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SOCIAL STIGMA AND ASSOCIATED DISCRIMINATIONS THALASSEMIA PATIENTS ENDURE: A QUALITATIVE STUDY IN COMBINED MILITARY HOSPITAL, DHAKA

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ABSTRACT

This study aims to focus and find out the social condition of thalassemia patients. More specifically to know about the stigma and social discrimination thalassemia patients face and endure in their life time. Bangladesh has a significant level of thalassemia patients and the quantity is increasing day by day due to the lack of knowledge and awareness among people. Social dogmas, religious superstition, ignorance of premarital screening tests have been increasing the amount of thalassemia patients in upcoming days. Despite its location in the world's thalassemia belt, Bangladesh has little knowledge on the disease. Furthermore, there is a remarkable lack of knowledge of this life-threatening yet potentially treatable condition. However, raising public knowledge is critical to developing an effective prevention approach. But as our local community is not still aware enough of thalassemia and their life style sometime they intentionally or unintentionally do stigmatize the thalassemia patients. This paper seeks to explore the social stigma thalassemia patients' endure. For collecting data interview session took place with structured questionnaire developed on the basis of research objectives and research questions, simple random sampling method has been used to conduct the study, face to face interview of respondents 40 was held among them 23 were male respondents and 10 were female respondents and 7 parent respondents were selected on behalf of kids below age 10.The study findings shows that lack of disease consciousness and governmental initiatives to increase general awareness is contributing in stigma formation .

***Key words: Thalassemia patients, stigma, Social Stigma*.**

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Introduction

Thalassemia major is a genetic hematologic condition that lasts a lifetime. Thalassemia major can induce hemolytic anemia, as well as cardiac illness, malnutrition, bone abnormalities, spleen enlargement, as well as other organ failure if left unchecked (Cunningham, 2008). Blood transfusions are required every 2–6 weeks, as well as daily iron chelation therapy (L1-deferiprone) and a dermal infusions of Desferal via pumping 5–7 nights a week for 8–10 hours to remove the consequent iron accumulation (Cunningham,2008; (Brittenham, 2013) . Thalassemia is a major public health issue worldwide, particularly in developing countries. This disease manifests itself in a variety of ways. Two of these forms, known as alpha and beta, are the most common (Sachith Mettananda, 2015). According to WHO estimation, 3-4% of the population in Bangladesh is Thalassemia patient. Conservative Estimate suggests that almost 6-12% people are affected with different hemoglobin disorders like Beta thalassemia and Hemoglobin E (Mohammad Sorowar Hossain c. a., 2017) . These people are highly ignored by government facilities and at the same time due to lack of knowledge they face social stigma and discriminations.

Statement of the Problem

A significant non-biomedical element that causes individuals to confront serious social, economic, and psychological challenges is a lack of knowledge and understanding regarding thalassemia (Sidra Ebrahim, 2019). Family attitudes are primarily influenced by social, cultural, and religious influences, especially in conventional civilizations and rural areas. These elements influence the residents' living patterns and livelihoods in such societies. As a result, people in such societies manage with the obstacles of thalassemia as a result of widespread societal views. Any innovative method used at the individual level may conflict with local religious beliefs and customs. The experience of stigma is likely to be influenced even more by ethnic identification. According to research, a family is the primary and most essential source of social support for patients and their parents in order to reduce the mental and sociological cost of thalassemia. For their social adjustment, thalassemia patients require medical as well as social care from their families, medical experts, and other community members (Muhammad Abo ul Hassan Rashid c. a.-u.-R., 2020).

Rationale of the Study

In the field of health, social stigmatization has a wide range of implications on physical and mental health outcomes, as well as contributing to inequalities (Mark L Hatzenbuehler, 2013). People with stigmatized identities strive to minimize the personal and social consequences of their sickness by maintaining identities as "good," "regular" individuals and disavowing identities as "bad," "diseased" persons (Margarete Sandelowski, 2004). People can be subjected to various forms of stigma, such as performed or felt stigma (Charmaz, 2000) .The term "enacted stigma" refers to the effects of stigma, such as discrimination against those who are perceived to be distinct. "Concealable stigmas" have been defined as stigmas experienced by those who suffer from illnesses that do not show up on the surface, such as HIV, epilepsy, or mental health conditions (Earnshaw, 2013). Despite the significant incidence of thalassemia genetics in Bangladesh's demographic, accurate data on the illness burden of thalassemia is lacking. According to current estimates, 6–12% of the community is carriers of various hemoglobin diseases, primarily beta-thalassemia and hemoglobin E (HbE), with tribal communities accounting for up to 40% of the population. According to estimated data, approximately 60,000–70,000 children have been diagnosed with clinically acute thalassemia. In Bangladesh, diagnostic facilities and prenatal testing with therapeutic removal of afflicted fetuses are possible; however it is unknown how effective and better adopted these preventive strategies would be (Mohammad Sorowar Hossain, Lack of knowledge and misperceptions about thalassaemia among college students in Bangladesh: a cross-sectional baseline study, 2020) . There is not enough work on the social position of thalassemia patients. They are not getting the proper attention they need. Their medical treatments and medical care are not still developed; they are hidden but a vulnerable part of our society. If they are not given any voice to say their problems, ignorance, prejudices they would always lag. This study would talk the thalassemia patients and their family members to know their untold stories, what problems they and their family members face. How does society treat them!

Literature Review

Social Stigma and Thalassemia Patient

The management of thalassemia patients is a significant burden for both afflicted families and the medical system. Furthermore, the social stigma connected with thalassemia has a major mental and emotional influence on patients and family members. Being a thalassemia carrier resulted in social exclusion, marital strife, and social stigma in India. To limit the occurrence of this condition, it is critical to prevent the birth of infants with thalassemia major. Early diagnosis, according to scientific findings, has significantly lessened disease burden. On religious reasons, Muslim couples have been recorded to resist prenatal diagnostics (Li Ping Wong, 2011).

According to a study, the role of socio-religious elements in the spread of Beta thalassemia is significant. Due to continual despair, anxiety, and poor social interaction, the condition, which supposedly has a considerable protraction through repeated cousin marriages, causes social maladjustment in the parents of the sick children, as well as social isolation (Muhammad Abo ul Hassan Rashid S.-u.-R. S., 2020)

The majority of college students—67%—had never heard of thalassemia. Among those who were familiar with the word, there was a contrast between urban and rural colleges (46.4% from urban vs. 25.8% from rural colleges). Similar trends were seen for knowledge scores, with students from urban institutions scoring 5.07 1.87 and those from rural colleges scoring 3.69 2.23. Students with backgrounds in science had the highest knowledge scores (5.03 1.85), while those with backgrounds in the arts and humanities received the lowest (3.66 2.3). A thalassemia patient's buddy was not something that almost 40% of the students were certain about or wanted to be. While 39% either denied or showed hesitation about giving blood to aid thalassemia sufferers. However, the majority of responders (88%) expressed support for "premarital" screening to resist thalassemia (Mohammad Sorowar Hossain, Lack of knowledge and misperceptions about thalassaemia among college students in Bangladesh: a cross-sectional baseline study, 2020).

A study of Jordan, "Challenges of having a child with thalassemia major: a phenomenological study" by Ghada abu shosha and Mahmoud Al kalaldeh stated the struggle about having thalassemia major child and its consequences on financial problems. How they have to move from social events. Social stigma is causing havoc problem in their conjugal life also. There were reports of psychological anguish, social isolation, anxieties, and fear of the disease and its long-term repercussions (Ghada Abu Shosha, 2017).

The experience of stigma is likely to be influenced much more by ethnic identification. While thalassemia major is given a lot of attention in Singapore, no research has looked at the experiences and views of people who are afflicted. In the context of medicine, social stigmatization has a wide range of implications on physical and mental health outcomes, as well as contributing to disparities (Hatzenbuehler, 2013).

Discrimination and Thalassemia Patients

After completing written examinations and interviews, the three, surnamed Tang, Xie, and Zhou, were refused civil servant positions by the Foshan human resources and social security departments last year because they were diagnosed as thalassemia gene carriers. According to Xie, one of the three plaintiffs, 31 students who were confirmed as thalassemia gene carriers were denied civil servant positions by Foshan human resources officials last year (Quanlin, 2010).

Research Objectives

General Objective:

This study's broad objective is to evaluate the stigma & associated discriminations thalassemia patients face.

Specific objectives:

So this study's specific objectives would look forward to-

1. Social life of thalassemia patients & family.
2. How much they know about this disease.

3. Social stigma and discriminations they face.

Theoretical Framework

In Erving Goffman's theory of social stigma, a stigma is an attribute, behavior or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable rejected stereotype rather than in a normal one (Goffman 1963:3). Stigma, as defined by Erving Goffman, is the phenomena where a person who possesses a quality that is highly disliked by their society is rejected as a result of the quality. According to Goffman, stigma is the result of other people's reactions tainting one's ability to be oneself.

According to him there are three main types of stigma-

1) Stigma associated with mental illness
2) Stigma associated with physical deformation
3) Stigma Associated with particular race, ethnicity, religion, ideology etc.

Goffman saw stigma a process by which the reaction of others spoils normal activities. A stigma is an attribute or behavior which socially discredited in causes a person to be mentally classified by others in an undesirable way rather than in an accepted normal way.

According to Goffman the person's relation to a stigma into three categories:

1. Stigmatized- those who endure the stigma.
2. Normal- those who don't bear the stigma
3. The Wise- those among normal who are accepted as wise by the stigmatized to the condition.

The principles of stigma as a social theory were introduced by Erving Goffman, who interpreted "stigma" as a technique of sabotaging identity. In other aspects of self, he meant the stigmatized trait's tendency to "spoil" recognition of the individual's conformity to social standards.

In this theory Goffman showed how society can make stigma based on some particular attributes of an individual and characteristics.so regarding thalassemia patients they are often stigmatized due to their physical weakness and biological problems. As they are not like other regular person so they face stigma based on the physical problems they go through (Goffman, 1986). According to Goffman division, thalassemia patients face stigma due to the physical deformation.

Research Methodology

In this study qualitative method would be conducted. There will be semi-Structured questionnaire & face to face interview to collect data. This method goes well with this study type. Respondent's spontaneity would be maintained through this technique. In-depth interview of parent's for those who are below age 10 is maintained here to get the actual information from them; to get the data properly from them is the main focus while selecting the procedure.

To conduct the study both primary and secondary sources of data have been used to get strong valid base of information. Primary sources of data have been collected from face to face interview and secondary sources of data have been collected from existing literature to this relevant study area like standard websites, textbook, journal, research reports, newspaper article have been gone thoroughly to find out relevant literature regarding the study topic.

Place were chosen according to the preferences of the respondents. Interview session started with simple questions from demographic aspects. Each interview lasted from 30-45 minutes. With a phone audio recorder all participants were recorded with their permission. This study is conducted in Combined Military Hospital (CMH), Dhaka. It's located at the center of Dhaka cantonment.

In this qualitative study total amount of respondent's 50 is used to collect data. Where 10 were parents as there are some respondent' below 10 so to gather data their parent's would response on behalf of them rest 40 respondents are adult here. Male respondents are 23 and female respondents are 10 and 7 parents of children below age 10.

Data Analysis and Findings

The data analysis of this study fully based on the evicted information through data collection method by face to face interview, in-depth interview of parents, structured questionnaire to get the gist of the stigma and discrimination issues they had faced. To evaluate qualitative data, also known as categorical data, the qualitative data interpretation approach is utilized. Texts, instead of numbers or patterns, are used to describe data in this technique.

Themes	**Categories**	**sub-categories**
Social Stigma	Stigma at family stage	Parents perception about the disease
		Comparison with siblings
		Familial support
	Stigma from relatives	Relatives perception about disease
		Assistance in time of need
	Peer group stigma	Peers perception about the disease
		How much Comfortable with them
Discrimination	Work life discrimination	Organization's attitude
		Colleague's support
		Consideration about the disease
	Social life Discrimination	Engagement in social activities
		Disease Disclosure Concern
		Presence in Social Functions
		Neighbor's attitude

Table: Theme Settings for Interview

Qualitative Results

Social Stigma at family stage

The first stigma a thalassemia patient face is by own family member. Family works as the first institution also works for the first stigmatizers. A 15 year old boy said,

"My mother said it would be good if you were not born, because of you I have to face mental torture by your father and my in-laws for giving birth to a sick boy"

In comparison with siblings question one girl said about how her own family does stigma against her that is,

"I have to face stigma in comparing with my cousins and they sometime taunt me that I would not be able to get married. My parents think about my marriage, as a girl I feel social pressure due to the disease I'm suffering in uncertainty" (Female respondent, age 16)

Academic life is a great reason contributing as stigma factors for thalassemia patients. Most parents take the academic life very challenging for the sick children. Thinking about the mental pressure and physical illness they don't want to let their children go distant study areas. One Varsity going respondent said,

"I wanted to study in renowned public university but due to my disease my parents didn't let me study outside from my hometown so now I'm studying at a local varsity. I couldn't study my favorite subject and my dream died due to this disease. My parents won't let me go outside as I need constant care and medicine." (Male respondents age, 23)

Another respondent talked about familial stigma that,

"My parents feel constant pressure about my future and my marriage. I know they are concerned as my parents but sometime their words hurt me." (18 years old female patient)

A patient's mother responded that,

"As a mother of girl patient I feel constant pressure from society due to patriarchal social structure. Sometime I feel very depressed and frustrated due to the pressure I feel but I don't let her know I'm feeling. I don't want her to feel depressed".

Another respondent replied that,

"My father feels the tension more than anyone. Sometime I feel depressed seeing him all time tensed. As his government job would end soon than there would be no treatment from CMH. The

expenditure is huge and costly so sometime he shows his concern regarding me. I feel very bad then. I think it would be good if I was healthy." (19 years old female patient)

Another patient replied that,

"I wanted to study outside of my area but due to constant care and medical treatment my parents didn't let me go outside. I wanted to do job like other normal person but they also didn't let me go, I wanted to do freelancing but as I have to work at late night my parents didn't allowed me. I wanted to business but due to not enough capital I couldn't started my business. As I'm living with my parents I have to obey them. Beside than that they take care of everything." (25 years old male patient)

Stigma from Relatives

After family relatives are close source where thalassemia patient's face stigma and from where the stigma produces to other forms. They can give patients family courage and at the same time they can bully or stigmatize them. About stigma from relatives one respondent said,

"The very first time one of my close relatives heard about the disease their very first comment was that- this must be the result of parent's sin now the son has to suffer" (male respondent, age 17).

The illiteracy related to this disease and lack of knowledge the relative's sometime does stigma unintentionally.

"Some of my relatives came to know about my disease, but as they are illiterate they started spreading that I'm possessed by blood eater jinn 'rokto kheko' and they spread it to the whole village. Now I feel awkward to go to village". (23 years old patient)

In response to relative's assistance in time of need, one respondent replied-

"As all medicines are not always available in CMH, so sometime we have to buy medicine from outside also for treatment purpose sometime I go to India so there is huge expenditure for my

treatment. So my father asked his portion of property form my paternal uncle but my uncle rejected to give him money and any kind of property." (24 years old male patient)

Relative's stigma can affect a person most in time of their need. One respondent replied that

"My relatives had some issues with us. So when they came to know about this disease they spread that I'm suffering from blood cancer though they know my blood group and all details about my disease but due to enmity they spread this misinformation." *(19 years old male patient)*

Another respondent talked about the stigma from relatives that,

One of my relatives said about my girl that she is a girl how would you give her marriage? She is a thalassemia patient. Now I don't talk to her anymore. (Patient's mother)

Another respondent stated about relatives stigma that,

"When my relatives used to spread different stigma about my disease my parents would save me from those things but due to corona my mother died last year now I have just my father alive. I miss my mother so much." (23 years old male patient)

Peer Group Stigma

Peer's is the most important part to a person' life after family. Their behavior impacts the most. Regarding peer group stigma one respondent replied that,

"From play to till now I kept hide my disease from my friends. *They don't know about my disease or I'm a thalassemia patients. They would feel bothered about my disease or could be intentionally or unintentionally would hurt me. So I keep it confidential". (15 years old female patient)*

They are not like other normal person; they have some barrier regarding physical and psychological issues. One respondent replied that,

"I can't play like my other friends regularly. Sometime I feel physically weak so I don't go outside. After that when I go to play with them they don't want to take me with them. I feel very lonely and sad sometimes. I have very few friends." (10 years old boy patient)

Because of their physical weakness they are not equally brilliant like other thalassemia patients.so sometime they are weak in studies and sports not equal like other normal kids. So friends make mocks on that. One respondent said that,

"My friends mock at me by saying that look he would fail at every exam, you would get double zero at every subjects. You are not regular at school, often miss school how you can pass at exam!" (11 Years old boy patient)

Often they have to miss school due to illness and physical weakness. So due to illness they are irregular student and often miss lectures of teachers. So when they want to understand any study they look for their friends but don't get response from them. One respondent said,

"When I want to understand anything from my classmates they say that why don't you take a tutor?" (17 years old girl patient)

Discrimination

Work life included job life, tuition and other activities.

Regarding work life discrimination one patient said that,

"I'm doing internship at a multinational corporation. I didn't tell my organization about my disease, I fear that they wouldn't want any employee who is less physically fit and weak. I need this job for financial stability so I kept it confidential." (25 years old female patient)

One respondent talked about the problems she face at tuition, she said that-

"I do some tuition beside my study. So sometime I had miss tuitions due to my illness and weakness. So I don't tell them about my disease in the fear of that they would hire someone better than me but I badly need this tuition. "(19 years old female patient)

Another respondent talked about work life discrimination,

"I'm doing a part time job beside my study but due to my illness now I can't take much pressure. As I didn't tell anyone about my disease not to my organization in the fear of rejected I had to silently take the burden". (24 years old male patient)

Regarding organization and colleagues support one patient responded that,

My organization knows about my disease they are supportive but I give some extra effort to not get any stigma from them. If I'm not doing well performance there could be chance of stigma." (24 years old male patient).

Social Life discrimination

Regarding engaging in social activities one respondent replied that,

"I'm not physically well and fit like other persons so whenever I tried to join any social organizations social activities they say me to it's better for me and my health to not to join any social activities." (15 years old girl patient)

About joining any social function one respondent replied that,

"I don't go any function anymore because of the food they serve. Maximum are not allowed for me to eat because of the food restriction of thalassemia patients have to maintain. Mostly there is no menu particularly for me. That's why I quit joining social functions."(20 years old male patient)

Regarding neighbor's attitude one patient's mother replied that,

"Sometime my neighbor says that, alas you have a sick child it would be better if she was a boy. Sometime they say others may Allah give you a healthy baby in front of me. I feel very insulted." (A patient's mother)

Another patient told that,

"In our building anyone didn't know about my disease but one neighbor from old building came to this building and she told everyone now they keep asking me every day that's very disgusting to me" (15 years old female patient)

Another patient also responded a similar reply that,

"I didn't tell anyone anything about my disease. But one medical assistant from CMH told everyone about my disease to the whole building now I have to suffer a lot." (17 years old girl patient).

Regarding disease disclosure concern one respondent replied that,

"My parents want to get me married so I'm taking mental preparation like that. But regarding my marriage anyone doesn't know. I and my family are in constant fear that anytime anyone could know about my disease. When others would know about my disease it would be difficult for me to get married". (22 years old female patient)

Another patient told that,

"All was set to get married but when they came to know about my disease and sickness they cancelled the marriage." (23 years old female patient)

Regarding neighbor's attitude one respondent replied that,

"I'm a thalassemia patient and also a girl due to social structure of patriarchal social system my parents have to hear constant superstitious words and social dogmas regarding my disease." (18 years old female patient)

Findings

Study shows that the stigma thalassemia patients have to face sometime due to the lack of knowledge and sometime due to lack of social integration. Because of their stigma they are lagged behind from social, educational, financial aspect from others of this society. Their development process should bring forward by working on the sectors that need to bring in lime light for their betterment. Findings shows that the amount stigma patients face are by mostly girl due to the patriarchal social structure, social system, religious stigma, social dogmas and huge amount illiterate population. Mostly male patients face stigma in terms of their financial sector. When there would be more knowledge among people and governmental initiatives for thalassemia patients there would be fewer stigmas and less discrimination for thalassemia patients.

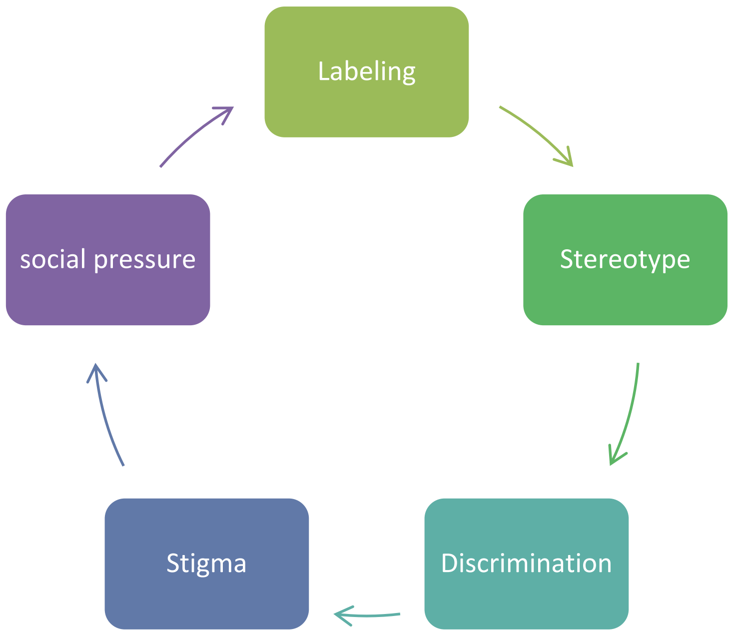

Figure-1: Cycle of stigma process

RECOMMENDATION

Thalassemia is spreading rapidly in our country due to the unconsciousness of parents. Pre-marital pregnancy tests, knowledge about the disease, less educated mother all these are the main reasons behind the disease. Our academic books are not enough to educate students regarding the disease and how it should be prevented; especially in rural areas people are way more in dark regarding the disease. More awareness programs should be held and free tests should be done before marriage. More thalassemia foundation should be formed to assist the patients. Organization regarding thalassemia is very less so the awareness programs are. Governmental initiatives regarding disabled child made their burden less than before due to the initiatives governmental organization had taken so in

CONCLUSION

Thalassemia is a tension topic as its increasing day by day. According to the WHO, Thalassemia is defined as “rare”; nevertheless, due to the migration flows and the lack of prevention measures, it has recently become an issue of great concern, in 2006 WHO designated thalassemia as a major public health concern. Our people and government none of them are not enough aware of this disease. People take it as a hassle to go for pre-marital tests to ensure a bright future. Our concern level is really at low level both about the disease and the behavioral pattern with the patients. The study shows that there is huge lack of general people awareness and consciousness regarding the disease. They do stigma intentionally and unintentionally due to lack of knowledge. Governmental initiatives and mass media awareness is needed to mitigate the stigma in society. There is huge discriminative perception towards them in society. Due to the perception they lag behind in educational, social and financial aspects.

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