Clinical assessment of quality of life of the patients with chronic blood transfusion and chelation therapy

Abstract

Background: The patient with hemoglobinopathy like thalassemia major (TM), bone marrow dysfunction, and sickle cell disease are requiring chronic blood transfusion for their life time to survive. Among these, TM is one of the most common hemoglobinopathy worldwide. **Objective:** This study is done to assess the quality of life (QOL) of the patients with chronic blood transfusion and chelation therapy. **Materials and Methods:** The QOL scores were obtained through the self-administered SF-36 questionnaire. The study subjects were asked to answer the SF-36 questionnaire once every 3 months. **Results:** After 6 months, the SF 36 general health mean score was 63.58 ± 12.98 (P < 0.05). The highest mean score was 69.37 ± 11.61 . The mean difference after the final reviews was statistically significant. **Conclusion:** The preponderance of scores used to assess QOL suggests that there is a direct and independent effect on QOL when treated with transfusion and iron-chelation therapy.

Key words: Blood transfusion, chelation therapy, quality of life

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INTRODUCTION

The patient with hemoglobinopathy like Thalassemia major (TM), Bone marrow dysfunction, and Sickle cell disease are requiring chronic blood transfusion in their life time to survive. Among these, TM is one of the most common hemoglopinopathy in world wide. The purpose of the blood transfusion is to restore the blood hemoglobin (Hb) level and to eliminate the complication of TM. State that patient are transfused at an early age may develop complications of iron overload in tissues, blood transfused infections, heart failure, diabetes mellitus, liver fibrosis, delayed puberty and growth retardation.^[1,2] Iron chelators like desferrioxamine and defriprone are used to eliminate the toxic iron load and reduce the complications of iron overload in tissues since introduction of iron chelators, the mortality and morbidity rate associated with thalassemia have been significantly reduced.^[3] The quality of life (QOL) is one of the important indexes of effective treatment. QOL is a focused study on the individual's views on their well-being and aspect of life. A model of QOL is proposed that integrates objective and subjective indicators, a broad range of life domains, and individual values. It takes account of concerns that externally derived norms should not be applied without reference to individual differences. It also allows for objective comparisons to be made between the situations of particular groups and what is normative. Considerable agreement exists that QOL is multidimensional. Coverage may be categorized within five dimensions: Physical well-being, material well-being, social well-being, emotional well-being, and development and activity.^[4]

The SF-36 questionnaire yields an eight-scale profile of functional health and well-being scores as well as psychometrically-based physical and mental health summary measures and a preference-based health utility index. Accordingly, the SF-36 has proven useful in surveys of general and specific populations, comparing the relative burden of diseases, and in differentiating the health benefits produced by a wide range of different treatments.^[5-8]

Objective

QOL is a focused study on the individual's views on their wellbeing and aspect of life. This study is done to assess the QOL of the patients with chronic blood transfusion and chelation therapy.

MATERIALS AND METHODS

This prospective study was performed on transfusion dependent patient with hemoglobinopathy in the Department of Transfusion Medicine at Government General Hospital, Guntur, Andhra Pradesh India. The study was approved by Institutional Review Board. The inclusion criteria were both genders with the age more than 5 years, a diagnosis of hemoglobinopathy having more than 20 blood transfusions so far. Patient with bone marrow transplantation and the history of chronic disease like chronic obstructive pulmonary disease (COPD) and acquired immunodeficiency syndrome (AIDS) were excluded from the study. In total 147 patients were interviewed, 142 qualified, and 137 completed the study. The QOL scores were obtained through the self-administered questionnaire. These patients were assessed once in every 3 months with SF-36 questionnaire. Patient who were unable to answer the questionnaire were assisted by their parents or guardians. The subject's medical record was reviewed to assess the morbidity associated with chronic blood transfusion. Hb threshold of 6.0-7.0 g/dl was the baseline.

Outcome measures

The SF-36 questionnaire is a self-administered health status measure that is widely accepted and validated.^[9] It consists of 36 questions in eight dimensions such as physical function, physical health, role emotional, energy/fatigue, emotional well-being, social functioning, pain, and general health. All questions are scored on a scale from 0 to 100, with 100 representing the highest level of functioning possible. The mean scores of SF 36 for each patient at 0 month are underlined as a baseline score. This baseline score is used to evaluate the difference in mean scores after every 3 months for a period of 6 months.

Statistical analysis

Documented data was analyzed by using analysis of variance (ANOVA). Statistical significance was taken at 95% level (P < 0.05). Results were expressed as mean \pm standard deviation (SD).

RESULTS

Primary variables

Out of 137 patients, most of them belong to the age group between 10 and 15 years (42.3%). Male (67.1%) patients were greater than the female (32.9%) patients. Most of the patients have the family history of hemoglobinopathy (66.4%) [Table 1].

Physical function

The mean baseline score of SF-36 physical function was $62.87.87 \pm 23.58$. The mean score difference was not statistical significant after 3 months (63.14 ± 21.02). However, at final review mean score (73.72 ± 21.98) showed statistical significant from the base line mean score (P < 0.05).

Role physical health

The mean baseline score of SF-36 role physical health was 43.75 ± 11.57 . The mean score difference was statistical significant after

Table 1: Demographic characteristics of the studysample ($n = 137$)		
Characteristic	No	%
Age (years)		
5-10	42	30.6
10-15	58	42.3
More than 15	37	27.1
Sex		
Male	98	67.1
Female	39	32.9
Family history of hemoglobinopathy		
Yes	91	66.4
No	40	29.1
Do not know	06	04.5

3 months (50.00 ± 18.89) (P < 0.05). The final review mean score 56.87 ± 12.32 showed statistical significant from the baseline mean score (P < 0.05).

Role emotional

The mean baseline score of SF-36 role emotional was 58.50 \pm 21.57. The mean score difference was statistical significant at every review. The final review mean score 65.96 \pm 21.96 showed statistical significant from the baseline mean score (P < 0.05).

Energy/fatigue

The final review mean score of SF-36 energy/fatigue was 43.75 \pm 11.57. The mean score was statistically significant form baseline mean score of 72.32 \pm 19.94 (P < 0.05). The first review mean score (59.32 \pm 17.69) which did not show statistical significant from the baseline mean score.

Emotional well-being

After 6 months, SF-36 emotional well-being mean score was 63.83 \pm 21.52 (P < 0.05). The final review mean score 71.69 \pm 22.46 (P < 0.05) was showed statistical significant from the baseline mean score of 56.22 < 17.39.

Social functioning

The highest mean score of SF-36 social functioning was 75.69 \pm 21.32 (P < 0.05) which was obtained after 9 months. The mean base line score was 62.22 \pm 32.25.

Pain

The mean score 54.81 \pm 21.25 at final review was not statistically significant with baseline mean score of 52.64 \pm 24.43.

General health

After 6 months the SF-36 general health mean score was 63.58 \pm 12.98 (P < 0.05). The highest mean score was 69.37 \pm 11.61. The mean difference after the final reviews was statistically significant.

	Table 2: Comorbidity assessment			
No of patients	Percentage			
41	29.9			
12	08.7			
3	02.1			
11	08.4			
7	05.1			
2	01.4			
5	03.6			
48	35.0			
8	05.8			
	41 12 3 11 7 2 5 48			

Comorbidity assessment

Out of 137 patients, 35% had headache which is high among other comorbidities. 29.9% had hepatitis; injection site infection/ allergy was 8.7%. Cardiomyopathy, jaundice, lymphadenopathy, hypothyroidism, and vertigo also reported. Refer [Table 2].

DISCUSSION

In developing countries TM has become a major health problem.^[10] TM is usually recognized in childhood, at which time patient begin treatment with blood transfusion to maintain Hb level and chelation therapy to overcome iron overload in tissues later. This study results support the other studies on the QOL of TM patent with other chronic disease like hepatitis, hypothyroidism, ulcerative colitis, cystic fibrosis, congenital heart disease, epilepsy, and diabetes.^[11] Very good scores were obtained for the physical, emotional, role, and social function domains. In the current study, we found that patients rated their overall health significantly better with transfusion and ironchelation therapy. The differences were mainly found in perceived physical health that they considered themselves less dependent on other and medical aids, having good energy and less fatigue in their daily activity. The regimen of iron chelation probably has significant influence on the QOL of conventionally treated patients. The current study has demonstrated that patient on chronic blood transfusion with chelation therapy had significantly better self-rated QOL in physical mental and social domains.

CONCLUSION

The measurement of health-related QOL is fraught with methodological difficulties, and comparison across is often impossible. But the preponderance of scores used to assess QOL suggests that there is a direct and independent effect on QOL when treated with transfusion and iron-chelation therapy. We often do not have the capacity to cure disease, but we can focus on improving symptom complexes, such as fatigue, lack of energy, and functional capacity.

Limitations

Hb threshold of 6.0-7.0 g/dL was the baseline. This recommendation, however, may not take into account the range of potentially normal Hb concentrations. For example, it assumes that a man with a baseline Hb concentration of 18 g/dL and a woman with a baseline Hb concentration of 12 g/dL will have a similar tolerance to an acute decrease in Hb to 7.0 g/dL.

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