

“A STUDY ON THE PSYCHOSOCIAL IMPACT OF THALASSEMIA ON THE QUALITY OF LIFE OF CHILDREN WITH THALASSEMIA”

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Abstract:

Thalassemia, an inherited blood disorder affecting millions globally, poses profound challenges, particularly for children, encompassing physical, emotional, and social dimensions. This study investigates the psychosocial impact of thalassemia on the quality of life of affected children and their families, employing a mixed-method approach across various Chennai hospitals specializing in thalassemia treatment. Through non-probability snowball sampling, participants are identified to capture the experiences inherent to this population. Utilizing validated scales the DASS and KIDSCREEN 10 alongside tailored questionnaires, the research uncovers a spectrum of psychological distress among respondents, with 44% within the normal range, 24% exhibiting mild symptoms, 12% moderate, 18% severe, and 2% extremely severe. The study sheds light on the socioeconomic dynamics within these families, where fathers predominantly engage in daily wage labor or formal employment, while mothers primarily assume caregiving roles, often foregoing full-time employment. Despite the prevalence of depression falling within normal ranges, discrimination against thalassemia-afflicted children persists, underscoring the necessity for inclusive environments. The research also highlights educational challenges, with a significant proportion struggling to keep pace academically, prompting the advocacy for holistic support mechanisms. Recognizing the fundamental role of Social Workers, the study advocates for their involvement in school settings to provide comprehensive assistance, bridging the gap between physical and psychological needs. The findings of the study emphasize the importance of governmental and non-governmental initiatives in ensuring the effective dissemination of resources to mitigate the hardships faced by those most vulnerable.

Keywords: Thalassemia, Psychosocial impact, Quality of life, Children, Intervention

Introduction:

“Every person with a disability is an individual”, said by Itzhak Perlman clearly states that disability is not only for certain individuals but each one acquires it over a while. Thalassemia is an inherited blood disorder caused when the body doesn't make enough of a protein called hemoglobin, an important part of red blood cells. (Centre for diseases control and prevention. Thalassemia was first linked to an irregular hemoglobin structure in 1946. Some people experience symptoms from birth. Others can take several years to show any results. Around the globe, Thalassemia affects approximately 4.4 out of every 10,000 live births throughout the world. In our country, an average of 5 crore Indians are thalassemia carriers. Every year around 12,000 children are born with beta-thalassemia major in different states, castes, and communities. (Taylor & Francis online). Being a child with thalassemia the major issues the children face is depression, anxiety and stress. Children with Thalassemia patients have lower adaptive behavior and communication. Thalassemia majorly has mild affection for psychosocial and adaptive functioning (Elzaree.F.A.,2018). Quality of life is majorly affected in Children with Thalassemia, their emotional functioning is lower than physical, school, and social functioning (Jajhara.I., 2021). Children with Thalassemia major should undergo regular blood transfusions. Transfusion-dependent patients face behavior disturbances and suffer from a combination of psychopathologies. There was a high impact of psycho-social issues in children with thalassemia, people who are treating thalassemia should screen and manage the psycho-social disturbances and it should also be a part of regular management protocol (Kumaravel.K.S., 2016). Parents often face negative responses from society. They are hesitant to talk

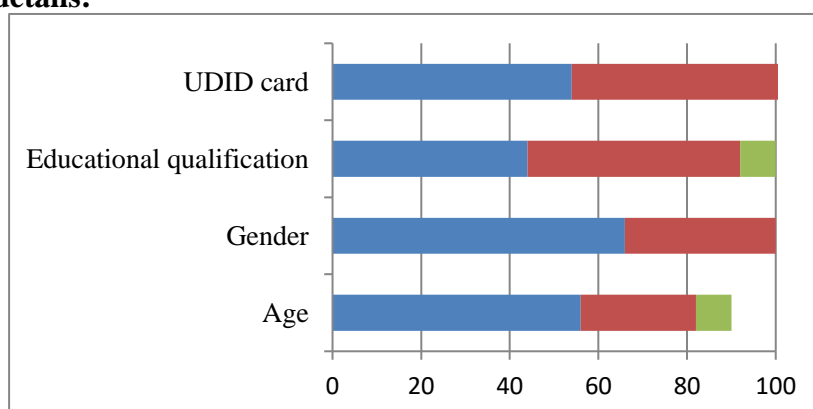
about illness with others, even a few people think that the birth of a child with thalassemia is a god's punishment for sin. This study may provide insights on the specific issues and give ideas to provide suitable interventions for children with Thalassemia, to reduce the various problems faced by them due to psychological and social factors and make an inclusive society for them. The major reason to do this research at this point is that every individual in this world is disabled at a certain point of a time in their life due to various reasons, but children with thalassemia are disabled by birth and face various complications either physical, social, emotional, financial or due to other aspects. In this generation, we have a shift from a social approach to a human rights approach toward disability which clearly states in enabling inclusive environments. As a Professional social worker, the researcher feels responsible for studying the barriers of children with thalassemia in the advanced improvement of the medical world. The need and significance of this research topic is to provide evidence-based information that can help improve the quality of life of children with thalassemia and their families by addressing their psycho-social needs and challenges. It can also help raise awareness and advocacy for this population and promote better health care and social policies for them.

Methodology:

The main objective of the research is to study the psychosocial impact of Thalassemia on the quality of life of children with thalassemia. The field of study is at various hospitals in Chennai where children are undergoing their treatment for thalassemia. A pilot visit was done at Voluntary Health Services to check the feasibility of the participants. The researcher utilized a mixed-method approach, by combining quantitative and qualitative methods to collect and comprehensively explore the psycho-social impact of thalassemia on the quality of school life among children with the condition and the experiences of their parents. The researcher applied a non-probability sampling method due to the unknown population size and the challenges associated with participation. Specifically, snowball sampling was used to identify participants from hospitals with an acceptance of children undergoing treatment for thalassemia, starting with the initial contacts made during the pilot visit. This tool is used to collect appropriate data through verbal and non-verbal communication by making the respondents understand each question. The tool also consists of the DASS (Depression, Anxiety, Stress Scale) scale KIDSCREEN 10 scale. A pre-test was conducted with 6 respondents with 20 self-prepared questionnaires which aimed to study the feasibility and reliability of the research tool.

Analysis and Interpretation:

Demographic details:



Most participants constituting 56% fall within the 8-11 age group, indicating younger individuals among the participants. The next age group 12-15 years comprised 36% of the participants. The least represented group consists of participants between the age group of 16-19 years, accounting 4% of the participants. 66% fall under the male category and the rest 34% of the participants fall under the female category. 48% falls under the group of secondary education. The next group of 44% of participants falls under the group of primary education. The least represented group consists of

participants pursuing higher secondary education which is 8%. Most participants constituting 54% have UDID cards, whereas 46% of the participants don't have UDID cards.

DASS score of the respondents:

| S.no | DASS score | Percent |
|------|------------------|---------|
| 1 | Normal | 44 |
| 2 | Mild | 24 |
| 3 | Moderate | 12 |
| 4 | Severe | 18 |
| 5 | Extremely severe | 2 |

The overall DASS score range of the respondents. 44% of the respondents fall under the normal range, 24% of the respondents fall under the mild range, 12% of the respondents fall under the moderate range, 18% of the respondents fall under the severe range and 2% of the respondents fall under the extremely severe range.

School functioning aspects:

| S.no | Domains | Yes | No |
|------|--|-----|----|
| 1 | Attention to class | 62 | 38 |
| 2 | Keep up with school work | 28 | 56 |
| 3 | Missing their school | 72 | 28 |
| 4 | Missing their class | 42 | 58 |
| 5 | Teachers support | 62 | 38 |
| 6 | Friends assistance | 54 | 46 |
| 7 | Ability to perform well in academics | 48 | 52 |
| 8 | Ability to perform well in extra-curricular activities | 44 | 56 |

38% of the respondents mentioned that they are not able to pay attention to their class. 46% of the respondents mentioned that they can keep up with their schoolwork. The majority 72% mentioned that they miss their school when they are not feeling well. 42% of the respondents mentioned that they miss their classes due to doctor's visits. 38% of the respondents mentioned that their teachers don't support them with their homework. 54% of the respondent's friends help them with class notes when they are absent. 52% of the respondents mentioned that they don't perform well academically. 56% of the respondents mentioned that they are not able to perform well in extra-curricular activities.

Case Study Interpretation:

Among the participants majority of the fathers were working for daily wages and the rest of the participants were working for a company and involved in business.

Among the participant's majority of the mothers were homemakers since they were forced to take additional care for their children. 2 participants mentioned that they are involved in a part time job.

Most of the parents feel emotionally weak to see their child facing difficulty during examination and recreational activities. The parents feel that extra care is needed for their children. Among them, a participant mentioned that

"Everyday is a challenge to know if my child is okay or not"

Most of the participants mentioned that their children face challenges in daily activities during the last few days of transfusion or when the transfusion is delayed, as they feel low energy and tiredness. During these days their child is not able to actively socialize with others.

Few participants mentioned that their child used to be active and extroverted but nowadays they are quiet and don't like to interact much with others. Initially, it affected their children because they were confused about what is happening to them. A participant also mentioned that

“He used to cry silently when we restrict him from going out with his friends often. Sometimes he feels hopeless when he is unable to perform certain activities due to restrictions.”

Concerning their self-esteem most of the participants mentioned that they feel low when they cannot do things physically, especially during transfusion days. Among that 1 participants mentioned,

“My daughter thinks she can't do certain things like her friends and she created her own limitations, so her self-esteem is poor”.

The mothers are indirectly forced to leave their job or work only part time jobs to take care of their children and spend more time with them. A mother also mentioned,

“My husband thinks it's my fault for my children's condition. I can't go anywhere without my daughter”

Most of the participants mentioned that thalassemia has a severe impact on their children's Quality of life. A participant mentioned that

‘My biggest fear is about my child's future, whether he will finish school, go to college and get a job?’

The participants feel they are responsible for their children's future.

Suggestions to :

Social Workers:

- Encourage peer group of the children to paly recreational sessions to cope up with their anxiety.
- Educate the public about thalassemia and related myths around them.
- Encourage volunteering opportunities to make children with thalassemia involved in the community.
- Collaborate with doctors, nurses, NGO'S, and various other stakeholders to provide various network of support for family and children with thalassemia.
- Advocate for research initiatives to identify the possible problems and provide suitable interventions for children with thalassemia.

NGO:

- Offering counseling and therapy services to address anxiety, depression, stress issues among children with thalassemia.
- Organize social events and recreational activities to help connect children with thalassemia with their peer groups.
- Connect children, with thalassemia mentors who have experience, living with the condition facing similar challenges.
- Organize community awareness campaigns to educate the public about thalassemia and relying myths around it.
- Collaborate with other NGO'S, policy makers and advocacy groups to share resources and increase advocacy efforts.

Government:

- Provide financial assistance to NGO'S and community groups offering psycho-social support and community engagement opportunities for children with thalassemia.
- Launch national awareness campaigns to educate the public about thalassemia, emphasizing challenges faced by children.
- Invest in school based initiatives to promote inclusivity and acceptance.

Public:

- Practice empathy by showing compassion and understanding towards children with thalassemia and their families.
- Get involved with organizations that support children with thalassemia.
- Donate to worthy causes by contributing to the organization that provides essential support.
- Speak up against discrimination, challenge misconceptions and promote inclusive space for

Conclusion:

The study finds that range of depression is normal among children with thalassemia. Concerning the social aspect, half of the population faces discrimination due to their condition which indirectly says we have to work more to promote inclusive space for children with thalassemia. Corresponding to the school functioning majority of the respondent are not able to keep up with their school work. At this point, the researcher would like to bring in the point that, the role of a Social Worker in the School setting will be beneficial. Just like dealing with any other children with Disability, children suffering from Thalassemia also need a holistic approach and support system so that they can overcome challenges that are affected due to Physical and Psychological conditions. Government, NGO and various other stakeholders working for Children with Thalassemia should ensure that the existing schemes, assistance and other possible resources are reaching the expected and people in severe need.

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