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A research study on Thalassemia among Patients of Thalassemia Children in a Tertiary care Hospital

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Abstract

Background: Thalassemia is hereditary blood disorder that is defined by the diminished synthesis of haemoglobin and anaemia. There are two–alpha and beta thalassemia, and it is classified that they are widespread in many countries, including Pakistan and Azad Kashmir. This, indeed, staggers the flow of the normal development of the personalities of these people since early diagnose combined with the corresponding management produces a significant impact on the quality of the life of afflicted people. However, the general public awareness of thalassemia remains low among parents and caregivers, this situation puts the individuals at disadvantages since diagnosis is likely to occur late and the management is usually grossly inadequate and the health impacts are bound to be terrible.

Aim: The purpose of this work was to find out how much parents and caregivers of children with thalassemia know about this disease, what misconceptions they have and what informational gaps should be filled.

Methods: This type of cross-sectional descriptive study was carried out at a tertiary care hospital located in District Poonch, Azad Kashmir having a specialized thalassemia clinic. The target group in this study comprised parents or caregivers of children with the thalassemia disease. Information was obtained using a structured self-administered and self-developed questionnaire that included closed and/or open-ended questions about the causes, symptoms, treatment, genetic factor, and prevention of thalassemia. Mean, standard deviation, and frequency tables were used to summarize quantitative data and qualitative data was analysed by making frequency distribution of the misconceptions identified from the open-ended questions.

Results: The survey revealed that, although people knew the symptoms of thalassemia well (85%), their understanding of the issues related to inherited gene and prevention measures was considerably less (35%). The study showed that knowledge about breast cancer and its treatment depended on the socio-economic status and educational level of the respondents; the families with low income and with low educational level had the lowest level of awareness. Many people had wrong perceptions about this disorder as a genetic disease and about the methods used to prevent it.

Conclusion: This is much so because the research points out some fatal misconceptions about thalassemia among parents and caregivers most of whom evidently do not understand modes of inheritance and prevention tactics. Just like the study revealed, patients and the public generally do not have adequate knowledge of the condition, which justifies the need to undertake awareness campaigns that would help fight the disease through early diagnosis and prevention. An important step that has to be

taken by the affected healthcare providers, is to ensure they take an active part in providing information in these diseases to the families affected. Primary care providers and other local health authorities may want to engage in educational it means that further efforts should be made to increase public attention, especially for rural and other regions which have not yet paid enough attention to OFE programs.

Keywords: Thalassemia, Awareness, Genetic Inheritance, Prevention, Healthcare Education, Azad Kashmir, Parents and Caregivers.

Introduction

Thalassemia is a group of hereditary diseases in which the body produces an abnormal form of haemoglobin – the protein in the red blood cells required for the transportation of oxygen to the body tissues and organs. The disease is primarily categorized into two major types: such as alpha thalassemia and beta thalassemia because the effects occur depending on which part of the haemoglobin is impacted [1].

Alpha thalassemia results from a mutation or a deletion of the genes for the alpha-globin chain of the haemoglobin. This ultimately leads to reduced synthesis of alpha-globin and unbalanced synthesis of the globin chains leading to ineffective red blood cell manufacture. Beta thalassemia is caused by a damaged beta-gene hence no production or very little production of beta-globin chains. That is why people having beta thalassemia act like they do not have any beta-globin chains, but at the same time they have an excess of known alpha-globin chains that also result irregular red blood cell formation [2].

Thalassemia can be found most frequently in those Mediterranean, Middle Eastern, Southeast Asia, and parts of Africa where the hereditary danger of getting malaria gives some inside advantage to those with the pollution. Incidence of thalassemia also occurs widely in these regions such that a large percentage of the population can be detected with the disease. Pakistan in South Asia has one of the highest rates of thalassemia available in world. Currently, it is putatively that over 5% of population of Pakistan is a carrier of thalassemia and it is reported that thousands of children suffers from thalassemia major every year. Pakistan's Azad Kashmir is not an exception to this spread either. There is also a serious lack of genetic counselling and health awareness adding to the problem; many children with thalassemia major result as there is no cure for this type of illness, and sufferers need lifelong care, including transfusions and occasional bone marrow transplants [3].

It should, therefore, be emphasized why knowledge about thalassemia is significant. A detailed appreciation of the disease remains vital to its prompt identification and control, as well as its prevention. If thalassemia is diagnosed as early as possible, the patient's quality of life will improve because early treatment will help avert several illnesses and lessen the severity of the disorder. Furthermore, increasing awareness will further decrease stigma related to thalassemia and families will approach the physicians in the right time. Knowledge is also a focus of genetic counselling that is crucial in trying to avoid the birth of children who are likely to have severe manifestations of the disease, as carriers of the trait are often unaware of dangers of transmitting the gene to their offspring [4].

Despite the heightened awareness campaigns in most countries, families are still inquisitive especially on when they develop symptoms of thalassemia and how they should handle it. This lack of knowledge normally results in late diagnosis or poor management of the diseases. Some parents never know they are producing affected children; they continue to produce more children with the same complications. In addition, as misconceptions circulate that thalassemia is an incurable or untreatable disease to encourage proactive healthcare-seeking behaviour, people often remain ignorant of governments and medical centers.

The current study was conducted in District Poonch, Azad Kashmir, a high prevalence area of thalassemia where existing knowledge amongst the parents and care givers of thalassemia children is inadequate. Although there are health care services many people have little or no information regarding the inheritance, signs, management/treatment and prophylaxis of thalassemia. Some of the negative consequences include late diagnosis, poor management, and worse prognosis in children affected by such illnesses. For instance, parents may neglect certain signs that suggest their child could be having thalassemia and this leaves the child tested and treated very late. Additionally, without a detailed understanding of thalassemia as a hereditary disease, parents might be able to get with each other multiple children with the problem, which makes the load on households and healthcare much bigger [5].

Further, there is very low awareness of the treatment also, which includes replacement of blood transfusions, iron chelation therapy and the possibility of bone marrow transplant. Families may never come to know of these treatments and therefore never get the right medical attention that their children need, especially since the condition will worsen and cause complications that include among them organ dysfunction, dwarfism, and reduced life span. The consequence is a cycle of neglect, poor management, and elevated emotional, financial and social pressures for families.

Moreover, no adequate counselling is done on the inheritance pattern of the disorders and the role of carrier testing makes the problem even worse. Most people and especially the families within the thalassemia carrier population do not understand the disaster that lies in marrying a carrier since there are high chances of having a child with thalassemia major [6].

The aim of this research task is to evaluate the existing level of knowledge about thalassemia among the parents and guardians of children with thalassemia in one of the largest tertiary care hospitals in District Poonch, Azad Kashmir. They intend to assess the level of this group of people and their awareness of the disease, factors that lead to it, signs to look for and treatment options. Through the current study, it is envisaged that the gaps observed in awareness will be outlined and described in detail to shed light on the difficulties experienced by families that are affected by thalassemia in the management of the condition and the factors discouraging them from seeking early treatment.

In addition, this study proposes to establish the areas of confusion and lack of information concerning thalassemia. Primary and secondary prevention interventions may convey wrong information to the general public since many people especially the rural and the less educated ones have a wrong perception of the disease probably thinking that it is infectious or untreatable. These misconceptions are vital to eliminating from the public domain to help foster accurate health information while encouraging families to seek right medical attention for their kids.

Besides the knowledge assessment, the participants' beliefs and perceptions about genetic nature of thalassemia and their willingness to engage in genetic counselling and carrier testing will be examined. It will also help to establish whether there is need for specialized education for the affected as well as counselling for ideal prevention measures in the next generations [7].

This study is important for several reasons. First, it will help to determine general knowledge of the thalassemia in the country with the high incidence of this disease. Knowledge deficits about parenting are important to identify for creating educational activities for parents and caregivers. In this regard, the study will be useful to healthcare providers as well as policymakers so that they can facilitate the education program according to the needs of the families of District Poonch. For example, if the study shows that most caregivers are ignorant on genetic screening then the health providers could organize a public awareness on the merits of carrier testing and consultation.

Secondly, the publication of the study will assist in the formulation of public health preventive and management strategies for thalassemia since the result shows low levels of awareness of this disease. Enhancing defence of the value of early reporting and treatment might help contain costs of care for families and the health system since various complications and authorities might not be required [8].

Finally, it will be beneficial to the improvement of health literacy with focus on community supported personal and group decision making processes. This work could offer a reference point for other regions in Pakistan and South Asia where thalassemia is other regions in Pakistan and South Asia where thalassemia is prevalent. In light of the establishment of targeted awareness campaign strategies as evidenced from the study, it can provide a basis for formulating the national health policies towards the fight against thalassemia and better living of the affected population [9].

Materials and Methods

This work utilizes a cross-sectional descriptive research design, which is ideal for determining the existing level of knowledge on thalassemia amongst the parents and caregivers of affected children. This type of study enables the researchers to make a single-time analysis of the state of the art, beliefs, and approach to thalassemia of the targeted population. Consequently, the overall focus of the study is to provide an informative description of the participant's knowledge about the disease and its treatment. In light of the present study, this design was helpful in identifying gaps in knowledge, misconceptions and factors that may affect awareness, which can help design subsequent interventions and learning activities.
The work was carried out in a tertiary health care facility in District Poonch, Azad Kashmir where a thalassemia clinic is available. The selection of this site was deliberate since the hospital that was involved in this study is the main referral point for thalassemia management in the district whereby numerous families access medical assistance. The hospital is however well-established with a health professional staff who are charged with the responsibility of handling thalassemia care both as treatment and support. Since the establishment of a thalassemia clinic makes it possible to identify hospitals with a large number of thalassemia patients, the proposed study will take place in such a hospital in order to assess the parents' awareness effectively. Further, the current hospital is a tertiary care centre, hence enrolling a wide panel of patients would be possible addressing a diverse variety of responses concerning thalassemia and its treatment [10].
The tertiary care hospital offers routine blood transfusion, iron chelation therapy and other required treatments to the patients of thalassemia in children. It is also the location where parents of such kids receive genetic counselling and where they are taken for genetic tests. By targeting this context, the study can recruit participants who have access to health care and are at different levels of child's handling of thalassemia. This difference in the level of healthcare exposure broadens the assessment of their knowledge of thalassemia among the caregivers.
The target participants of the study are parents or caregivers of children with thalassemia attending the thalassemia clinic in the tertiary care hospital of District Poonch, Azad Kashmir. Parents and caregivers are selected as the purposive samples for the study since they are the key decision-makers in the treatment of thalassemia in children and are the direct care givers of the child. Most often the caregivers themselves are also responsible for the child's medical treatment, including blood transfusion, medicines, and follow-up appointments. Their knowledge about the disease is therefore essential to its management and prevention.
Inclusion criteria for participation in the study include [11]:
Patients who have come with their children and are also taking thalassemia treatment at the thalassemia clinic.
Participants must agree to receive and comprehend the information given concerning the research to qualify to be included in the study.
Exclusion criteria for the study include:
People who do not have Al Thalassemia or else they won't be aware of the disease and its prevalence.

People who refuse their participation as participation can only be solicited if an individual has agreed to be part of the research due to ethical consideration.

The key inclusion and exclusion criteria guarantee the study population and sample of the research represent the population with first-hand experience in thalassemia, thus, assessing the level of awareness among major stakeholders – caregivers of children with thalassemia.

For the purpose of this study data were collected from parents and caregivers through a structured questionnaire developed specifically to evaluate the level of awareness about Thalassemia. HCPs with experience in managing thalassemia were consulted to construct the questionnaire and the study drew from the published literature to establish knowledge about thalassemia. They used both, close ended questions where quantitative data was obtained and also used open ended questions where qualitative data was obtained.

Understanding of thalassemia: To this regard, aspects such as disease awareness, disease causes, disease indications and disease cure were discussed with participants. Contained questions that were designed to address areas of concern including if they understood the disease to be genetic, if they had knowledge of the two forms of thalassemia, alpha and beta and if they knew the different forms of treatment including blood transfusion, iron chelation and bone marrow replacement [12].

Knowledge of genetic inheritance: In the questionnaire, the level of knowledge was determined about how thalassemia is inherited and if they were aware in order for a child to be affected the parents need to be a carrier of the thalassemia gene. Other questions asked them about the services they knew existed within the genetic counselling services, and if they had ever been informed about the carrier screening.

Awareness of healthcare services and management strategies: Respondents were queried on the following questions: What was the possibility of blood transfusion for Thalassemia patients in the region? Are there facilities for Iron chelation therapy for Thalassemia patients in the region?; Were there specialized diagnostic and medical care facilities available for the Thalassemia patients. Also, they were asked whether they had any knowledge concerning the need for close follow-up after treatment had been administered.

The open-ended questions were included to capture more detailed and nuanced information, including:

Their misunderstanding of what thalassemia was and how any misconceptions were initially corrected.

Thalassemia: A Need for Effective Health Education: Perhaps the best advice on how the handling of thalassemia could be improved together with tips on how the public can be more acquainted with this condition.

These sort of questions provided vast amount of qualitative data which may be analysed to find out misconceptions in the participant's knowledge, areas of high or low knowledge and sections where the caregivers felt the need of further information.

This tool was similarly self-completed but read out and completed by trained research assistants to the participants so that they could understand the reasons for data collection and individual questions as well. This approach was selected in order to avoid ambigoныities and misunderstanding or misinterpretation of the questions, and to allow the participants to ask questions in case they did not understand something.

Completed structured questionnaires were used and analysed both quantitatively and qualitatively to determine the participants' level of awareness about Thalassemia.

Quantitative Analysis: Regarding the closed-ended questions, descriptive statistics were used to compute frequency and percentage scores of participants' requisite consciousness in different areas. For example, the proportion of caregivers that provided correct information on the genetic factor associated with thalassemia or the proportion that had knowledge on the kinds of treatment which is available were estimated. Descriptive statistics made it also possible to compare the awareness level with demographic variables like the participant's education level or the socioeconomic status of the family, as well as the age of the child diagnosed with thalassemia [13].

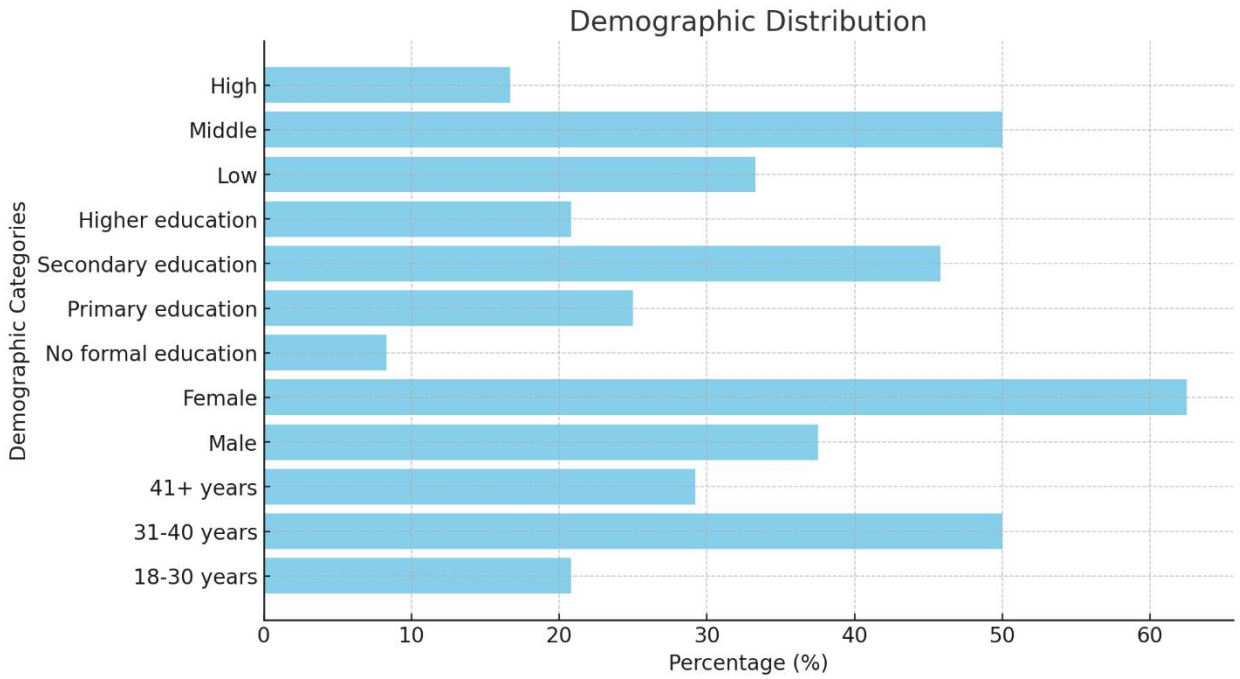
The qualitative and quantitative methods are both used to complement each other to address research questions and generate needed recommendations for the improvement of future caregiver awareness education.

Results

Demographic information about the participants was collected for purposes of identifying factors that could explain the level of awareness about thalassemia. One hundred and twenty parents or caregivers responded, and gender, age, education level, occupation, and socioeconomic status were standardized. The details of key demographic factors listed age size and growth rate is given below in the Table 1.

Table 1: Demographic Details of Participants

Demographic Factor	Frequency (%)
Age	
18-30 years	25 (20.8%)
31-40 years	60 (50%)
41+ years	35 (29.2%)
Gender	
Male	45 (37.5%)
Female	75 (62.5%)
Education Level	
No formal education	10 (8.3%)
Primary education	30 (25%)
Secondary education	55 (45.8%)
Higher education	25 (20.8%)
Socioeconomic Status	
Low	40 (33.3%)
Middle	60 (50%)
High	20 (16.7%)

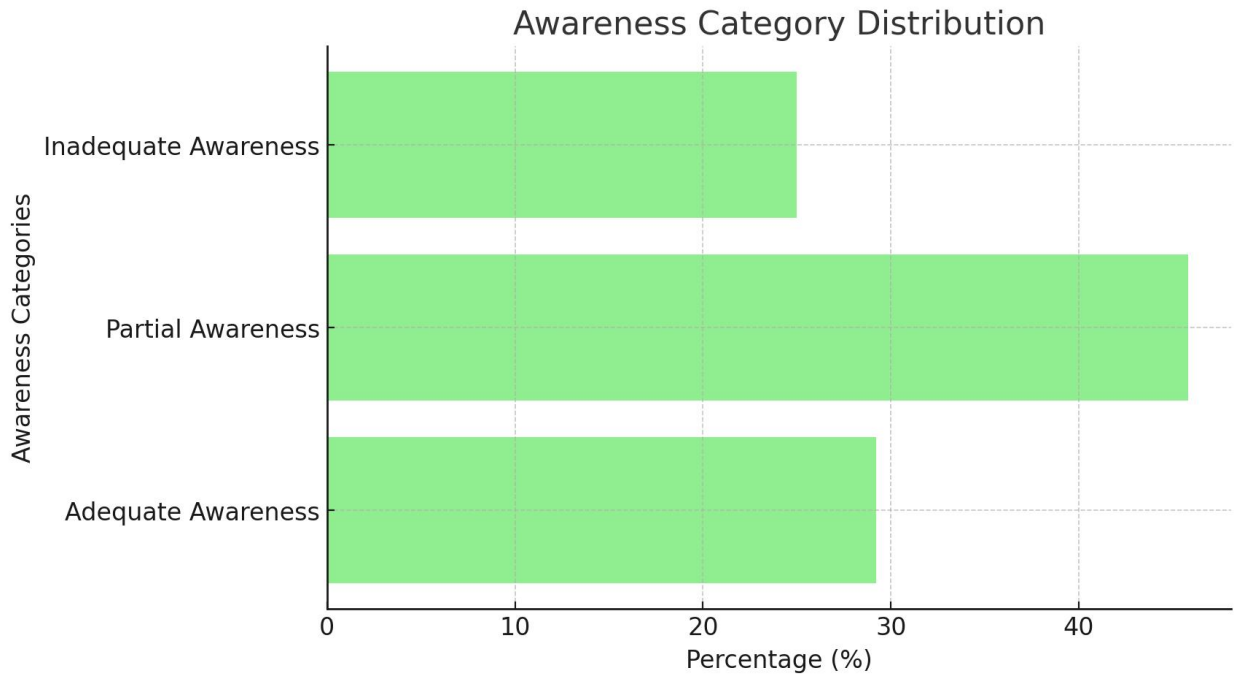


About 50% of the participants were within the age group of 31-40 years; and female participants comprised 62.5%. For education level, 45.8% had only secondary level education; 33.3% had low income background; 50% had middle income background.

To this effect, the participants' knowledge of the disease was questioned in the aspects that included but were not limited to symptomatology, aetiology, management and genetic traits of thalassemia. Based on their responses, participants were categorized into three awareness levels: are classified as adequate, partially, and inadequate. The outcome of the analysis is presented in Table 2 herein below [14].

Table 2: Independently, two of the domains stand out with regard to the level of awareness of Thalassemia – the Health Assessment domain and the Life Plan/Financial Planning domain.

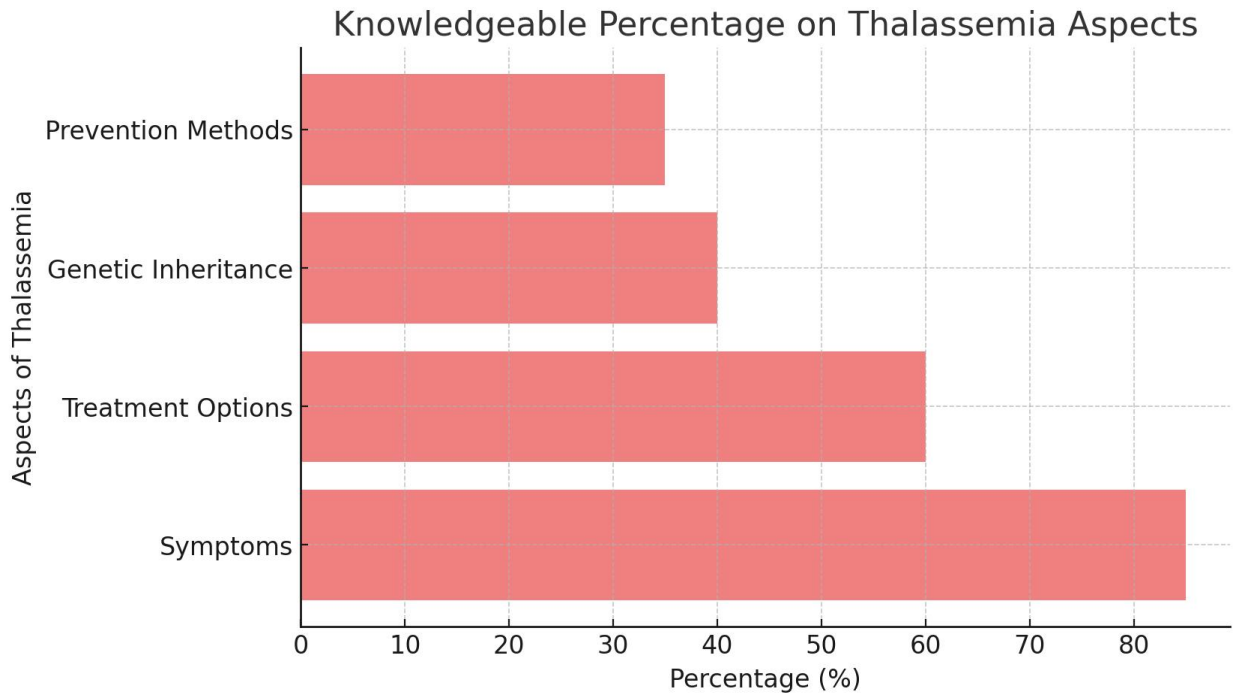
Awareness Category	Frequency (%)
Adequate Awareness	35 (29.2%)
Partial Awareness	55 (45.8%)
Inadequate Awareness	30 (25%)



The results on understanding of thalassemia are shown in Table 2 As it can be observed only 29.2% of participants only had acceptable level of knowledge about the causes, signs, treatment and mode of inheritance of thalassemia. The greatest number of participants (45.8%) demonstrated practical awareness and fully realised the deficiency of their limited knowledge of vital elements of thalassemia management. 25% of the participants demonstrated inadequate awareness, admitting that they had significant gaps in the knowledge that is essential for effective thalassemia management.
In the eighth evaluation criterion where I analysed the specific topics in the questionnaire, the following patterns of awareness emerged. Table 3 shows the percentage of participants who reported that they have knowledge about a plethora of features of thalassemia [15].

Table 3: Knowledge Regarding Basic Facts of Thalassemia

Aspect of Thalassemia	Knowledgeable (%)
Symptoms	85%
Treatment Options	60%
Genetic Inheritance	40%
Prevention Methods	35%



Concerning the level of awareness of the most prevalent knowledge about thalassemia, 85 percent of participants stated that they have sufficient understanding regarding symptoms of thalassemia. These types of patients exhibit an enamel fiver level of awareness that may be attributable to the physical nature of some symptoms including anaemia, fatigue and jaundice which are usually initial signs.

Even deeper knowledge was demonstrated regarding long-term treatment options: 60% of participants recognized the regular blood transfusions and iron chelation therapy, while 40% of interviewed still had not clear understanding of long-term treatment programs. Nonetheless, understanding about genetic consideration or prevention was still low. Regarding knowledge about inheriting Thalassemia genetically, only 40 percent participants had sufficient knowledge about it, and about 35 percent participants had knowledge about state preventive measures like carrier screening and prenatal diagnosis, which play an important role to stop Thalassemia from passing down to the generations.

The most elementary observations are made on this level; the general misconceptions and the gaps in knowledge are as follows:

Some of the misconceptions and pieces of knowledge which were not shared by respondents at the school were established in the process of open-ended responses analysis. The most frequent misconceptions included:

Confusion between thalassemia and other forms of anaemia: Several caregivers defended ideas that all types of anaemia were similar to thalassemia and could be treated in the same way, that's why they didn't have a conception about concrete treatments of thalassemia.

Underestimation of genetic inheritance: Some of the participants provided with the knowledge test did not comprehend fully the genetic model of inheritance of thalassemia, ill the some of the believes stated that it could be inherited from one of or non-carrying parent or that it could be treated [16].

Lack of awareness about prenatal testing: Although reported to care for children with a genetic disorder, a large portion of the caregivers had not heard of the availability of the possible genetic counselling and prenatal screenings which may allow for identification of carriers as well as persons and pregnancies at risk before birth.

These misconceptions justify the call for enhanced educational efforts for the purpose of increasing public awareness with regard to the existing gaps in their knowledge of the disease, as well as the misconceptions which they hold regarding its prevention.
In order to understand whether certain demographic characteristics influenced awareness level, the data was subjected to statistical analysis in regard to the education level and the socioeconomic status of patients.
Thus, alongside with awareness, dependent variables, such as socioeconomic status, were identified to have an effect. Based on their SES, 16.7% of the participants from high SES had higher awareness than the participants from low SES (33.3%). It then becomes clear that attention should be paid to access to information and healthcare services in general and, particularly, to the needs of populations that have limited access to communications technologies.
Although, in the study, there was no direct health outcome data on children, the respondents' answer pattern showed a similar pattern. Finally, with respect to awareness regarding the treatment and prevention, the findings found that the perceived health status of children of the caregivers who indicated higher awareness of the available treatment options and prevention activities was better than others and these children experienced a lower hospitalization rate and better compliance with the treatment plan. This has implications for enhancing the health literacy of thalassemia among affected children as well as improved health management.

Discussion

The study outcomes identified here show that insufficient knowledge about thalassemia among parents and caregivers of children with thalassemia was found. More than half of the participants demonstrated partial awareness (45.8%) of human genetic inheritance and prevention; however, only slightly more than one-third (35%) of the students had comprehensive understanding in these and other categories. The state of knowledge of the participants was not very high; a meager 29.2% of the participants was able to answer general questions about thalassemia correctly together with its treatments and preventive measures. These outcomes correspond with the generally noted picture in other areas: people with fewer opportunities to receive the health care knowledge are usually less aware of such hereditary disorders as, for instance, thalassemia.
With regard to the high awareness of the symptoms (85%), those participants frequently reported clinical symptoms of thalassemia, which are visible, apparent signs of possible illness such as fatigue, jaundice, and anaemia that prompt individuals to seek medical intervention and, consequently, the diagnosis of thalassemia. On the other hand, the knowledge of genes in people as well as methods of preventing diseases related to the genes still appears to be more limited. This lack of awareness indicate that despite the community knowing the common symptoms of thalassemia they are unaware of the significance of genetic counselling, carrier testing and prenatal screening [17].
The findings are in concordance with other studies done in countries with high level of thalassemia such as in Pakistan and some parts of the Middle East where there was partial awareness, though this is well understood where preventive measures are concerned. A cross-sectional study done on community members living in Pakistan noticed a high proportion of participants know that thalassemia is a blood related disease, but less than half knew that it was a genetic disease, and even fewer correctly understood the purpose of prenatal screening for pregnant women who may be at risk of giving birth to a child affected by thalassemia. These results underscore the importance of continuing educational campaigns to overcome not only the manifest signs of the disease but its hereditary and disease prevention aspects as well.

There could be many reasons for obtaining such gaps in the awareness of the participants. One chief among them is Education having no resources to fall back on. Thalassemia information is scarce in many regions like District Poonch, Azad Kashmir, specially in countryside or backward zones. Most of the caregivers interviewed complained that they rarely consulted health care workers that could educate them more about the disease, its cause, genetics, and how to prevent it. Further, professionals acting in declared healthcare-related capacities may not be sensitive to educating their clients on genetic transmission or risk reduction since patients may wish to learn how to manage symptoms.

Other possible reason could be related to culture and beliefs and other misconceptions. This disease may not be well understood in some communities and some families may still not fully comprehend the need for genetic counselling or carrier testing. For instance, some genetic disorders may be considered as simple diseases that can be cured through medications, and not as preventable or as capable of being controlled by the use of the early interventions. Furthermore, prejudices originating from culture that connect gene disorders with negative consequences and the fear of social consequences that arise with identification of a person as a carrier also may stop families from receiving genetic consultation or taking part in preventive testing.

The level of awareness is also dependent on the participants' socioeconomic status. This is because families with low socio-economic status suffer from poor health literacy since they receive poor healthcare and education on diseases such as thalassemia. In this study, participants from low socioeconomic status had the least awareness and the above analysis resembles research studies that have demonstrated that healthcare education and utilization differ concerning SES [18].

The findings presented in this paper point to the problem that deserves attention for enhancing patients' knowledge about thalassemia and its prevention. Genetic counselling about thalassemia in region where it is prevalent is very crucial in order to minimize on the causative factors of the illness. Since most parents and caregivers lack adequate knowledge about genetics, primary care givers such as doctors, nurses and genetic counsellors are critical in educating them especially when the child is diagnosed early. Through simplifying the transmission of culturally appropriate, accurate knowledge about thalassemia, healthcare workers may decrease misconceptions, increase timely diagnosed rates, and improve overall disease control.

Based on the findings it can be argued that the healthcare providers have a central role in providing information. In addition to treating the disease, healthcare professionals should help families understand the value of genetic testing, prenatal and carrier counselling and screening so as to avoid future generations inheriting thalassemia. As a part of this process, health care providers need to engage in the distribution of printed material like brochures and fliers and make use of particular programs in the community that are used in disseminating awareness campaigns to the general public so as to reach out to different families across the country.

Furthermore, healthcare workers need to support policy reforms in health care to enhance coverage of genetic counselling and screening services in deficit zones. To provide particular education to the high-risk groups, it may be necessary to create such centres as thalassemia clinics and launch numerous community programmes.

There are various factors that have limited this study in arriving at its findings which must be put under consideration. Another is bias in geographic coverage, as data was only collected from hospitals. Since the study has been done in the tertiary care hospital, it largely provides picture of knowledge and awareness among the population already having access to healthcare facilities. This could happen if there is selection bias, since the families are more involved with the healthcare service it's safe to assume that they have a higher knowledge than the cross sectional sample. Conversely, the families living in rural or remote areas, which often have poor access to healthcare services, could be demonstrated to have a lower awareness level even in populations from which this study was drawn.

Moreover, it also depends on the information supplied by individuals in the study, which might be infected by the biases into responses. Some participants may have overestimated their knowledge while others might have misunderstood some of the questions especially in case the used terms were unfamiliar or complex. This is particularly important when discussing such matters as genetic testing as those using lay language to refer to 'medical jargon', may not fully understand what is being said.

In order to extend knowledge from this paper and to evaluate the effectiveness of education in increasing awareness of thalassemia, subsequent studies are needed. Specific educational intervention based investigations that incorporate a program or crusade could provide direction on whether focussed education delivers the aimed augmentation in designed information in the less served regions. Such interventions may include local theatre and drama performance, printed materials such as pamphlets and subtle use of electronic media-based awareness campaigns, including individual counselled sessions, targeted to the local setting and cultural belief systems.

Future research should also analyse these campaigns focusing on the audience of rural and other low-populated areas where such information and related services are scarce. Exploring the impact and coverage of these campaigns may help a lot for achieving better awareness at community level.

However, studies should offer evidence of the sustained benefits of enhanced awareness including, but not limited to, requests for healthcare services, compliance with recommended medical therapies and prevention of new thalassemia cases. This could help give more information to establish health care policy and financing of thalassemia educational and prevention initiatives.

Third and last, more research would be useful with the aim of identifying possible cultural misconceptions regarding genetic diseases and if these misconceptions are eliminated, they could help create better educational tools and approaches.

Conclusion

In conclusion, this study established the evidence that the parents and caregivers of the children with thalassemia had a reasonable level of knowledge of the disease symptoms but had poor knowledge on the genetic cause of the disease and how it could be prevented. These observations stress the need to increase familiarity to address problems of early detection and control of diseases. The absence of deep understanding of changes in the participants' perception once more emphasizes a necessity of introducing effective educational campaign aimed at parents and caregivers. Consequently, health care managers should provide awareness programs in clinical and community settings, particularly regarding genetic characteristics of thalassemia, preventive measures, and healthcare services to fill these knowledge deficits and enhance patients' outcomes.

References

[1] Rishmitha, "Awareness on thalassemia and opinion of carrier screening among young women from selected undergraduate colleges of udupi district," *Clinical Epidemiology and Global Health,* vol. 14, p. 100978, 2022.

[2] S. S. Datta, "Current challenges of blood transfusions in patients with thalassemia in India and future perspectives," *Transfusion Clinique et Biologique,* vol. 31, no. 3, pp. 162-166, 2024.

[3] M. P. Inayat Ur Rehman PharmD, "Challenges of having a child with thalassemia in Pakistan: A phenomenological study," *Journal of Pediatric Nursing,* vol. 72, pp. e179-e186, 2023.

[4] S. Nazari, "The survey on the relationship between frustration and social relationships among patients with Thalassemia major in Tehran, Iran," *International Journal of Africa Nursing Sciences,* vol. 17, p. 100441, 2022.

[5] S. Waseem, "The battle against Thalassemia in Pakistan: Way to move forward," *Transfusion Clinique et Biologique,* vol. 30, no. 2, pp. 177-178, 2023.

[6] N. Aziz, "Erythroid induction activity of Aquilegia fragrans and Aquilegia pubiflora and identification of compounds using liquid chromatography-tandem mass spectrometry," *Journal of King Saud University - Science,* vol. 33, no. 1, p. 101227, 2021.

[7] A. Farhad, "Prevalence of familial hypercholesterolemia in a country-wide laboratory network in Pakistan: 10-year data from 988, 306 patients," *Progress in Cardiovascular Diseases,* vol. 79, pp. 19-27, 2023.

[8] R. Jabeen, "Exploring the perceptions and experiences of female's with ß-thalassemia major in a Tertiary Care Private Hospital in Pakistan," *Transfusion Clinique et Biologique,* vol. 31, no. 4, pp. 244-252, 2024.

[9] A. Hanif, "Prevalence and severity of gingivitis in b-thalassemia Major patients," *International Dental Journal,* vol. 74, pp. S407-S408, 2024.

[10] H. Setiawan, "The effect of mobile application based genetic counseling on the psychosocial well-being of thalassemia patients and caregivers: A randomized controlled trial," *Patient Education and Counseling,* vol. 130, p. 108457, 2025.

[11] R. Njeim, "Unmet needs in β-thalassemia and the evolving treatment landscape," *Transfusion Clinique et Biologique,* vol. 31, no. 1, pp. 48-55, 2024.

[12] B. A. A. MD, "Thalassemia and iron overload cardiomyopathy: Pathophysiological insights, clinical implications, and management strategies," *Current Problems in Cardiology,* vol. 50, no. 1, p. 102911, 2025.

[13] A. Vitrano, "Development of a Thalassemia International Prognostic Scoring System (TIPSS)," *Blood Cells, Molecules, and Diseases,* vol. 99, p. 102710, 2023.

[14] H. S. M.Si.Med., "The role of nurses to control beta thalassemia disease in Indonesia: A perspective," *Journal of Taibah University Medical Sciences,* vol. 18, no. 5, pp. 964-966, 2023.

[15] R. A. Shaker, " Deferasirox adherence in patients with thalassemia: Exploring the association with patient knowledge and ferritin levels," *Pharmacia,* vol. 71, pp. 1-6, 2024.

[16] S. S. PhD, "The Need for Translational Epidemiology in Beta Thalassemia Syndromes: A Thalassemia International Federation Perspective," *Hematology/Oncology Clinics of North America,* vol. 37, no. 2, pp. 261-272, 2023.

[17] A. S. C. Chai, "Non-compliance to iron chelation therapy in patients with transfusion-dependent thalassaemia," *Pediatric Hematology Oncology Journal,* vol. 6, no. 4, pp. 207-215, 2021.

[18] N. Agarwa, "The DKMS-BMST Thalassemia program: Description, scope and impact," *Pediatric Hematology Oncology Journal,* vol. 8, no. 3, pp. 158-160, 2023.