of SCD, regular follow up and medication history.

PART 2: STRUCTURED KNOWLEDGE QUESTIONNAIRE

It consist of structured knowledge questionnaire. The tool has 20 items. Each item has 4 option to answer the question. The researcher were score the item as correct response as 1 and incorrect response as 0. Maximum score was 20 that indicate adequate knowledge level.

Poor knowledge: 0-6

Good knowledge: 7-13

Very Good knowledge: 14-20

PART 3: SHORT FORM 36 (SF-36) QUESTIONNAIRE

RAND developed the 36 item Short Form Health Survey (SF- 36) in 1992. SF36 is a set of generic, coherent, and easily administered quality of life measured. Scoring of RAND 36 item Short Form Health Survey is a two-step process. First, precoded numeric values are recoded per the scoring key. All items are scored so that a high score defines a more favorable health state. Each item is scored on a 0 to 100 range so that lowest and highest possible scores are 0 and 100. In step 2, items in the same scale are averaged together to create the 8 scale scores.

RESULTS

SECTION I:

DESCRIPTION OF FREQUENCY AND PERCENTAGE DISTRIBUTION OF SAMPLE BASED ON THE DEMOGRAPHIC VARIABLE OF THE SICKLE CELL ANEMIC PATIENTS.

Table 1: Frequency and percentage wise distribution of the demographic data of sickle cell anemic patients in selected area of Dadra & Nagar Haveli.

(n= 100)

Demographic variables	Frequency	Percentage
1.Age in years:		
18-28 years	64	64
29-38 years	28	28
39-48 years	3	3
49 and above	5	5
2.Sex:		
Male	36	36
Female	64	64
Transgender	0	0
3.Marital Status:		
Married	55	55
Unmarried	43	43
Widow/ widower	2	2
Divorce	0	0
4.Caste:		
Dhodia	39	39
Kokana	3	3
Varli	51	51
Others	7	7
5.Occupation:		
Farmer	5	5
Private Job	11	11
Govt. Job	1	1
Self-employee	3	3
Unemployed	80	80
6.Educational status:		
Professional degree	0	0
Graduate	10	10
Intermediate/diploma	11	11
High school	38	38

Middle school	25	25
Primary School	16	16
7. Have you heard of SCD Before:		
Yes	10	10
No	90	90
8. From where have you heard about Sickle Cell Disease:		
Health professional	100	100
TV/Radio	0	0
Internet	0	0
Friends/Family	0	0
9. **Do you have any Family history of sickle cell anemia:**		
Yes	70	70
No	20	20
Don't know	10	10
9.1 if yes, Reason:		
Both parents trait	43	43
Father trait	11	11
Mother trait	9	9
Father disease	2	2
Mother disease	5	5
10. Receive regular medical check-ups related to your Sickle Cell Disease?		
Yes	99	99
No	1	1
11. **Which medication you take daily**:		
Diclofenac	0	0
Paracetamol, pantoprazole	4	4
Hydroxyurea, Folic acid	96	96

SECTION II:

ASSESS THE LEVEL OF KNOWLEDGE AMONG SICKLE CELL ANEMIC PATIENTS IN SELECTED AREAS OF DADRA AND NAGAR HAVELI.

(n=100)

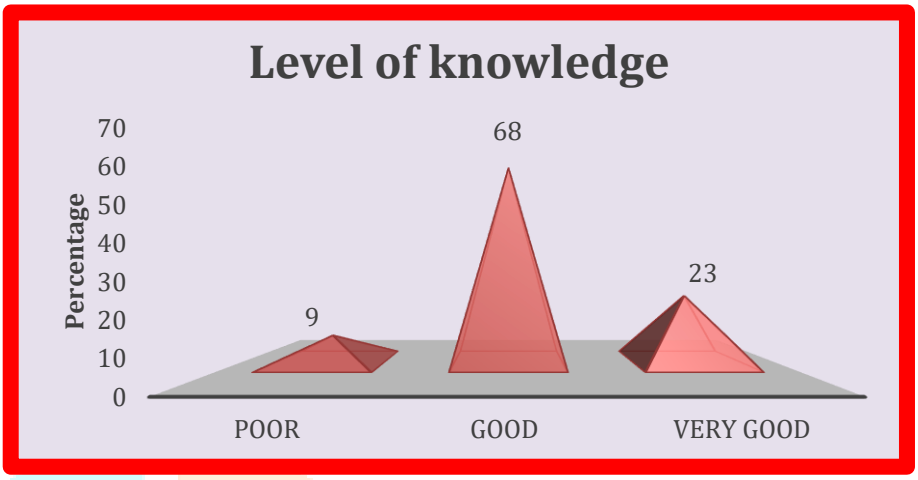

Figure 1: The figure show the frequency and percentage of level of knowledge of among sickle cell anemic patients. Out of 100 participants 68 (68%) had good knowledge, 23 (23%) had very good knowledge and 9 (9%) had poor knowledge.

SECTION III:

ASSESS THE QUALITY OF LIFE AMONG SICKLE CELL ANEMIC PATIENTS IN SELECTED AREAS OF DADRA AND NAGAR HAVELI.

(n=100)

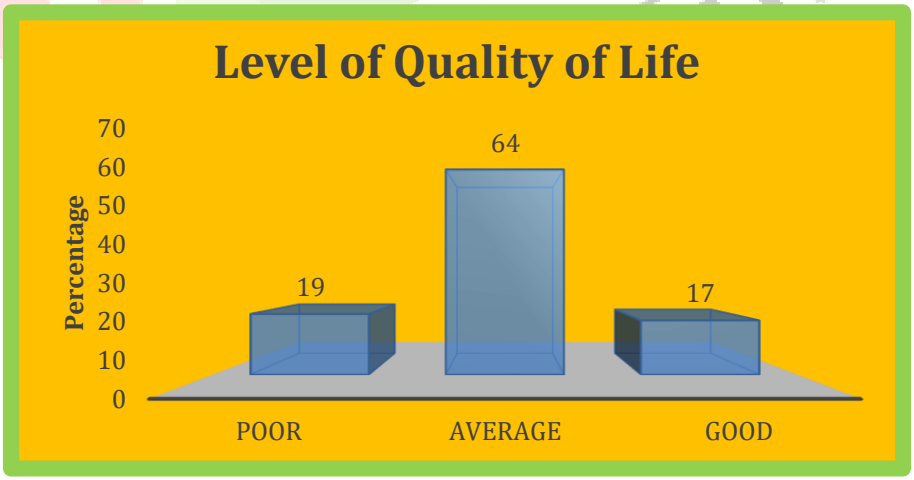

Figure 2: The graph shows the frequency and percentage distribution of level of quality of life among sickle cell anemic patients. Out of 100 participants 64 (64%) had average quality of life, 19 (19%) were having poor quality of life and 17 (17%) had good quality of life.

SECTION IV: Association for level of knowledge and selected demographic data.

(n=100)

Demographic variables	Inadequate		Moderate		Adequate		χ2-value	p-value
	F	%	F	%	F	%		
1.Age in years:								
18-28 years	4	4	44	44	16	16	4.18	0.652
29-38 years	3	3	19	19	6	6	(df=6)	NS
39-48 years	1	1	2	2	0	0		
49 and above	1	1	3	3	1	1		
2.Sex:								
Male	2	2	24	24	10	10	1.31	0.518
Female	7	7	44	44	13	13	(df=2)	NS
3.Marital Status:								
Married	6	6	37	37	12	12	1.38	0.847
Unmarried	3	3	30	30	10	10	(df=4)	NS
Widow	0	0	1	1	1	1		
4.Caste:								
Dhodia	3	3	24	24	12	12	6.47	0.372
Kokana	0	0	3	3	0	0	(df=6)	NS
Varli	6	6	37	37	8	8		
Others	0	0	4	4	3	3		
5.Occupation:								
Farmer	1	1	3	3	1	1	7.94	0.440
Private Job	1	1	7	7	3	3	(df=8)	NS
Govt. Job	0	0	0	0	1	1		
Self- employee	0	0	1	1	2	2		
Unemployed	7	7	57	57	16	16		
6.Educational status:								
Graduate	0	0	5	5	5	5	13.86	0.085
Intermediate/diploma	0	0	8	8	3	3	(df=8)	NS
High school	3	3	23	23	12	12		
Middle school	4	4	19	19	2	2		
Primary School	2	2	13	13	1	1		

7. Have you heard of Sickle Cell Anemia before you diagnosed:							5.05	0.080
Yes	0	0	5	5	5	5	(df=4)	NS
No	9	9	63	63	18	18		
9. Do you have any Family history of sickle cell anemia:							3.65	0.445
Yes	5	5	46	46	19	19	(df=4)	NS
No	2	2	15	15	3	3		
Don't know	2	2	7	7	1	1		
9.1 if yes, Reason:								
Both parents trait	3	3	31	31	9	9	6.77	0.561
Father trait	2	2	5	5	4	4	(df=8)	NS
Mother trait	0	0	5	5	4	4		
Father disease	0	0	1	1	1	1		
Mother disease	0	0	4	4	1	1		
10. Receive regular medical check-ups related to your Sickle Cell Disease?							0.475 (df=2)	0.788 NS
Yes	9	9	67	67	23	23		
No	0	0	1	1	0	0		
11. Which medication you take daily:							2.17	0.337
Diclofenac	0	0	0	0	0	0	(df=2)	NS
Paracetamol, pantoprazole	1	1	3	3	0	0		
Hydroxyurea, Folic acid	8	8	65	65	23	23		

SECTION V: Association for level of quality of life and selected demographic data.

(n=100)

Demographic variables	Poor		Average		Good		χ2-value	p-value
	F	%	F	%	F	%		
1.Age in years:								
18-28 years	10	10	40	40	14	14	8.77	0.189
29-38 years	5	5	20	20	3	3	(df=6)	NS
39-48 years	2	2	1	1	0	0		
49 and above	2	2	3	3	0	0		
2.Sex:								
Male	7	7	19	19	10	10	4.95	0.084
Female	12	12	45	45	7	7	(df=2)	NS
3.Marital Status:	13	13	36	36	6	6		
Married	6	6	27	27	10	10	5.14	0.273
Unmarried	0	0	1	1	1	1	(df=4)	NS
Widow								
4.Caste:								
Dhodia	6	6	24	24	9	9	3.73	0.713
Kokana	1	1	2	2	0	0	(df=6)	NS
Varli	11	11	34	34	6	6		
Others	1	1	4	4	2	2		
5.Occupation:								
Farmer	0	0	4	4	1	1	9.37	0.312
Private Job	1	1	7	7	3	3	(df=8)	NS
Govt. Job	0	0	0	0	1	1		
Self- employee	0	0	2	2	1	1		
Unemployed	18	18	51	51	11	11		
6.Educational status:								
Graduate	0	0	6	6	4	4	15.45	0.051
Intermediate/diploma	2	2	8	8	1	1	(df=8)	NS
High school	4	4	26	26	8	8		
Middle school	6	6	17	17	2	2		
Primary School	7	7	7	7	2	2		
7. Have you heard of Sickle Cell Anemia before you diagnoseg:							5.59	0.061

Yes	0	0	6	6	4	4	(df=2)	NS
No	19	19	58	58	13	13		
8. From where have you heard about Sickle Cell Disease:							0	1
Health professional	19	19	64	64	17	17	(df=1)	NS
TV/Radio	0	0	0	0	0	0		
Internet	0	0	0	0	0	0		
Friends/Family	0	0	0	0	0	0		
9. Do you have any Family history of sickle cell anemia:							7.76	0.101
Yes	9	9	48	48	13	13	(df=4)	NS
No	6	6	10	10	4	4		
Don't know	4	4	6	6	0	0		
9.1 if yes, Reason:	8	8	28	28	7	7		
Both parents trait	1	1	6	6	4	4	8.15	0.419
Father trait	0	0	7	7	2	2	(df=8)	NS
Mother trait	0	0	2	2	0	0		
Father disease	0	0	5	5	0	0		
Mother disease								
10. Receive regular medical check-ups related to your Sickle Cell Disease?							4.93	0.085
Yes	19	19	64	64	16	16	(df=2)	NS
No	0	0	0	0	1	1		
11. Which medication you take daily:	0	0	0	0	0	0	3.25	0.196
Diclofenac	2	2	1	1	1	1	(df=2)	NS
Paracetamol, pantoprazole	17	17	63	63	16	16		
Hydroxyurea, Folic acid								

SECTION VI: Correlation between knowledge and quality of life:

(n=100)

	'r' value	**p-value**
level of knowledge –level of quality of life	0.3738	p<0.001*** (HS)

DISCUSSION

A total 100 respondents who met the sampling criteria were selected by purposive sampling technique. The data were collected through structured knowledge questionnaire and SF-36 questionnaire. The result of the study shows that 9% were having inadequate knowledge, 68% of them were having moderate knowledge and 23% were having adequate knowledge on sickle cell anemia. 19% of the participants having poor Quality of Life, 64% had average Quality of Life and only 17% had good Quality of Life. There is no significant association between knowledge and quality of life with selected demographic variables. There was low positive correlation between level of knowledge and quality of life among sickle cell anemic patients.

CONCLUSION

As many research articles shown that knowledge is must to improve the health related quality of life among sickle cell anemic patients. This study revealed that the participants had moderate knowledge and average quality of life. So, the study result proposes that improvement in knowledge level for improving health related quality of life among sickle cell anemic patients.

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