

Quality of Life of Thalassaemia Patients Attending a Public Sector Thalassaemia Day Care Center

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ABSTRACT

Introduction: WHO defines health as a state of complete physical, mental, and social well-being. Patients suffering from β -Thalassaemia suffer from a lot of complaints which may be directly or indirectly related to their chronic illness. This also affects their compliance with their medication and their overall feeling of well being. Our study aims to examine factors associated with quality of life among thalassaemia patients.

Methods: This study was a cross-sectional analytical study with convenience sampling studying 101 patients 2 years and above with regular follow-up attending the thalassaemia day care center at Sir Ganga Ram Hospital, Lahore from 1st October 2011 to 31st December 2011. Data was collected using a structured questionnaire after getting verbal informed consent from the patient by a trained interviewer; patients less than 10 years of age were assisted by their parents.

Results: About 49% of the patients strongly agreed that they were depressed due to their illness and 5% had suicidal ideation and had planned to end their life. Forty two percent patients (> 10 years) had limited activities because of their illness and 26.7% needed the help of other persons with personal care needs and 34.7% patients (> 10 years) required help of others for handling their routine daily activities. About 67% had arthritis, 64.4% had back/neck problem, 52.5% had lung/breathing problem, 25.7% had depression/anxiety/emotional problems, 20.8% had heart problem, 19.8% had fractures/ bone/joint problem, and 17.8% had eye/vision problems.

Conclusion: Quality of life issues must be dealt with in order to improve the health and promote multidisciplinary approach in the care of thalassaemia patients.

INTRODUCTION

Thalassaemia is a chronic disease which requires lifelong treatment.¹ This treatment includes regular blood transfusions as well as iron chelation therapy which at times may be tedious because of its subcutaneous route of administration.² These patients are susceptible to bone pains due to osteopenia, abdominal pain due to hepatosplenomegaly, short stature due to hemosiderosis in the endocrine glands.^{3, 4} All this when put together may significantly affect the quality of life of a thalassaemia patient.

Thalassaemia patients whose disease is well managed usually do not present with the above mentioned complications of the disease primarily due to adequate blood transfusions and adequate chelation therapy.⁵ Proper management prevents the complications of iron overload such as

cardiomyopathy, endocrine abnormalities, short stature, pulmonary hypertension, and phagocytic defects.

The World Health Organization defines health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.⁶ Knowledge of the factors associated with health-related quality of life among patients with thalassaemia is essential in developing more suitable clinical, counseling, and social support programs to improve treatment outcomes of these patients. In light of the limited research in this area, this study aimed to examine factors associated with quality of life among thalassaemia patients.

METHODS

The objective of the study was to assess the quality of life in thalassaemia patients in a public

sector hospital. This was a cross-sectional analytical study and non-probability convenient sampling technique was employed for subject selection. A total of 101 patients 2 years and above with regular follow-up attending the thalassaemia day care center at Sir Ganga Ram Hospital, Lahore from 1st October 2011 to 31st December 2011 were enrolled in the study. Those patients who were suffering from any acute illness or who were hospitalized were excluded from the study. Data was collected using a structured questionnaire after getting verbal informed consent from the patient or patient's parent by a trained interviewer; patients less than 10 years of age were assisted by their parents. Information was sought regarding demography, iron chelation, ferritin levels, blood transfusion, and major impairments, physical and mental health of thalassaemia patients. SPSS version 15.0 was used for data entry and analysis. Initial analysis included computing frequency distribution for categorical variables, and mean and standard deviation for continuous variables. Chi-square test or Fisher's exact test, as appropriate, was used to test for statistical significance between categorical variables. A p-value less than 5% was considered as significant.

RESULTS

A total of 101 thalassaemia patients from the thalassaemia centre of Sir Ganga Ram hospital, Lahore participated in this study; 55% males and 45% females. About 34% were aged between 15 to 19 years and the mean age was about 16 years. Most of the cases (54%) belonged to a lower socioeconomic class based on their family income. Above half of the cases (56%) were living in the rural areas. About 41% of the patients were illiterate (had no formal schooling), whereas, fathers of 30% patients, and mothers of 53% cases were illiterate.

The average age of the patients at the time of diagnosis of thalassaemia was 6 months, 43.1% were diagnosed when they were more than 10 months. A majority of patients (75.2%) had beta-thalassaemia major. Serum Ferritin levels of 39% patients were maintained between 2500 – 5000ng/ml, whereas 29% patients had levels above 5000ng/ml. About 31% patients had pre-transfusion hemoglobin (Hb) level less than 7 g/dl, followed by 41% between 7-9g/dl, and 29% had above 9 g/dl.

Eighteen percent patients required blood transfusions once a month, a large number of the patients (45%) required twice a month, 25% thrice a month, and 11% four or more times per month. Majority cases (96%) had received a blood transfusion during the previous three months and 66% of the patients were receiving some form of iron chelation therapy. A greater proportion of patients (78.2%) were receiving a regular medication (folic acid, calcium supplements); 63% of the patients were not compliant with desferrioxamine, and 62% had to be hospitalized due to a blood transfusion reaction.

About 49% of the patients strongly agreed that they were depressed due to their illness and 45.5% considered as having a life threatening illness. Five percent of the patients reported having had suicidal ideation and had planned to end their life. Forty two percent patients (>10 years) had limited activities because of their illness, and 26.7% needed the help of other persons with personal care needs (eating, dressing, or getting around the house). Whereas, 34.7% patients (> 10 years) needed the help of other people in handling their routine needs (everyday household chores, doing necessary business, shopping, or getting around for other purposes) (Table 1).

Table 2 shows other health related problems and issues among thalassaemia patients. About 67% patients had arthritis, 64.4% had back or neck problem, 52.5% had lung/ breathing problem, 25.7% had depression/ anxiety/ emotional problem, 20.8% had heart problem, 19.8% had fractures, bone/joint problem, 17.8% had eye/vision problem, and 28.7% had other impairment problems that had limited their activities (Table 2).

Fifty eight percent of the patients had poor physical health for more than 15 days (average 22.18 days). About 20% of patients were affected by mental health problems (including stress, depression and emotional problems) up to 15 days (average 14.4 days). In 38% of the patients, their illness kept them from doing their usual activities such as selfcare, work, or recreation up to 15 days (average 19.11 days), and 56% of the patients had limited activities because of major impairment up to 15 days (average 28.30 days). Thirty nine percent of patients had felt sad, blue, and depressed up to 15 days (average 11.54 days), 38% patients remained worried, tensed, or anxious up to 15 days (average 11.74 days). Thirty three percent thalassaemia patients had incomplete rest

Table 1: Depression and Impairment in Thalassaemia Patients (> 10 years). (N=101)

Attribute	Frequency	Percentage
Depressed because of your illness		
Strongly disagree	30	29.7
Disagree	11	10.9
Neutral	1	1.0
Agree	10	9.9
Strongly agree	49	48.5
Ever considered ending life		
Yes	5	5.0
No	96	95.0
Planned ending life		
Yes	5	5.0
No	96	95.0
Consider thalassaemia a life threatening illness		
Strongly disagree	28	27.7
Disagree	12	11.9
Neutral	2	2.0
Agree	13	12.9
Strongly agree	46	45.5
Thalassaemia has limited my activities		
Yes	42	41.6
No	55	54.5
Don't Know	4	4.0
Need help for personal care needs		
Yes	27	26.7
No	70	69.3
Don't Know	4	4.0
Need help for routine needs		
Yes	35	34.7
No	61	60.4
Don't Know	5	5.0

or sleep up to 15 days during last month (average 3.77 days), and 29% of the patients were affected by pain for 15 days (average 8.25 days). Twenty five percent of patients reported that they felt very healthy and full of energy for more than 15 days (average 16.07 days).

The results of Chi square test showed no significant association of father's or mother's education with quality of life of thalassaemia patients. A statistically significant difference between male and female thalassaemia patients were observed regarding duration of limited activities because of major impairments (arthritis, back or neck problem depression, fractures, bone/joint injury), duration of pain making hard to do usual activities (self-care, work, or recreation), duration of felt sad, blue, or depressed, duration of feeling worried, tensed, or anxious, and duration of incomplete rest or sleep (p-value<0.05).

Table 2: Complications or Health Related Issues among Thalassaemia Patients.(N=101)

Complication	Frequency	Percentage
Arthritis	68	67.3
Back or Neck Pain	65	64.4
Fractures, Bone/Joint Injury	20	19.8
Lung / Breathing Problems	53	52.5
Eye / Vision Problems	18	17.8
Heart Problems	21	20.8
Diabetes	4	4.0
Depression, Anxiety/Emotional Problems	26	25.7
Other Impairment Problems	29	28.7

DISCUSSION

In Pakistan there are about 90,000 to 100,000 Beta-thalassaemia major patients with an average life expectancy of 10 years.⁷ This leads to a significant burden on the health care system in Pakistan.

In the present study, about 75% of the patients were diagnosed with b-thalassaemia major and 78% of the patients were on regular treatment. Sixty five percent were receiving iron chelation therapy of which 62% of the patients had sub-optimum and

38% of the patients had optimum compliance with desferrioxamine. This is very similar to the data regarding iron chelation in the Asian population.⁸ Inadequate iron chelation and poor compliance was seen in this study which is quite representative of our Pakistani population.

Only 28.7% of patients in this study population maintained their pre-transfusion Hb \geq 9g/dl. This study found that low pre-transfusion Hb levels and receiving a blood transfusion during the three months prior to QOL assessment were significant predictors of QOL among thalassaemia patients. This could be explained by the fact that lower Hb level is associated with a number of symptoms, such as fatigue, general weakness, and decreased mental alertness, which might lead to impaired QOL of the patients in several domains.

Arthritis, back pain, fractures, breathing problems, heart problems and an additional chronic illness such as diabetes all added to serious impairment in the quality of life. About 20% of our patients were affected by mental health problems within the last month including stress, depression and emotional problems with the mean of (14 \pm 12.5 days). Other studies done in Turkey and Iran showed that patients with thalassaemia have significant mental health problems due to their disease.^{9, 10} This coincides with the mean score for a physical functioning impairment of 22.2 \pm 10.3 days in our study sample, while in most of the previous studies lower mean score were seen for physical health.¹¹ This can be explained by the poor compliance to iron chelation due to cost and route of administration of desferrioxamine.

In the present study, 38% of the patients agreed that their illness kept them away from doing their usual activities such as self care, work, or recreation. The mean score for these limited activities was (19 \pm 10.3 days). In the study by Khani, 52% of patients agreed that they did not have excellent physical health due to their illness.¹²

Thirty nine percent of patients had felt sad, blue and depressed, 38% worried, tense or anxious up to 15 days with the mean scores (11.5 \pm 9.8, 11.7 \pm 9.7) . Incomplete rest or sleep up to 15days during the last month was seen in 33% of our study population (8.3 \pm 3.3 days). The study by Ahmad showed that 50% of their patients suffered from sleep disorders.¹³

The present study revealed that about 38% of the patients were affected by pain for up to 15 days/per month with the mean scores (13 \pm 9.7

days). This is quite low as compared to the findings from the study by Ahmad which reported pain in 73% of the patients¹³. This difference could be due to adverse effects of poorly managed thalassaemia patients in that study. Forty nine percent of children were most likely to report impaired quality of life due to several difficulties in pain/discomfort by Shaligram D.¹⁴ Female gender had a significant effect on pain, psychological disturbances, and anxiety in our study.

It is highly recommended to involve health care professionals in providing health education and counseling programs regarding thalassaemia. Furthermore, policy makers and stakeholders should provide social support networks and monetary support schemes for family members that in turn comprehensively improve the management of the disease and the quality of life (QOL) in thalassaemia patients. A well planned health education campaign should be initiated to improve the management and health care seeking behavior of both thalassaemia patients and parents regarding their quality of life.

CONCLUSION

Quality of life issues must be dealt with in order to improve the health and promote multidisciplinary approach in the care of thalassaemia patients.

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