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Impact of Chronic Disease on Patient's Social Life, A Case Study of Thalassaemia Center Islamabad

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Abstract: *Thalassaemia is a hereditary disease that is transmitted from parents to children. The most prominent cause of thalassaemia is cousin marriage. Thalassaemia major is mostly found in South Asian countries. Many people are not aware of it because of a lack of knowledge. There are two major types of it. One is thalassaemia major, through which patients need regular transfusions of blood because their bodies can't generate blood, and the other is thalassaemia minor, which is also anemia. A person with thalassaemia major suffers in many dimensions and different ways. Their medical, as well as social lives, get disturbed by regular hospital visits for transfusions. The study aims to witness how thalassaemia major impact the patient's social life, how this chronic disease shapes the patient's social activities or relationships, and to understand how they cope with life. To meet the aim Qualitative research methodology is selected.*

Key Words: Chronic Disease, Thalassaemia, Social Life

Introduction

Health is the greatest possession. In the present era, chronic illnesses are expected to become the core cause of disability and death in the world. Healthcare workers are incapable to cope with chronic conditions efficiently, and yet several governments are not able to manage the increasing disease burden and costs (Bengoa and Sabate 2001). Thalassaemia is a blood disorder that transmits from parents to their children. There is no effective technique to cure the disease because this disorder causes great damage to red blood cells (Ishfaq and Naeem 2016). People who are suffering from thalassaemia major depend on regular transfusion of blood all over to maintain their life. Complications and haemosiderosis (accumulation of iron deposits) necessitate constant treatment that includes regular medical supervision, iron chelation treatments, repetitive admission to the hospital, and different operations. Thalassaemia arises more in people who are

living in a subtropical region of Africa and Asia and those who live in the Mediterranean basin. 1.5% of the global population carries β -thalassaemia. 60,000 asymptomatic individuals are annually born and most of them are in developing countries (Rashid and Shazad 2020).

In Pakistan, the disease is seen in all areas of the country. Every year 9000 β -thalassaemia children are born in Pakistan. Patients suffering from thalassaemia face many other problems too like liver, heart, and skin. Bone marrow transplant is the only cure of thalassaemia major which is beyond the reach of many families in the country. Approximately 8000 to 10000pk per month are required for the medicine of patients. In Pakistan, the major reason for thalassaemia deaths is only because of noncompliance of treatment due to economic factors (Ishfaq and Naeem 2016). Different strategies are made to prevent thalassaemia, which include parental education, genetic counseling, and

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population screening. Genetic counseling tests are important to reduce the rate of thalassemia major but unfortunately in Pakistan, these tests are still not in common practice. Thalassemia challenges both family members and patients at emotional, physical, and cognitive levels which leads to disruption of their normal psychological life [_\(Kshaish and Radha 2020\)](#).

Thalassemia is a chronic illness. So the patient needs to indulge in daily activities, which is helpful to reduce its impact on the patient's psychological, physical, and cognitive development. Different kinds of domestic tasks of daily activities are used to understand the dependence or disabilities of young children. Daily life activities are those which are performed by children independently, but young children need the help of their parents to get socialized and play independently outside or at home [_\(Kshaish and Radha 2020\)](#).

Literature Review

Thalassemia places remarkable psychosocial and financial effects on patients and their families. Patients needed consistent care throughout their lifetime. A study directed that thalassemia major patients required blood twice a month for survival, so it is difficult to arrange blood twice a month for parents. Most of the parents were uneducated and their monthly income was low to tolerate the cost of medicines and blood transfusion. The most important reasons in the thalassemia major families are first cousin marriages [_\(Ishfaq and Naeem 2016\)](#). Thalassemia may not be considered a terminal illness that it needs an alteration to daily living activities due to its long life treatment to shrink its impacts on the patient's psychological, physical, and cognitive development over the primary childhood stage that may cause social limitations or minimal effects on a feature of life. Other activities of everyday living which comprise domestic tasks that it frequently used to measure the disabilities or the dependence of the old patients like cleaning, cooking, shopping, driving, and use of mobile [\(Kshaish and Radha 2020\)](#).

Social Support

A study showed of the psychological well-being of thalassemia patients has a very high frequency of depression and anxiety amongst them. One reasons that raise the level of depression and anxiety are the absence of social support. Social support received by people can play a defensive role besides physical and mental health problems and reduce levels of depression and anxiety in life problems. Social support means financial and moral support from people near to the person who is in a traumatic situation. Thus, with concern to the high occurrence of depression among patients and the role of social support. The study was directed to define whether PSS is linked to anxiety and depression in thalassemia patients and if it is, which measurements of PSS (family, friend, and significant others) more expressively predict anxiety and depression in the target group [_\(Siddiqui, et al. 2014\)](#).

Cousin Marriages

The major cause of thalassemia which has been reported is cousin marriage. In countries like Pakistan, Iran, India, and Bangladesh traditional values and practices regarding cousin marriages are dominated rather than genetic counseling and prenatal screening; due to strong patterns of collectiveness it is very difficult to alarm them about the concerns of consanguinity and create awareness amongst families [_\(Rashid and Shazad 2020\)](#).

In Pakistan, the Termination of pregnancy is considered unethical because there is also a religious perspective attached to it regarding termination of pregnancy with major thalassemia. The solution regarding minimization of mortality rate due to thalassemia major is only by public awareness regarding chronic ailment. [\(Plantania and Nuovo 2017\)](#).

Impact on Education

Thalassemia major is a severe life-limiting and possibly life-threatening that cause trouble in education and all social activities, because of illness patients suffer from unhappiness, annoyance, and aloneness. This

is because of the chronicity of the disease state that impacts the patient's amusing activities, skills, and family relationships. A study directed that more than half of the children stated that their education was affected because of the serious nature of the illness. This may be because of their regular hospital visits for blood transfusion, iron injections chelation therapy producing disturbed sleep at night. Constant absence from school originates low academic performance. Parents are found to be overprotective about their thalassemic children. Parents confronted lots of problems due to their suffering thalassemic children. They avoid social gatherings and even had drawn relations with each other. Also, it was found by the study that a maximum of the thalassemic patients worried about their future life and their goals. This is because of their terror of possible difficulties of the illness and can considerably contribute to other psychosocial problems [_\(Siddiqui, et al. 2014\).](#)

Psychological Effects

In past decades, a number of cases are registered with a chronic disease that can directly affect the quality of life. Thalassemia has a huge impact on the functioning of a patient's psychological and social life behavior. Quality of life defined by WHO (1996) is the individual perception of their position in terms of the system of values and the specific culture. In which a person lives in relation to their expectations, concerns, standards, and goals. Chronic disease has a negative impact on patient's psychological wellbeing and their life. Some recent research found an inability among young adults of thalassemia major to engage in daily goals [\(Plantania and Nuovo 2017\).](#)

Research Methodology

Research methodology is defined as the process of scientifically conducting an inquiry or research and understanding the entire research process [_\(Punch 2000\).](#) The objectives are to explore the impact of thalassemia major on a patient's social life, activities, and relationships. The philosophy of research is nominalist and the approach is

interpretive to avoid one fixed meaning. The inductive method is used in research because the nature of the research is a qualitative methodological research method. Qualitative research is a sort of social science research that collects and works with primary and firsthand data and focuses on the emic perspective using an anthropological lens [\(Bernard 2006\).](#) This study sought to define the social life of people who are facing thalassemia major. The reason for choosing this method is to get an in-depth and holistic view related to the patient social life.

In-depth interviews were used as a tool to collect data from the field and focus on how and why questions to provide opportunities for participants, to tell the story in their own words.

The sample for the study was taken from Thalassemia Center Islamabad, which is located in PIMS hospital Islamabad. The data has collected by 7 individuals as a case. The research is characterized by a non-probability sample in general and a purposive sample in particular. The study was conducted in the thalassemia center in Islamabad to learn about the social life of patients, whose age group was 15 to 25. The study's goal is to look into how severe illnesses and frequent hospital visits affect patients' social lives and careers.

Discussion

Parents are found as over-protected their thalassemic children, even if they try to avoid social gatherings. Patients also try to avoid social gatherings and even had withdrawn relations with relatives [_\(Siddiqui, et al. 2014\).](#) Patients of thalassemia majors have a different lifestyle as compared to the normal individual, their choices, studies, health issues, activities, fears, and whole social life are linked to their disease. The researcher has found different case studies and different life patterns of thalassemia major patients, these all are contrasting because every individual has a different social background. When the researcher asks to them about their involvement in social gatherings their answer was related to their social background.

It has been found that the reason for avoiding the gatherings is different kinds of

social barriers and insecurities that prevail in the patient's personality. They are not able to match the energy of their peer groups, researcher also found that different kinds of physical insecurities which include dark color, pale teeth, and short high also restrict patients to home.

According to Respondent

"I like to avoid social gatherings as much as possible because I don't feel comfortable when lots of people are around. Most of the time people ask me different questions regarding thalassemia and start to show sympathies that hurts me a lot"

Another Respondent said that

"Because of difference in physical appearance as compared to other peers I feel like a prominent figure in gatherings this is the reason to avoid social gatherings"

According to Another Participant

"My parents and I both try to avoid social gatherings because when thalassemia major was diagnosed they hide it from all relatives and friends so that over social relationships with our relatives gets so much restricted"

Apart from social gatherings, their studies are also affected, most of the individuals left their schools because of lots of absentees from school and poor health. Poor academics are linked with nonappearance in school. Anemic symptoms are perceived as the main factor to poor academics. Some people think that thalassemia itself is a reason which causes children to be slow learners [\(Politis, et al. 1990\)](#).

A researcher has found that most of the patients have left their school because of the repetitive visit to hospitals, also patients are not able to focus on their studies because of health issues. It has been found that different other diseases which include heart and skin problems, irregular blood transfusions, and hepatitis, and also the reasons of poor academics.

Respondent said that

"I left my school when I was in 6th class because school was far away from my home

and I was not able to walk for so long and when I went to senior section the studies got tough and it started to put me in stress which I was not able to bear, my class fellows were good in studies and I was nil and not able to perform well that's was reason to left the school"

Not going to school or constant absence from school originates low academic performance, which leads to many psychological problems such as loneliness or depression.

According to Respondent

"I never went to school because my parents decided that for me, my other siblings go to school regularly. I stay at home with my mother and help her out in domestic work because I know that I am not able to go to school regularly but I have no friends because I am restricted to domestic work"

Another Respondent said that

"I was always good in studies and like to go to school my teachers were very helpful to me but in 10th class because of an irregular blood transfusion my legs were affected so that I have to leave my school without appearing in exams"

Social support refers to the help from those who are near to the patients who are suffering from thalassemia major. Social support received by people can play a defensive role besides physical and mental health problems and reduce levels of depression and anxiety in life problems. Social support means financial and moral support from people near the person who is in a traumatic situation. [\(Siddiqui, et al. 2014\)](#).

One Respondent said that

"My mother left me when I was a child she asks my father for a divorce. After the divorce I was so alone and lonely I needed her support but she left us I was so depressed and I stop believing in anyone"

According to Respondent

"Whenever my family asks any relatives for blood they always find a way to refuse and sometimes they avoid our calls and messages,

most of the time we upload a status on Whatsapp, Instagram, and Facebook so that any random person can donate blood"

Thalassemia major challenge to both patient and family members at an emotional and cognitive level which leads to disturbance of their normal psychological life. (Kshaish and Radha 2020).

The researcher found that because of low self-esteem and less social support from relative patients feels stressed. Patients are dependent on their parents throughout their life which causes depression. One respondent had 2 siblings and both died because they too had thalassemia major.

Respondent said that

"I see no future for myself, sometimes I think that just like them I will be dead soon"

According to Respondent

Whenever I start to think about my future I see nothing but a dependent life. It makes me depressed.

Many other diseases affect patients and contribute to making their life tougher. An excessive amount of iron in the blood is a major problem because it affects other organs of the body too.

According to Respondent

"Because of the excessive amount of iron in my blood affected my spleen so I had to operate it"

It has been found that many different health problems and diseases make a patient's life even more difficult and restrict them to home.

Another Participant said that

"I try to avoid social gatherings because I have sugar and I inject 4 times insulin in a day, to inject insulin again and again and to carry them along with me is tough so I try to remain at home"

Patients are dependent on their parents and all other people who are close to them. A high level of depression has been seen in them because of a lack of social support. (Maher, et al. 2018).

Patient and their parents most of the time wanted their relatives to show their support because when they are in pain they needed someone to console them so that they cannot lose hope, and the patient gets motivated and fight against thalassemia.

One Respondent said that

Whenever we needed someone to help us or to donate blood they always come with an excuse. My mother is a housewife and it is very tough to leave my other younger siblings at home and to come with me to the hospital twice a week but she had to because no relatives show any concerns.

According to Another Participant

Mostly my mother's side relatives help us financially and emotionally too but my father's side relatives don't even like to visit our place. My grandparents live with us only they support us, even sometimes my grandmother visits to the hospital with me for my blood transfusion.

It has been found that because of the slow process of maturation patients feels insecure, both male and female face different issues and insecurities in life. Some respondents said that it causes a lack of confidence.

According to Respondent

"I had periods when I was 18 years old, and because of periods I use to bleed 20 to 25 days after every one month. It causes lots of problems because I use to visit twice a week for blood transfusion"

Another Respondent said that

"I am 25 years old but I look like a 15-year-old boy because of no beard and short high and even I am not able to match my peer's stamina and energy so I feel insecure many times"

The findings mentioned above the display that patients have a huge impact of chronicle diseases like thalassemia major on their health as well as on social life. It has a huge impact on their studies, physical activities, and mental health as well as on their relationships too.

Conclusion

Patient with thalassemia major needs constant care to sustain their life. Patients who do not get good care and regular transfusions on time face many problems and there are lots of chances to die because it is a blood disorder and when the body is not able to produce red blood cells patients die. Patients are dependent on their parents throughout their life because they are not able to perform all daily living tasks on their own. Most of the patients are uneducated because they had to leave their schools because of health issues. The main cause of thalassemia major is cousin marriages, because of a lack of awareness among people they don't take it seriously until they had a thalassemic child. In countries like Pakistan, Iran, India, and Bangladesh traditional values and practices regarding cousin marriages are dominated rather than genetic counseling and prenatal screening, due to strong patterns of collectiveness it is very difficult to alarm them about the concerns of consanguinity

and create awareness amongst families. Patients' family members are always in need of help from others, they use different strategies so that they can get the blood on time. Family plays a significant role to make patients psychologically stable. Patients are dependent on their families throughout their life. It has been found that parents are overprotective towards their thalassemic children even if they don't want them to marry because they think that no one can take better care of them. Different insecurities are found among them. A slow process of maturation, short height, and dark skin color put them in isolation, so their social circle gets restricted. It has been found that most of the patients are uneducated because they left their studies because of regular visits to the hospital. Different kinds of social barriers also exist because patients are always dependent and in need of financial and moral help from others around them. Different coping strategies are used by them so that they can have good terms and relations with others.

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