A Strategy to Assess Morbidity Pattern, Mental Health of Patients with Thalassemia: Physiological and Mental Health Conditions

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Abstract Thalassemia is an autosomal recessive disease. According to the WHO data, there are 269 million carriers of thalassemia worldwide, out of which 40 million are in South East Asia. This study was conducted with the primary objective to assess physiological and mental health condition of patients with thalassemia at a tertiary care hospital. It has been noticed by the study that there are frequent chances of diseases among thalassemia patients as the assessment found 20% of study patients jaundice manifested at least one time on their lifetime, 19% cardio-vascular disease, 18% hepatic diseases, 15% fever, 12% respiratory problems, 10% kidney disease and 6% diarrhoea. According to age category our study found that 18 to 25 years age category had 15.4% chances of having diseases, 26 to 30 years age category had 14.3% chances, 31 to 35 and 36 to 40 years age category had 24.6% and 42% chances of having diseases. It clearly indicates that increase in age increases the chances of disease occurrence. In our study, 57.5% patients with thalassemia manifested depression comprising 19.5% chronic depression, 20.3% minimal depressed, 8.5% mild and 9.1% moderately depressed. This study found that patients with thalassemia face mental health problems which requires planning of authorities and experience consultants to educate the life skill and to survive in a healthful manner.

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1. Introduction

Thalassemia is emerging as a global public health concern. An estimated 320,000 babies are born each year with a clinically significant hemoglobin disorder [1]. Nearly 80% of these births occur in developing countries. Most conservative estimates suggest that at least 5.2% of the world population (over 360 million) carry a significant hemoglobin variant [1] and in excess of 100 million beta thalassemia carriers with a global frequency of 1.5% [2].

Thalassemia is a common problem in Bangladesh. According to World Health Organization (WHO) about 4.8 million people in Bangladesh are now carrying the gene of this silent killer disease, which is four per cent of the total population of the country. It is estimated that approximately 6000 babies with different types of thalassemia are born in Bangladesh each year. [3] Bangladesh is one of the most densely populated countries in the world, with a population of over 160 million people. Over 70% of the population live in highly

resource-constrained rural areas [4], while most tertiary hospitals are located in big cities, notably in Dhaka, the capital city. Public hospitals are often overcrowded and lack resources (such as specialized and basic medical equipment, healthcare professionals and essential drugs) [5]. On the contrary, some private clinics and hospitals are relatively resourceful but these are not accessible to the general population due to the associated costs. The treatment drop-out rate among a population plagued by poverty is expected to be very high, and is presumably driven by lack of access, either due to lack of awareness or income of patients seeking care on the demand side, or inadequate expertise, facilities, knowledge, and infrastructure from the supply side of health care.

Despite the fact that Bangladesh lies in the world's thalassemia belt, the information on different aspects (epidemiology, clinical course, mortality, complications and treatment outcomes) of thalassemia's is lacking.

Malnutrition affects the growth, efficacy of treatments and quality of life in patients suffering from thalassemia. Nutritional deficiencies are common in thalassemia, due to haemolytic anaemia, increased nutritional requirements,

and morbidities. Thalassemia is a chronic disease that presents a range of serious clinical and psychological challenges. The effects of thalassemia on physical health can lead to physical deformity, growth retardation, and delayed puberty [6]. Its impact on physical appearance e.g., bone deformities and short stature, also contributes to a poor self-image [7].

The aim of the study is to assess physiological and mental health condition of patients with thalassemia at a tertiary care hospital. Thalassaemia is the most common congenital disorder in Bangladesh. It is estimated that nearly 14,000 thalassaemia children are born every year in Bangladesh. Treatment facilities are limited due to the high cost of medicine and limited availability of blood for transfusion. Furthermore, medicines are not available readily other than in specialised thalassaemia centres in Dhaka and Chittagong. As treatment is expensive and lifelong, majority of the patients hardly afford proper treatment and thus suffer from the complications of the disease. Therefore prevention is the fundamental way of uprooting thalassemia disease through knowledge dissemination. But where the disease already exists there is no option to prevent but curing becomes essential to make the life sustainable. So, to get acquainted with the usual dietary intake pattern, nutritional status and the usual morbidity pattern both physiological and psychological is a way through which a thalassemia patient go may be good factor to make the life more comfortable and sustainable for a thalassemia a patient.

2. Methodology

Methodology simply refers to a way of doing research or should the way to proceed. It is a structure of approaches and methods which are employed by researchers.

Type of study: The study was a descriptive cross-sectional study.

Data sources: The study was mainly based on primary data, however prior to collect primary data, relevant document were reviewed and collected.

Study population: The study was conducted among 120 thalassemia patients (not less than 18 years) in the selected hospitals in Dhaka city.

Places of study: The study was conducted in Bangladesh Thalassemia Samity Hospital and Thalassemia hospital and institute by frequent visiting.

Time period: December 25, 2018 to June 30, 2019.

Sampling method: Random sampling

Sample size determination:

Sample size has been calculated using following formula:-

$$n = z^2 pq / d^2$$

Where Z= 1.75 at 92% confidence interval
P= 50%=0.5
q= 1-P=0.5
d=Acceptable error=8% =0.08

$$n = z^2 pq / d^2 = (1.75)^2 * (.5) * (0.5) / (0.8) * (0.08) = 119.$$

For the study a sample of 120 patients will be randomly selected to collect information on the proposed study.

A pre-coded, clarified and pre-tested questionnaire is formulated to collect information from the patients.

Sampling selection criteria:

Inclusion criteria -
- The respondents must be thalassemia patient age with age not less than 18 years.
- The respondents must be among admitted patients in the hospitals.
- Apparently willing to participate.

The respondent satisfying the above condition were randomly selected to form a sample size of 120. A pre-coded, clarified and pre-tested questionnaire was formulated to collect information from the selected respondent.

Exclusion criteria -
- Not willing to participate in the study
- Refusal from the family.
- Demand money to participate.

Pronouncement of consent

The purpose and nature of the study were explained to each participant and after getting the verbal consent, they were included in the study.

Data processing: The data set was first checked, scrutinized, cleaned and entered into the computer from the numerical codes on the form. The data was edited to check if there was any discrepancy (double entry, wrong entry). The frequency distribution of the entire variable was checked using SPSS 23 windows program. It gave overall information about the variables.

For purposive data analysis the raw anthropometric data of SPSS 23 windows program for further analysis. The new variables were recommended on the basis of the analysis such age, education, income etc. After summarizing the collected data for each of the suggested indicators to answer the questions on the objectives of the study, the analysis was preceded according to the plan.

Ethical Issue: All participants in the study were asked for their consent before collection of data and venous blood, and all had complete rights to withdraw from the study at any time without any threat or disadvantage. Any participants with high blood pressure or other disorders were referred to appropriate facilities for further investigation and treatment. This study protocol was approved by the Ethical Review Committee of Bangladesh Medical Research Council (BMRC), Dhaka, Bangladesh. Informed written consent was taken from every subject. The questionnaire was designed considering the privacy of the subject. The subject's personal information was kept confidential.

Data analysis: Both qualitative and quantitative aspects of data were analysis followed descriptive to inferential statistics. Different types of variables were taken to see the association by using statistics such as to examine relationships among nutritional status, dietary diversity, food adequacy etc.

3. Result

Table 1 shows the number of thalassemic patients based on certain characteristics such as sex, relative's disease history, religion and income. Among study subjects 54% were male and 46% were female. Relative's history of

disease for positive response was 66.67% and for negative response was 33.3%. 73% were Muslim and 27% were Hindu and their familial income below 5000 taka was 4.2%, within 5000 to10000 was 70.8% and above 10000 was 25%. 70.8% of study patients were married and 29.15 were unmarried.

Table 1. Certain characteristics of the study subjects with thalassemia

Characteristics	N=120	Percentage
Sex		
Male	65	54%
Female	55	46%
Relative's history		
Yes	80	66.67%
No	40	33.33%
Religion		
Muslim	88	73.3%
Hindu	32	27%
Marital status		
Married	85	70.8%
unmarried	35	29.1%
Economic burden (income in taka)		
<5000	5	4.2%
5000-10000	85	70.8%
>10000	30	25%

Figure 1 indicates that 20% of study patients manifested jaundice on their lifetime, 19% cardio-vascular disease, 18% hepatic diseases, 15% fever, 12% respiratory problems, 10% kidney disease and 6% diarrhoea.

Table 2 indicates that 18 to 25 years age category had 15.4% chances of having diseases, 26 to 30 years age category had 14.3% chances, 31 to 35 and 36 to 40 years age category had 24.6% and 42% chances of having diseases. It clearly indicates that increase in age increases the chances of disease occurrence.

Table 3 and Figure 2 show the distribution of diseases among different age category of study patients. It indicates that 18 to 25 years age category manifest 6.7% acute respiratory infections, 16.1% liver diseases, 11.6% cardio-vascular disease, 15.7% kidney disease, 17.6% jaundice and 25% diarrhoea.

26 to 30 year age category manifest 8.4% ARI, 18.3% liver disease, 17.9% cardo-vascular disease, 11.8% kidney disease, 18.6% jaundice and 10.7% diarrhoea.

31 to 35 years age category manifest 9.2% ARI, 16.1% liver disease, 15.8% CVD, 27.5% kidney disease, 47.1% jaundice and 32.1% Diarrhoea.

36 to 40 years age category manifest 53.2% ARI, 49.5% liver disease, 54.7% CVD, 45.7% kidney disease, 16.7% jaundice and 32.1% Diarrhoea.
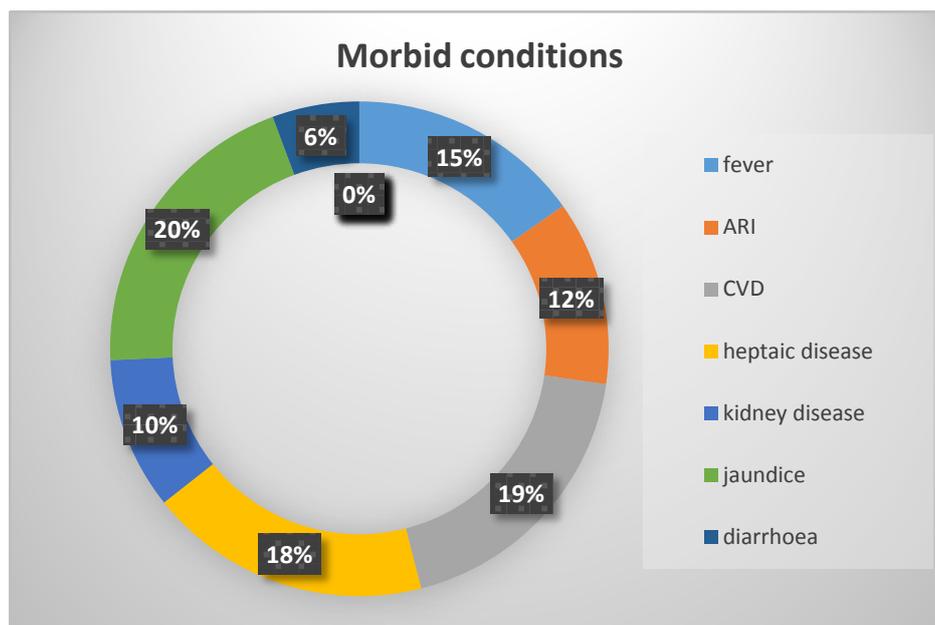
Figure 1. Percentage distribution of different diseases among thalassemia patients

Table 2. Distribution of disease rate according to age category

Age category in years	OR	90% CI for OR		p-value
18-25	0.154	1.03	1.28	<0.1
26-30	0.143	1.02	1.20	<0.1
31-35	0.246	2.1	2.23	<0.1
36-40	0.420	4.2	4.40	<0.1

Table 3. Percentage distribution of diseases based on age category

Age category(years)	ARI	Liver disease	CVD	Kidney disease	Jaundice	Diarrhoea
18-25	6.7%	16.1%	11.6%	15.7%	17.6%	25%
26-30	8.4%	18.3%	17.9%	11.8%	18.6%	10.7%
31-35	9.2%	16.1%	15.8%	27.5%	47.1%	32.1%
36-40	53.2%	49.5%	54.7%	45.7%	16.7%	32.1%
Total	100	100	100	100	100	100
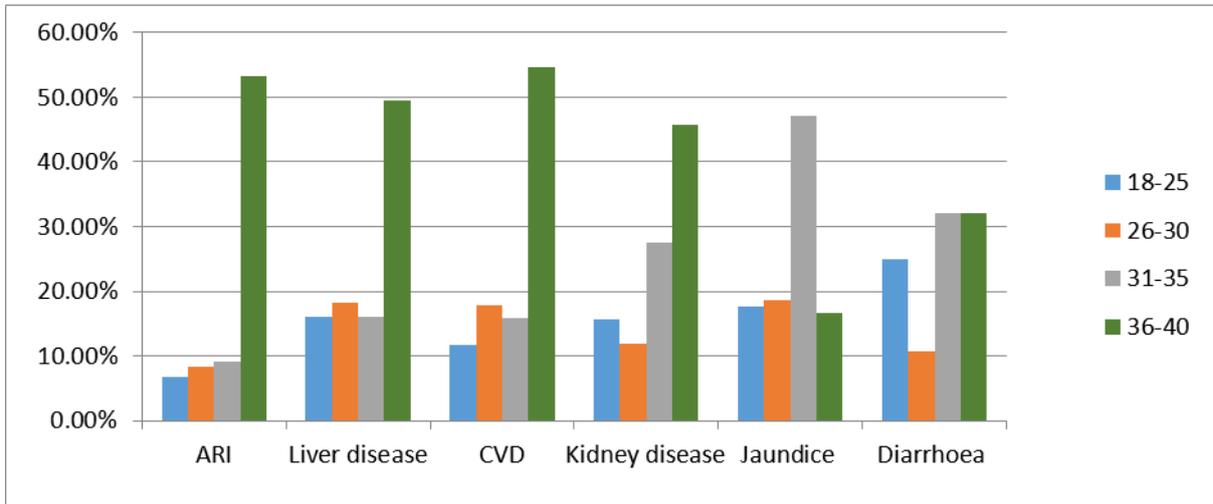
Figure 2. Distribution of diseases among thalassemia patients in different age

Table 4. Distribution of level of depression among study population

Level	Frequency	Percentage
Depressed	25	19.5%
Minimal	26	20.3%
Mild	7	8.5%
Moderate	11	9.1%
Not depressed	51	42.5%
Total	120	100%

Table 4 shows that 69% of study patients were under depression criteria among which 19.5% were depressed, 20.3% were minimally depressed, 8.5% were mildly and 9.1% were moderately depressed. About 42.5% study patients were out depression category.

Table 5. Distribution of core indicators of mental health status in thalassemia patients

Mental health category	Applicable	Often applicable	Not applicable
Thinking failure in life	32.8%	32.8%	27.3%
Inferiority complex	29.7%	41.4%	21.1%
Lack in self confidence	36.7%	37.5%	19.5%
lamentation	48.4%	34.4%	10.9%
Irritability	35.2%	43%	15.6%
Failure in decision making	49.2%	31.3%	11.7%
Lack of attention	45.3%	29.7%	18.8%
Forgetfulness	39.8%	42%	10.9%
Low interest in sexual matter	36.7%	40.6%	16.4%

Table 5 shows that, 49.2% of study patients fail to make decisions on different issues. 43% of study patients get irritated at any time. Again 32.8% of patients thinks that they are failure inn life, 41.4% of patients suffer from inferiority complex, 48.4% of patients suffer from insomnia 43,4% of patients cannot pay attention to important issues. Furthermore, 42% of patients suffer from forgetfulness and 40.6% of patients had no sexual desires.

4. Discussion

Now-a-days, of the common inherited disorder, Thalassemia is becoming the most prevalent disorder among various groups of population in different parts of the world. It has been noticed by the study that there are frequent chances of diseases among thalassemia patients as the assessment found 20% of study patients jaundice manifested at least one time on their lifetime, 19% cardio-vascular disease, 18% hepatic diseases, 15% fever, 12% respiratory problems, 10% kidney disease and 6% diarrhoea. According to age category our study found that 18 to 25 years age category had 15.4% chances of having diseases, 26 to 30 years age category had 14.3% chances, 31 to 35 and 36 to 40 years age category had 24.6% and 42% chances of having diseases. It clearly indicates that increase in age increases the chances of disease occurrence. In our study, 57.5% patients with thalassemia manifested depression comprising 19.5% chronic depression, 20.3% minimal depressed, 8.5% mild and 9.1% moderately depressed. Mental health conditions were analysed based on some core indicators e.g. irritability, failure to decision making, lack of attention to any topics, forgetfulness, lack of self-confidence, lamentation, inferiority complex, thinking failure in life and lack of interests on sexual matters. Among all indicators 49.2% of patients fail to make decision, 48.4% face insomnia, 45.3% of patients are indifferent to any matters, 41.4% patients suffers from inferiority complex and 36.7% patients were reluctant to sexual matters. A study from Iranian people found that the most common psychological health disorder among thalassemia patients were depressive disorder (11.6%) and anxiety disorder, somatic disorder and social dysfunction were in next ranks respectively [8]. In a similar study in India, the most common psychiatric disorder in patients with thalassemia was anxiety disorder (67%) and in the next degrees stood affective disorders, major depressive disorder and conduct disorders [9]. Our study only analysed depressive status by depression rating scale among patients with thalassemia.

In developing countries adults with thalassemia are not treated because of public awareness, unavailability of drugs and experience mood disorders including despair, sadness, depression, fear of death, lack of self-esteem, isolation and anger. This issue will disrupt self-care, mental health status, and interrupt the treatment procedure.

This study found that patients with thalassemia face mental health problems which requires planning of authorities and experience consultants to educate the life skill and to survive in a healthful manner.

5. Conclusion

The study finding indicates higher number of thalassemia patients attend tertiary-care centre for regular blood transfusion and for treatment of other medical complicatons as most of the patients manifest morbid conditions. So it is necessary to take it as a public health problem because thalassemia causes a huge psychological and financial drain on patients and their families. Thalassemia patients and their parents require life-long psychological support for prevention of mental health issues. Proper use of iron chelation are safe and efficacious and should be made available, Spending more time listening to patients in the clinic and perhaps including a psychologist in the multidisciplinary team to understand patients' individual needs might enhance adherence with medication.

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