



PSYCHOSOCIAL PROBLEMS OF THALASSEMICS IN A TERTIARY CARE CENTRE, INDORE

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ABSTRACT

Introduction: Chronicity of thalassemia is a powerful source of emotional problems. During adolescence and young adulthood various complications may occur and patient under goes a period of psychological readjustment.

Material and Methods: This was a cross sectional, interview based study of 30 adolescents and young adult thalassemic patients at Choithram Hospital and Research centre, Indore, MP, India. General Wellbeing Scale, Helplessness Scale and Psychological Wellbeing Scale were used to assess the psychosocial problem of thalassemic patients.

Results: Thalassemia disease deteriorated the school performance of 56.66%. Seventeen percent thalasseemics had low general wellbeing. Majority (70%) of diseased persons need to change their goals of life (ambitions) because of disease. Helplessness was felt by 37% and moderate psychological well being among 66.7%. No gender difference was noticed ($P>0.05$).

Conclusion: Majority of thalasseemics felt helpless and their general wellbeing and psychological wellbeing was average.

Key words: Thalassemia, general wellbeing, psychological wellbeing, helplessness

INTRODUCTION

Thalassemia is an inherited impairment of haemoglobin production. Failure to synthesize beta chains(beta-thalassemia) is the most common type of thalassemia, most prevalent in the Mediterranean area.¹ In different regions the incidence varies between 3-17%.² There are about 45 million carriers of the beta thalassemia gene in India.² While 15000 affected infants are borne every year, contributing to about 10% of the total thalasseemics born all over world.² Difficulties resulting from lifelong transfusion and chelation therapy, can have a critical effect on the survival and quality of life of patients.³ Chronicity is a powerful source of emotional problems. The decrease in haemoglobin during the transfusion interval may allow the symptoms of fears of being contaminated and anxiety about death. Dependence at the physical level can invade the mental status, limiting personal development.

During adolescence or young adulthood various complications may occur and patient undergoes a period of psychological readjustment.³ There are four categories of problem- physical exhaustion, mental and spiritual restlessness, society's behaviours and beliefs and surviving a hard life.⁴ As thalassemia a chronic disease but very less is known about their psychosocial problems. This study was planned to assess the general wellbeing, helplessness and psychological wellbeing of thalassemic adolescent

MATERIAL AND METHODS

This was the study of adolescent and adult thalassemic patients of day care Centre for for Thalasseemics, CHRC, Indore. This was a cross sectional, interview based study. The sample size was 30. It was convenient minimum sample. Total 46 persons

registered in the hospital. Only 30 were in the required age group. Those who were 10 (adolescent age 10- 19) and young adults were included in the study. Four proformas were used for each sample member.

Proforma I was for general information, whereas Proforma II was General Well Being Scale (GWBS).⁵Proforma III was helplessness Scale (HS), and⁶Proforma IV was psychological Well Being Scale (PWBS).⁷

General wellbeing scale consists of four categories. Amongst these, Physical wellbeing had 11 items , whereas Emotional wellbeing had 14 items. Social wellbeing and School wellbeing contained 17 and 13 items respectively.

The total items in GWBS are 55. The interpretation of GWBS was High general wellbeing, Average general wellbeing and low general well being.

The Helplessness scale consists of total 22 items.Susceptibility-3, coping difficulties-3, inadequacy-2, failure to uncontrollable factors-3, Anxious, over concern and fruitless tendency to worry-2, syndrome of cognitive, motivational disturbances-3, problem avoidance and low cognition-3, lack of self evaluation and selfesteem-3.

The interpretation of levels of helplessness were Extremely High Helplessness

(89 and above), High helplessness(82-89), Above average helplessness(76-82), Average/moderate helplessness(66-76), Below average helplessness(60-66), Low helplessness(53-60) and Extremely low helplessness(53 and below).

Psychological wellbeing scale had total 50 items. The distribution is as- satisfaction-10, efficiency-10, sociability-10, mental health-10, interpersonal rela-

tions-10. The interpretation of levels of psychological wellbeing were- very low(score 50-58), low (score 58-83), moderate(score 83-217), high (score 217-242) and very high(score 242-250). The data tabulated manually and analysed by Graphpad software online calculator.⁸ Fisher exact test has been applied.

RESULTS

Most of the subjects (40%) were in the age group 16-19 years, followed by 24-27 years i.e. 23%. Sixty six percent subjects belonged to a nuclear family. Out of 30, 20 were males (66.7%) and 10 females (33.3%). Forty percent were graduate and 33.3% were secondary educated. Most of the subjects (70%) had 1-2 siblings. Only 2 (6.7%) reported to have a another thalassemic child in the family.

Table 1 Age of detection of Thalassemia with school performance and change of goal

| Status of performance | Deterioted school performance | Changed goal of life |
|------------------------|-------------------------------|----------------------|
| < 3 yrs (n=9) (30%) | 5 (16.66) | 5 (16.66) |
| 3-6 yrs (n=2) (6.7%) | 2 (6.66) | 2 (6.66) |
| 7-10 yrs (n=6) (20%) | 5 (16.66) | 6 (20) |
| 11-14 yrs (n=2) (6.7%) | 1 (3.33) | 2 (6.66) |
| ≥15 yrs (n=11) (36.7%) | 4 (13.33) | 6 (20) |
| Total | 17 (56.66) | 21 (70) |

Table 2: General Well Being of Thalassemics

| General well-being scale ⁵ | Male (%) | Female (%) | Total (%) | P value |
|---------------------------------------|-----------|------------|-----------|---------|
| High (231-275) | 3 (10) | 2 (6.66) | 5 (16.66) | 1 |
| Avg (168-230) | 13(43.33) | 7 (23.33) | 20(66.66) | 1 |
| Low (<167) | 4 (13.33) | 1 (3.33) | 5 (16.66) | 0.64 |
| Total | 20(66.66) | 10 (33.33) | 30 (100) | |

Table 3: Helplessness among Thalssemics as per their sex

| Helplessness ⁶ | Male | Female | Total | P value |
|---------------------------|------------|-----------|-----------|---------|
| Extremely high(89 and <) | - | - | - | - |
| High(82-89) | - | - | - | - |
| Above average(76-82) | 3 (10) | 1 (3.33) | 4 (13.33) | 1 |
| Average(66-76) | 6 (20) | 5(16.66) | 11(36.66) | 0.42 |
| Below average(60-66) | 8(26.66) | 1(3.33) | 9(30) | 0.20 |
| Low(53-60) | 2 (6.66) | 3(10) | 5(16.66) | 0.3 |
| Extremely low(53 and <) | 1(3.33) | - | 1(3.33) | 1 |
| Total | 20 (66.66) | 10(33.33) | 30(100) | |

Table 4: Psychological wellbeing of Thalassemics

| PWBS ⁷ | Male (%) | Female (%) | Total (5) | P value |
|--------------------|------------|------------|------------|---------|
| Very low(50-58) | 1 (3.33) | - | 1 (3.33) | 1 |
| Low(58-83) | 1 (3.33) | 1 (3.33) | 2 (6.66) | 1 |
| Moderate(83-217) | 14 (46.66) | 6 (20) | 20 (66.66) | 0.69 |
| High(217-242) | 2 (6.66) | 3 (10) | 5 (16.66) | 0.3 |
| Very High(242-250) | 2 (6.66) | - | 2 (6.66) | 0.5402 |
| Total | 20 (66.66) | 10(33.33) | 30 (100) | |

Subjects who were suffering from thalassemia for more than fifteen years were 36.7%. Thirty percent were suffering only for three years or came to know only three years before. Thalassemia disease deteriorated the school performance of 56.66% subjects, more for detection age group < 3 years and 7-10 years. Majority (70%) of diseased persons need to change their goals of life (ambitions) because of disease. Mostly of the detection age group 15 years and 7-10 years.

Most of the thalasseemics were of average general wellbeing (6.66%). Seventeen percent had low general wellbeing.

No one reported extreme or high helplessness due to Thalassemia. Thirty seven percent reported average helplessness and 30% reported below average helplessness.

Around 10% (3.33+6.66%) were having very low and low psychological wellbeing. Majority 66.7% were moderately psychological well.

DISCUSSION

In this study 56.66% subject's school performance showed deterioration. Similarly, conduct problems, poor school performance and feeling of discouragement among teenagers were found in few studies.^{9,10,11} Seventy percent thalasseemics in this study changed their goal of life because of sufferings. It has been observed by J. Tsiantis that thalasseemics can not plan their future because of the disease burden.¹⁰ Whether it was school performance or setting goals, both were found to be similar in these studies as the disease burden was similar where ever they were.

Sixty seven percent of Thalasseemic adolescents and new adults were having average general wellbeing and 17% had lower general wellbeing. This finding was the repetition after the studies of D. Shaligram, Mohammadi, Fatemeh Behdani and Sarah H. Siddiqui, who found quality of life to be poor among thalassemia patients.^{9,12,13,14} Thalasseemics are always busy and stuck up with receiving blood transfusions every fortnight or so. They can not think about other aspects and engagements of their life.

In this study majority had moderate psychological wellbeing and 10% low psychological wellbeing. Self image was found to be low in two studies.^{15,16} Adolescents are already in a state of turmoil but the disease burden worsened their condition.

It was mentioned in many studies that thalasseemics have psychological and psychosocial problems.^{9,11,13,16,17,18} There was insignificant difference between genders, regarding psychological wellbe-

ing, in this study. Similarly, no gender difference was observed by Giussepina et al.¹⁵ Thus the psychosocial problems encountered by the thalasseemics were uniform without gender difference.

CONCLUSION

Majority of thalasseemics felt helpless and their general wellbeing and psychological wellbeing was average. Adolescents are sensitive and emotional. They are thus vulnerable to have psychological and psychosocial problems. Irrespective of gender difference they suffer from similar psychosocial and psychological problems such as poor school performance, poor setting up of goals, compromised quality of life and low self esteem.

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