Effectiveness of Sickle Cell Crisis Prevention and Management Teaching Programme on Knowledge and episodes of Sickle Cell Crisis

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Abstract: *Sickle Cell Disease (SCD) is a genetic abnormality and the control and cure still has no defined solution. It is the most prevalent inherited non communicable blood disorder world wide.[1] SCD is more prevalent among the tribal population. Sickle Cell Crisis (SCC) is a sudden and unpredictable episode of pain that occurs with varying frequency and severity in people with SCD, and is usually followed by periods of remission. Simple measures like vaccination in childhood, adequate oral intake of fluids with electrolytes and avoidance of exposure to extreme temperatures etc. can prevent the episodes of SCC and improve the quality of life.[2] The purpose of the study was to develop an effective Sickle Cell Crisis Prevention and Management Teaching Programme to reduce the number of episodes of SCC and to improve the quality of life of tribal individuals with SCD. This Pre-experimental study was conducted on tribal individuals in Wayanad District of Kerala, from 17 - 9 - 2014 to 17-5-2015. A total of 200 tribal individuals (both male and female) between the age of 11 to 20 years with SCD were the participants of the study. A structured knowledge questionnaire was prepared and used to assess the knowledge on SCC, Prevention of SCC and management of SCC. Checklist was used to assess the characteristics of SCC. Knowledge was assessed once before the teaching and 7 days after the teaching. Assessment of the characteristics of SCC was done once before the teaching and 6 months after the teaching. The mean score of the pretest was14.17 and the posttest was 19.89 which was found to be significant at P < 0.01. Findings of the study showed a significant association between the level of knowledge and frequency of hospitalization during the episodes of SCC is seen at 0.05 level (p < 0.05). With these findings it was evident that with some simple and inexpensive measures the episodes of SCC can be prevented and managed at home.*

I.   Introduction

Sickle Cell Disease (SCD) is an inherited (autosomal recessive) disorder of haemoglobin synthesis that is potentially life threatening. Researches show that about 5 to7% of the global population carries an abnormal haemoglobin gene.[3] SCD affects millions of people throughout the world and is particularly common among those whose ancestors came from sub-Saharan Africa; Spanish-speaking regions in the Western Hemisphere (South America, the Caribbean, and Central America); Saudi Arabia; India; and Mediterranean countries such as Turkey, Greece, and Italy. It is estimated that SCD affects 90,000 to 100,000 Americans, and sickle cell trait occurs among 1 in 12 African Americans.[4] According to African Literature of 1870s[5], SCD was locally known as "ogbanjes" (children who come and go"). A history of this condition tracked reports back to 1670 in one Ghanaian family. The first modern report of SCD appeared in 1846 in an autopsy of a slave, the key finding was the absence of spleen. The peculiar sickle shaped hemoglobin was first described in 1910 by James Herrick.[6] SCD is a genetic disorder which is usually inherited through generations; It cannot be "caught" and can only be inherited. The term Sickle cell disease was given by Verne Manson[5] in 1922 Pauling et.al found that SCD occurs as a result of an abnormality in the hemoglobin molecule in 1949. [7] Dr. James V. Neel identified it as hereditary disease in 1949. In 1952, Lehman H. & Cutbush M. described sickle hemoglobin among tribal population in India (Nilgiri hills).[1] Dunlop P. and Mazumdar S. reported presence of sickle hemoglobin in 1952 among tribals from Bihar and Odisha working at Assam's tea gardens.[8] Screening of 1,25,000 tribal population in Wayanad found prevalence of 18.2 to 34.1 %.[9] SCD is associated with painful and life threatening complications resulting in high morbidity and mortality. SCD patients require frequent hospitalizations for pain management, hydration and treatments including blood transfusions causing heavy economic burden.[10] Anxiety, unpredictable crisis, disability, high morbidity and mortality rates, lack of appropriate health services and

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ignorance add to the disease burden.[11] Knowledge about SCD can empower the victims to take preventive measures and reduce painful episodes. [12, 13] Mild episodes of Sickle Cell Crisis (SCC) can be managed in the primary health care clinic or at home with oral analgesia and fluids. Adolescents and young adults are prospective parents of tomorrow and empowering them with information can help them to avert the SCD by healthy choices. Studies related to sickle cell disease & its knowledge regarding preventive measures and management are scanty. It is important for newer generation to know the impact of SCD in their life and take adequate precautions.[14] Hence, the present study was undertaken to enlighten the tribal population on SCD , prevention and management of sickle cell crisis to empower them to have control on their suffering and improve Quality of Life.

II. Material And Methods

This Pre-experimental study was carried out in tribal individuals of Wayanad District of Kerala, from 17 - 9 - 2014 to 17-5-2015. A total of 200 tribal individuals (both male and female) between the age of 11 to 20 years with SCD were the participants in this study.

Study Design: Pre-experimental: One group pre-test and post- test design

Study Location: Primary Health Centers of Wayanad District of Kerala, India. Wayanad is a hilly District of Tribal People in North Kerala.

Study Duration: from 17 - 9 - 2014 to 17-5-2015.

Sample Size: 200 Tribal individuals with SCD

Sample size calculation: Sample size was calculated using Power Analysis .The desirable size was 166, but the researcher collected data from 200 samples.

Subjects and selection method: The study population was drawn from tribal individuals with SCD who registered at the PHCs of Wayanad District of Kerala.

 Criteria for sample selection

a) Inclusion Criteria :Tribal individuals with SCD between the age of 11-20 years, who can understand Malayalam, who are willing to participate in the study and who are available during the time of data collection.

b) Exclusion criteria: Tribal individuals with SCD and who are not registered at the PHC

Sampling Technique – Purposive sampling technique.

Methodology

Necessary sanctions were obtained from government officials to meet the tribal people with SCD at Primary Health Centre. Written informed consent was obtained from the selected subjects and pretest was conducted. Demographic data, knowledge regarding SCD, knowledge regarding prevention of episodes of SCC, knowledge regarding management of episodes SCC were assessed using structured questionnaire. Characteristics of episodes of SCC experienced before the teaching programme were assessed by using the checklist.

The instruments were prepared by the investigator after an extensive study of the related literature and with the guidance of experts. Content validity of the instrument and teaching module was established with 99.5% of agreement among 8 experts. The item with Content validity index (CVI) of more than 0.74 were selected. The reliability of the tool was calculated using the test-retest method , Cronbach's alpha (r = 0.748) and by using split-Half method (r = 0.737).

Structured teaching on SCD, prevention of episodes of SCC and management of episodes of SCC was given to subjects with the help of power point presentation followed by group discussion in small groups. After 7 days post test was conducted to assess the knowledge using the same knowledge questionnaire. Characteristics of episodes of SCC experienced after the teaching were assessed after six months of teaching using the same checklist.

Statistical analysis

The data was analyzed in terms of descriptive and inferential statistics with the help of SPSS software 21. Descriptive statistics: frequency, percentage, mean, and standard deviation were used to analyze the demographic variables. Paired t test was used to compare the pre-test and post-test knowledge. To find the association between the level of knowledge of tribal individuals and selected demographic variables, chi square test was used. Chi square test was used to find association between the level of knowledge and number of episodes and the characteristics of episodes of SCC.

III. Results

The data analyzed were organized under the following headings.
Section - 1: Analysis of the demographic variables of participants.
Section - 2: Analysis of the level of overall knowledge on SCC prevention and management of participants before and after the intervention.
Section - 3: Analysis of the association of the level of knowledge on SCC prevention and management of participants with the number of episodes and the characteristics of the episodes of SCC.
Section - 4: Analysis of the association of the number of episodes of SCC before intervention with number of episodes of SCC after intervention

**Section : 1 Analysis of the demographic variables of participants.**

Table :1 Analysis of the demographic variables of participants.
N = 200

Characteristics	Category	Frequency	%
Gender	Male	110	55.0
	Female	90	45.0
Age groups	11-13	39	19.5
	14-16	36	18.0
	17-20	125	62.5
Education	Illiterate	5	2.5
	Primary school	78	39.0
	High school	92	46.0
	+2 and above	25	12.5
Occupation	Student	77	38.5
	Household work	57	28.5
	Cooley	35	17.5
	Any other	31	15.5
Income	500-1000	165	82.5
	1001-1500	25	12.5
	1501-2000	6	3.0
	2001 and above	4	2.0

Most (55%) of the participants are male and 45% are female. Majority of them belongs to the age group of 17 – 20 years (62.5%) and   46% are having High School education. Majority (38.5 %) of the participants are students. Out of 200 participants 82.5% are having a monthly income of Rs. 500 - 1000 .

Section -2: Analysis of the level of overall knowledge on SCC prevention and management of participants before and after the intervention.
Assessment of overall knowledge before intervention
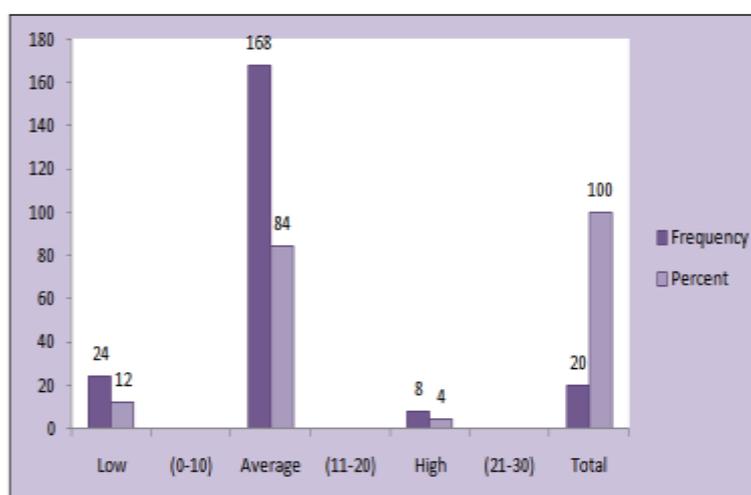
Figure1. Distribution of participants based on the level of overall knowledge before intervention

The data depicted in **Figure 1.** Majority (84%) of the participants have average level of overall knowledge and 4% of participants have high level of knowledge before intervention.

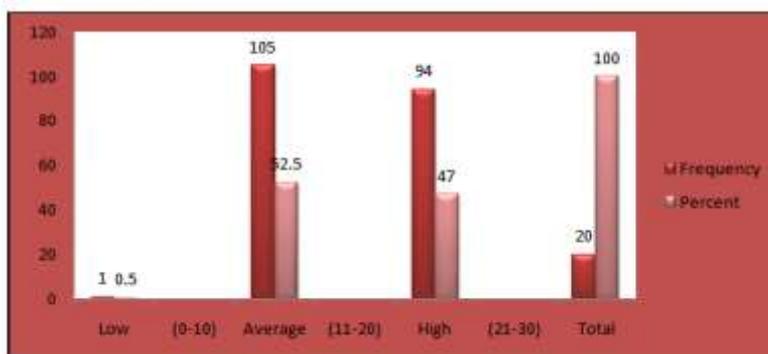**Assessment of overall knowledge after intervention**

Figure2. Distribution of participants based on the level of overall knowledge after intervention

Majority (52.5%) of participants have average level of knowledge and47% of participants have high level of knowledge after intervention.

Section – 3: Analysis of the association of the level of knowledge on SCC prevention and management of participants with the number and characteristics of the episodes of SCC.

Table: 2 Association of the of level of knowledge on SCC prevention and management with the frequency of the episodes of SCC

Fequency of the episodes of SCC experienced before intervention	Level of knowledge						Chi square Total	df	p-value
	Low		Average		High				
	f	%	f	%	f	%			
Only once so far	4	16.0	13	52.0	8	32.0	25		
							1.890^{ns}	6	0.930
Once in two years	4	11.8	22	64.7	8	23.5	34		
2-3 times a year	15	15.3	60	61.2	23	23.5	98		
More than 5 times	5	11.6	25	58.1	13	30.2	43		
Total	28	14.0	120	60.0	52	26.0	200		

ns – non-significant at 0.05 level

The findings show that there is no significant association of the level of knowledge on SCC prevention and management with frequency of the episodes of SCC at 0.05 level.

Table:3 Association of the of level of knowledge on SCC prevention and management of participants with the severity of the episodes of SCC

Severity of the episodes of SCC experienced before intervention	Level of knowledge						Chi square Total	df	p-value
	Low		Average		High				
	f	%t	f	%	f	%			
Very severe	17	16.5	64	62.1	22	21.4	103		
Severe	7	14.0	31	62.0	12	24.0	6.016^{ns} 50	6	0.421
Moderate	3	7.3	22	53.7	16	39.0	41		
Mild	1	16.7	3	50.0	2	33.3	6		
Total	28	14.0	120	60.0	52	26.0	200		

The ta depicted in **Table:3** shows that the level of knowledge on SCC prevention and management and severity of the episodes of SCC are not statistically significant.

Table: 4 Association between the level of knowledge on SCC prevention and management of participants with the Predominant symptoms of the episodes of SCC.

Predominant symptom of the episodes of SCC experienced before intervention	Level of knowledge						Chi square Total	df	p-value
	Low		Average		High				
	f	%	f	%	f	%			
Sever chest pain	9	14.1	41	64.1	14	21.9	64		
							7.053^{ns}	6	0.316
Breathlessness	5	25.0	9	45.0	6	30.0	20		
Abdominal pain	8	20.0	23	57.5	9	22.5	40		
Varying symptoms	6	7.9	47	61.8	23	30.3	76		
Total	28	14.0	120	60.0	52	26.0	200		

ns – non-significant at 0.05 level

The data depicted in **Table :4** shows that there is no significant association between the level of knowledge and selected variable at 0.05 level of significance

Table:5 Association of the of level of knowledge on SCC prevention and management of participants with the duration of the episodes of SCC.

Duration of the episodes of SCC before intervention	Level of knowledge						Chi square	df	p-value
	Low		Average		High				
	f	%	f	%	f	%			
1-3 days	4	13.8	15	51.7	10	34.5	29		
							5.635^{ns}	6	0.465
1 week	9	13.4	39	58.2	19	28.4	67		
More than 1 week	9	14.3	44	69.8	10	15.9	63		
More than 15 Days	6	14.6	22	53.7	13	31.7	41		
Total	28	14.0	120	60.0	52	26.0	200		

ns – non-significant at 0.05 level

The data depicted in **Table: 5** shows that there is no significant association with the level of knowledge on SCC prevention and management of participants with the duration of the episodes of SCC

Table : 6 Association of the of level of knowledge on SCC prevention and management of the. participants with the frequency of hospitalization during the episodes of SCC.

Frequency of hospitalization during the episodes of SCC before intervention	Level of knowledge							Chi square	df	p-value
	Low		Average		High		Total			
	f	%	f	%	f	%				
Only once	4	6.7	38	63.3	18	30.0	60			
1-2 times/year	9	13.0	42	60.9	18	26.1	69	12.642^{*}	6	0.049
3-5 times/year	14	25.9	31	57.4	9	16.7	54			
	1	5.9	9	52.9	7	41.2	17			
Total	28	14.0	120	60.0	52	26.0	200			

* –significant at 0.05 level

Table: 6 reveals that there is a significant association of the level of knowledge on SCC prevention and management of participants and the frequency of hospitalization as the p-value (0.049) is lesser than 0 .05 at 0.05 level of significance

Table:7 Association of the of level of knowledge on SCC prevention and management of participants with the frequency of blood transfusion during the episodes of SCC before intervention.

Frequency of blood transfusion during the episodes of SCC before intervention	Level of knowledge						Total	Chi square	df	p-value
	Low		Average		High					
	f	%	f	%	f	%				
Never	11	11.0	60	60.0	29	29.0	100			
								8.616^{ns}	6	0.196
2-3 times/year	11	24.4	25	55.6	9	20.0	45			

During each crisis	1	50.0	1	50.0	0	0.0	2		
Total	**28**	**14.0**	**120**	**60.0**	**52**	**26.0**	**200**		

ns – non-significant at 0.05 level

The data depicted in **Table :7** shows that there is no significant association of the level of knowledge on SCC prevention and management of participants with frequency of blood transfusion during the episodes of SCC.

Table: 8 Association of the number of episodes of SCC before intervention with number of episodes of SCC after intervention

No. of episode after intervention	Number of episode before intervention								Total	
	Only once so far		Once in two years		2-3 times/year		More than 5 times /year			
	No	Per cent	No	Per cent	No	Per cent	No	Per cent	No	Per cent
No episode	23	92.0	29	85.3	62	63.9	28	65.1	142	71.4
Only one	2	8.0	4	11.8	22	22.7	6	14.0	34	17.1
2-3 episode	0	0.0	1	2.9	13	13.4	9	20.9	23	11.6
Total	25	100.0	34	100.0	97	100.0	43	100.0	199	100.0
Chi square = 15.828*; p-value = 0.015										

* Significant at 0.05 level

All the participants in the study have experienced at least one episode of SCC before the intervention. But after the intervention 71.4 % of participants had not experienced any episodes of SCC within six months. Among the 25 participants who have experienced one episode of SCC before intervention , 92 % had not experienced any episode of SCC within six months after the intervention. Out of those who experienced 2-3 or more than five episodes of SCC before intervention, more than 60 % had not experienced any episodes of SCC within six months after intervention. Significance of chi square value shows that the number of episodes of SCC experienced after intervention is significantly depends on the number of episodes before intervention.

IV. Discussion

Research studies are scanty especially on the preventive aspect of SCC in India. Even from abroad, the studies found were with little scope for generalization as they were conducted on other aspects of SCD. The present study is a preliminary attempt to include the simple and inexpensive measures to prevent the episodes of SCC which have not been addressed in prior research studies involving the Indian population.

The findings of the study reveal that the participants who had high educational status had high level of knowledge regarding the preventive and management aspects of SCC. This is supported by another study conducted among youth in Nigeria which also showed a significant association of respondents' educational qualification with knowledge, attitude and practices related to SCD.[17] The present study showed a marked difference in the knowledge level of participants which reflects the effectiveness of teaching programme. Another study conducted in India indicates that the health education increased the knowledge of the people (Pre-intervention – 97% did not know about SCD. Post-intervention – 83.6% gained knowledge). The study also concluded that there is a need to intensify health education to people which should be directed towards prevention of SCC.[18] In the present study it is relevant that the increased level of knowledge on preventive measures and management of SCC decreased the number of episodes of SCC and hospitalization during the episodes of SCC.

V. Conclusion

The present study was an attempt to find out whether a teaching programme will be successful to reduce or prevent the sufferings of the tribal population with SCD. The findings showed that the episodes of hospitalization had reduced remarkably after improving their knowledge on preventive aspects of SCC. So preventive teaching may be continued to reinforce their knowledge and improve quality of life of these people.

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