A study to evaluate the effectiveness of sickle cell crisis prevention and management teaching programme on knowledge and episodes of sickle cell crisis among tribal individuals between the age of 11-20 years with sickle cell disease in a selected district of Kerala

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ABSTRACT

Sickle Cell Disease (SCD) is a genetic abnormality and the control and cure still has no defined solution. SCD is more prevalent among the tribal population. Sickle Cell Crisis (SCC) is a painful episode that occurs in people who have SCD. It is a sudden and unpredictable episode of pain that occurs with varying frequency and severity in different patients, 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. With healthy lifestyle habits and other steps people can prevent and manage painful episodes of SCC and improve the quality of life.

Objective: The present study is carried out to find an effective Sickle Cell Crisis Prevention and Management Teaching Programme to improve the quality of life of tribal individuals with SCD.

Material and methods: 200 Tribal individuals with SCD were identified. 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 seven days after the teaching. Assessment of the characteristics of SCC was done once before the teaching and 6 months after the teaching.

Results: The study shows an increase in the level of knowledge of participants after the intervention. The mean score of the pretest was 14.17 and the posttest was 19.89 at 0.01 level of significance, which states that the Sickle Cell Crisis Prevention and Management Teaching Programme was effective in enhancing the knowledge of tribal individuals with SCD. It was found that there were positive changes in the episodes of SCC in terms of frequency, severity, predominant symptom and duration of the episode of SCC and frequency of hospitalization and blood transfusion during the episode of SCC. In this study there is a significant association between the level of knowledge and education of the tribal individuals with SCD (p<0.001) and sex of the individuals with SCD (p<0.05). There is a significant association between the level of knowledge and characteristics of the episodes of SCC in terms of frequency of hospitalization during the episodes of SCC at 0.05 level of significance. The study also shows that there is no significant association between the level of knowledge and characteristics of the episodes of SCC in terms of frequency, severity, predominant symptom and duration of the episode of SCC and frequency of blood transfusion during the episode of SCC.

Conclusion: The Sickle Cell Crisis Prevention and Management Teaching Programme was effective for enhancing the knowledge and in bringing positive changes in the characteristics
of episodes of SCC in tribal individuals with SCD. It was evident that with some simple and inexpensive measures the episodes of SCC can be prevented and managed at home.

**Key words:** Sickle Cell Disease, Sickle Cell Crisis, Sickle Cell Crisis Prevention and Management Teaching Programme, Tribal individuals with SCD.