“PREVALENCE OF DEPRESSION AND ANXIETY IN CHILDREN BETWEEN 8-18YEARS WITH BETA THALASSEMIA MAJOR: AN OBSERVATIONAL STUDY FOR A PERIOD OF 1 YEAR”

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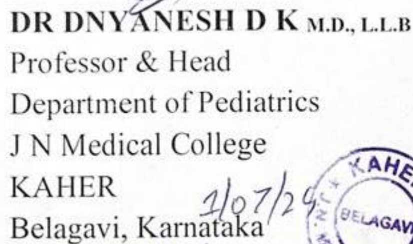
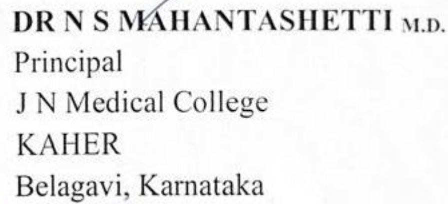

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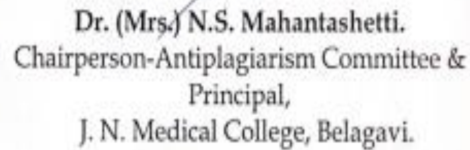

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ABSTRACT

Background

Beta Thalassemia Major (BTM) is a severe, chronic hematologic disorder characterized by a need for lifelong treatment, including regular blood transfusions and iron chelation therapy. Managing this chronic condition extends beyond physical health, presenting significant psychological and social challenges. The chronic nature of BTM and its demanding treatment regimen contribute to these elevated rates of mental health issues, impacting the quality of life and overall well-being of affected children. Identifying and managing psychological issues early is crucial for improving both immediate and long-term health outcomes for these children.

Objectives

The objectives of the study were to study the prevalence of depression and anxiety in children between 8-18years with beta thalassemia major, to study the quality of life in parents of children suffering from beta thalassemia and to study the sleep pattern of children suffering from beta thalassemia major

Methodology

A hospital-based cross-sectional study was conducted at KLEH Dr. Prabhakar Kore Hospital, Belgaum, Karnataka, from January 2023 to January 2024. The study included 100 children aged 8-18 years with BTM and assessed their mental health using the RCADS. Additionally, the quality of life of parents was evaluated using the WHOQOL-BREF, and children's sleep patterns were analyzed through structured questionnaires. Data were analyzed using descriptive statistics and appropriate comparative tests to identify significant factors influencing mental health and quality of life.

Result

The study had a gender distribution of 48% male and 52% female, and a mean age of 12.23±2.81 years.The mean RCADS total score for children with BTM was 13.53 ± 14.27, with separation anxiety symptoms prevalent in 35% of the children. The quality of life scores for parents indicated moderate physical (64.26 ± 15.83) and psychological health (61.01 ± 15.23), but significant challenges in social relationships (10.19 ± 1.46). The environmental score was moderate (25.22 ± 4.74). Children exhibited relatively stable sleep patterns, averaging 9.61 ± 1.50 hours per night, with minimal nighttime disturbances. The findings contrast with previous literature indicating higher rates of sleep disturbances and psychological issues in BTM patients.

Conclusion

Children with BTM in this study exhibited lower than expected levels of clinical anxiety and depression, except for separation anxiety. Caregivers face significant social challenges, underscoring the need for comprehensive support systems to improve the quality of life for both children and their families.

Keywords: anxiety, chronic disease, depression, RCADS, QoL, stress, thalassemia, BTM

LIST OF ABBREVATIONS

APA	American Psychiatric Association
BTM	Beta thalassemia major
CBC	Complete blood count
CBCL	Child Behaviour Checklist
CDC	Centre for Disease Control and Prevention
CSHQ	Children’s Sleep Habits Questionnaire
CSHQ	Children's Sleep Habits Questionnaire
DAS	Depression, anxiety, and stress
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
GAD	Generalized anxiety disorder
Hb	Haemoglobin
ICHOM	International Consortium For Health Outcomes Measurement
OCD	Obsessive-Compulsive Disorder
OSA	Obstructive sleep apnoea
QOL	Quality of life
RBC	Red blood Cells
RCADS	Revised Child Anxiety and Depression Scale
SD	Standard Deviation
TACIO	Transfusion-associated cardiac iron overload
WHO	World Health Organization

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1. INTRODUCTION

Beta thalassemia syndromes are a group of genetic blood disorders characterized by reduced or absent β-globin chain synthesis, resulting in reduced haemoglobin (Hb) in red blood cells (RBC), decreased RBC production, and anemia[1]. These syndromes result from mutations in the HBB gene, which provides instructions for making the beta-globin subunit of haemoglobin. Most thalassemia is inherited as recessive traits[2]. The severity of the condition can vary, and it is classified into different forms, including beta thalassemia major, intermedia, and minor[3]. Beta thalassemia major individuals have mutations in both HBB genes and often require blood transfusions frequently and continuing medical treatment. The beta thalassemia intermedia's symptoms vary widely, falling between the major and minor forms. Beta thalassemia minor, also known as beta thalassemia trait, causes mild anaemia symptoms and involves having one missing or defective beta-globin gene[4].

The condition can lead to complications such as iron overload, which may require chelation therapy to remove excess iron from the body[5]. Treatment strategies for beta thalassemia include blood transfusions, iron chelation management, hematopoietic stem cell transplantation, stimulation of fetal hemoglobin production, and gene therapy[1]. Medications such as luspatercept and hydroxyurea may also be prescribed to treat Thalassemia[6]. Bone marrow transplantation is a potential cure for some individuals[7]. Genetic counselling is important for persons with traits of beta thalassemia to understand the risk of passing the condition to their children[5].

Beta thalassemia major has a significant negative impact on the well-being of affected individuals, particularly children[8]. The condition is characterized by anaemia due to reduced functional haemoglobin levels and decreased production of red blood corpuscles, and reduced oxygen levels in the body[9]. Children with beta thalassemia major often require

frequent blood transfusions and lifelong medical treatment for lifelong. The symptoms can include progressive pallor, poor weight gain, fatigue, weakness, slow growth, and, in some cases, serious complications such as iron overload, which can affect the heart, liver, and endocrine system[4]. The impact of the disease on affected children can be substantial, requiring ongoing medical management and support. Treatment strategies for beta thalassemia major may include blood transfusions, iron chelation management, and, in some cases, gene therapy or hematopoietic stem cell transplantation[6].

Children with thalassemia major may face various psychological challenges that can impact their overall quality of life. It's important to address these psychological aspects to ensure the well-being of these children. Children with beta thalassemia major may experience emotional burden, hopelessness, and difficulty with social integration. The chronic nature of thalassemia and the need for ongoing medical interventions can contribute to feelings of anxiety and depression in children[8]. Anxiety may arise from concerns about medical procedures, potential complications, and the impact of the condition on daily life. These children may experience social and emotional challenges, such as feelings of isolation or being different from their peers. Suffering children may face challenges keeping up with their peers, potentially leading to frustration and a negative impact on their self-esteem[10]. Coping with the demands of the illness, including frequent medical appointments and treatments, can affect their ability to engage in social activities. Health-related absences and fatigue can impact a child's school attendance and academic performance[11].The disease and its treatment, such as blood transfusions and chelation therapy, can lead to social stigma and isolation, affecting the child's psychological well-being[12]. Fear of medical procedures, needles, or potential complications may be common among children with thalassemia[13]. Thalassemic children have been reported to show deficits in cognitive function, which can impact their academic performance and overall development[14]. The disease and its treatment, such as

blood transfusions and chelation therapy, can lead to social stigma and isolation, affecting the child's psychological well-being. Symptoms of thalassemia, such as fatigue and weakness, can impact the child's energy levels and ability to participate in physical activities, leading to reduced quality of life. Children with thalassemia may experience slow growth and development due to the disease's impact on their bodies and the side effects of its treatments[13]. Some children with thalassemia may experience pain and discomfort due to complications such as iron overload, which can affect their overall quality of life[15]. As children with thalassemia grow older, they face the transition from pediatric to adult healthcare. This transition can bring about uncertainty and concerns about managing their health independently[16]. The presence of a chronic illness can influence family dynamics, with parents and siblings adjusting to the demands of caring for a child with thalassemia. Balancing the needs of the affected child with those of other family members is essential for maintaining a positive family environment[17]. Developing healthy coping strategies and providing psychological support can help children manage their fears and anxieties. Facilitating connections with other children facing similar health challenges to reduce feelings of isolation[18].

It is essential to provide comprehensive care and multidisciplinary approach to care for children with thalassemia to help them cope with these challenges and improve their overall wellbeing and quality of life. Research studies specific to the Indian population can provide insights into the prevalence, risk factors, and effective interventions for psychiatric illness in Beta thalassemia major patients, contributing to better-informed and culturally sensitive healthcare practices. Therefore the current study was sought to estimate the prevalence of depression and anxiety in children with beta thalassemia major. The current study also aimed to study the quality of life of parents of suffering kids as well as sleep pattern of these children.

2. Review of Literature

Beta thalassemia major (BTM) is a hereditary blood disorder characterized by reduced or absent production of beta-globin chains, resulting in severe anaemia and often requiring lifelong medical management[19]. While advancements in medical care have significantly improved the prognosis for individuals with BTM, the psychosocial impact of the disease remains a critical aspect of holistic patient care[20]. Among the psychological challenges faced by children with BTM, depression and anxiety stand out as particularly significant concerns[21]. This review aims to explore the prevalence, risk factors, impact, and potential association with the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) criteria for depression and anxiety disorders in children aged 8-18 years with BTM. The review has following headings

2.1. Beta Thalassemia Major
2.2. Long term complications
2.3. Psychological Health
2.4. Prevalence of Depression and Anxiety
2.5. Sleep Habits in children with Beta Thalassemia Major
2.6. Quality of life of parents of in children with Beta Thalassemia Major
2.7. Thalassemia and its association with anxiety and depression

2.1. Beta Thalassemia Major

Thalassemia is a genetic blood disorder characterized by abnormal haemoglobin production, leading to a reduction in the oxygen-carrying capacity of red blood cells. There are two main types: alpha thalassemia and beta thalassemia, depending on which part of the haemoglobin molecule is affected[22]. BTM was originally described by an American physician, Thomas Cooley in 192. BTM is also known as Cooley's anemia[23].

2.2.1. *Causes*

The most common cause of beta thalassemia is an HBB gene mutation. In exceedingly rare situations, the illness is caused by deletion, which includes the HBB gene. Instructions for the production of proteins which play an important part in many functions of body are provided by genes. The protein product may be defective, inefficient, or nonexistent due to mutation of gene which can influence a variety of organ systems in the body based on the role of the specific protein. Mutation in one HBB gene occurs in case of individuals with beta thalassemia minor and these are carriers of the illness whereas mutations in both HBB genes occur for individuals with beta-thalassemia intermedia or major[24].

Normal hemoglobin is composed of specialized proteins known as globin, which consist of a central heme ring attached by two beta and two alpha chains. Chains of beta globin proteins are encoded from HBB gene. In spite of, the unaffected second copy of the HBB produces enough protein to prevent symptoms, there will be low or no production of these proteins in case of mutation in one of the HBB gene and red blood cells remain unusually tiny to cause mild anemia. In beta thalassemia intermedia, there will be severely reduced amounts of beta chains where as in case of beta thalassemia major there would be a complete absence due to a mutation in two HBB genes. This causes an imbalance with the typically formed alpha globin protein chains, resulting in poor red blood cell production, a lack of functional hemoglobin, and a failure to provide adequate oxygen to the body. In people with dominant beta thalassemia, the mutant HBB gene produces highly unstable hemoglobin. Affected people have erythropoiesis (poor red blood cell production).[9]

According to researches additional factors such as modifier genes influence the disease severity. Modifier genes influence the clinical severity of disease, unlike the gene that causes disease itself.[28]

Recessive genetic illnesses develop when a person receives a defective gene from both parents and Beta thalassemia is inherited as an autosomal recessive trait. If a person inherits one normal gene and one faulty gene, they will be a carrier of the disease but will not normally exhibit symptoms. Each pregnancy increases the likelihood of two carrier parents passing the faulty gene and having an afflicted child by 25%. With each pregnancy, there is a 50% chance of having a carrier child as parents do. There will be only 25% chance of a child to inherit normal genes from both parents. The risk is equal for both the genders.[29]

2.2.2. *Signs and Symptoms*

BTM is a severe genetic condition that manifests early in life, with a wide array of symptoms primarily driven by severe anemia and iron overload due to frequent blood transfusions. Infants exhibit symptoms like fatigue, jaundice, growth failure, and skeletal deformities. Splenic complications further exacerbate anemia and increase the risk of infections and bleeding. Over time, iron overload leads to significant damage to the heart, liver, and endocrine glands, with serious and potentially life-threatening complications. Lifelong medical care, including regular blood transfusions and iron chelation therapy, is essential for managing BTM and mitigating its severe impacts. Symptoms are discussed in detail below

Within the first two years of life, affected newborns develop symptoms, typically between three and six months after birth. Severe anemia manifests as weakness, fatigue, dizziness, shortness of breath, yellowing of the skin and headaches, whites of the eyes (jaundice), and mucous membranes. Affected newborns frequently do not grow and gain weight as expected based on age and gender norms. Some neonates get increasingly pale. Infants will have feeding problems, diarrhea, irritability, recurrent fevers, hepatomegaly, splenomegaly, and splenic complications[24].

Splenomegaly can induce enlargement and swelling of abdominal. Splenomegaly may be accompanied with a hyperactive spleen (hypersplenism), a disorder that occurs when the spleen accumulates and destroys an excessive number of blood cells. Hypersplenism can contribute to anemia in patients with increased risk of infection due to reduced white blood cells, and prolonged bleeding due to low amounts of platelets.[25]

BTM can cause the bone marrow to expand. The majority of the body's blood cells are created in the bone marrow. The bone marrow swells to compensate for persistent anemia. The aberrant expansion leads bones to thin, widen, and fracture. Affected bones may develop bone abnormalities, especially the long bones of the arms and legs, as well as specific face bones. When facial bones are compromised, it can cause distinguishing facial traits such as an unusually large forehead, full cheek bones, a low nasal bridge, and hypertrophy of the upper jaw which exposes the upper teeth. The damaged bones in the legs and arms especially the long bones are more likely to fracture. Few of them may develop 'knock knees' (genu valgus), Knock knees are characterised by the inward bending of legs which leads to touching of the knees even if the ankles and feet do not in when the individuals stand.[26]

Even after treatment iron may buildup in the body (iron overload). Iron overload is caused by the blood transfusions. Furthermore, affected individuals absorb more iron from the gastrointestinal system, contributing to iron excess. Iron excess can harm tissues and impede organ function, including the liver, endocrine glands and heart. Iron overload can harm the heart by producing irregular heart rhythms, pericarditis (inflammation of the membrane that lines the heart), heart enlargement, and dilated cardiomyopathy. Heart involvement can lead to life-threatening consequences like heart failure. Liver involvement can result in liver cirrhosis (scarring and inflammation), as well as portal hypertension in the major liver vein. Involvement of endocrine gland can result in hypothyroidism and, in rare

situations, diabetes. Iron overload has also been linked to growth retardation and the delay/failure of sexual maturation.[27]

2.1.2. Epidemiology

Beta Thalassemia is the most frequent autosomal recessive condition in the world. The general population's incidence of symptomatic cases is estimated to be about one in per 100,000. The disorder is most common in the Africa, Middle East, Mediterranean, the Far East, Central Asia, and the Indian subcontinent. A higher probability of developing beta thalassemia is seen in other parts of the world in individuals whose family come from these regions. 7% of the global population is a carrier of Thalassemia and 7% of the global population has thalassemia genes, with Asia accounting for 40% of them[30]. Every year, between 50,000 and 100,000 children died from thalassemia, with underdeveloped countries accounting for approximately 80% of the total. Approximately 1.5% of the global population has thalassemia. Thalassemia major kills between 50,000 and 100,000 children each year, with at least 3000 dying in their teens or early 20s from uncontrolled iron overload. This disorder is 90% prevalent in low-income or developing countries.[1]

2.1.3. *Diagnosis*

Beta thalassemia is diagnosed by identifying typical symptoms, doing a clinical evaluation, and performing a series of specialist testing. Initial indications of BTM, such as anemia, swollen abdomen and failure to thrive are common in the initial couple of years of life. In several jurisdictions in the United States, newborns are identified with a hemoglobin problem during new born screening a public health initiative that examines newborn newborns for a number of illnesses that are treatable but not immediately noticeable at birth. Each state's newborn screening program is distinct, as are the specific abnormalities tested for.[23]

Beta Thalassemia suspected individuals will have blood testing, such as a CBC (complete blood count). Hemoglobin electrophoresis is a specialized blood test that examines the many forms of hemoglobin contained in blood.[23]. A CBC is performed to determine the amount of hemoglobin as well as the number, shape, and size of RBC, which are less and smaller in size than in healthy people. RBC can also be pale in hue (hypochromic) and poikilocytosis (have various forms). Observation under microscope shows uneven distribution and a unique target appearance of RBC of beta thalassemia patients. A blood sample can be examined to determine the ferritin levels, which is commonly high in beta thalassemia patients.[31]

2.2. Long term complications

Long-term complications of beta thalassemia major include a range of medical issues that can significantly impact the health and quality of life of affected individuals. These complications result from chronic anaemia, iron overload, and the effects of treatment modalities. Here are the key long-term complications associated with beta thalassemia major

2.2.1. Chronic Anaemia

Chronic anaemia in beta-thalassemia patients is a significant concern due to the reduced or absent synthesis of the globin chain of haemoglobin. It can lead to fatigue, weakness, pallor, shortness of breath, and reduced exercise tolerance. Without regular blood transfusions, individuals with BTM may experience life-threatening complications due to severe anemia[32].

Managing chronic anaemia in beta-thalassemia patients involves treatments like blood transfusions to increase red blood cell count and oxygen-carrying capacity. Additionally, individuals may be prescribed folic acid supplements to aid in red blood cell development. However, the repeated blood transfusions can lead to iron overload, necessitating chelation therapy to remove excess iron from the body and prevent complications associated with iron accumulation in vital organs[33].

2.2.2. Iron Overload

Numerous transfusions of blood, increased gastrointestinal iron absorption and inefficient erythropoiesis all contribute to iron overload. Iron overload weakens the immune system, putting patients at increased infection risk and disease. Serum ferritin levels can indicate iron excess.[27] The majority of iron in the body is stored as ferritin. Ferritin is secreted in small amounts into the body's plasma. In the absence of inflammation, the content of plasma (or serum) ferritin correlates favorably with the total Continuous transfusions always result in iron overload since humans are unable to actively eliminate excess iron. If iron excess is not treated, the cumulative consequences might result in substantial illness and mortality. A unit of red blood cells transfused contains roughly 250 mg of iron and the body can only excrete 1 mg of iron each day[34]. In the absence of chelation, 25 units per year transfusion in a patient results in acquiring 5 grams of iron per year.[35] As loading of iron increases, there mabe be increased ability of the major iron transport protein - serum transferrin to bind and detoxify iron. After then, the non-transferrin-bound percentage of iron within plasma may stimulate the production of free hydroxyl radicals, which propagate oxygen-related damage[36].

Regular blood transfusions, while necessary to manage anaemia, can lead to iron overload in the body since each unit of transfused blood contains a significant amount of iron. Excess iron accumulates in organs such as the heart, liver, and endocrine glands, leading to tissue damage and dysfunction. Iron overload can result in complications including liver cirrhosis, heart failure, diabetes mellitus, hypogonadism, and growth retardation. This excess iron can cause complications such as endocrine dysfunction, liver dysfunction, and cardiac dysfunction, similar to those observed in primary hemochromatosis.[32]

2.2.3. Cardiac Complications

Iron overload in the heart can lead to cardiomyopathy, arrhythmias, and heart failure, collectively known as transfusion-associated cardiac iron overload (TACIO). These cardiac

complications are a leading cause of morbidity and mortality in individuals with beta thalassemia major.[37]

2.2.4. Endocrine dysfunction

Iron deposition in the endocrine glands, particularly the pancreas, pituitary gland, and thyroid gland, can lead to endocrine dysfunction. Individuals with beta thalassemia major are at risk of developing various endocrine issues, including hypogonadism, hypothyroidism, diabetes, and hypoparathyroidism. These endocrine complications can impact hormonal balance and overall health, requiring careful management and monitoring.[37]

2.2.5. Liver Complications

Chronic liver hepatitis is a common complication in beta thalassemia major patients, which can progress to cirrhosis and, in rare cases, hepatocellular carcinoma. Liver dysfunction is a significant concern and requires close monitoring and appropriate medical interventions to prevent severe complications.[37]

2.2.6. Growth and Bone Health

Long standing beta thalassemia major resulting in chronic anaemia and ineffective erythropoiesis can lead to can lead to growth retardation, skeletal deformities, and bone abnormalities due to bone marrow expansion. Patients may experience stunted growth, bone deformities, and osteoporosis, affecting their musculoskeletal health and overall well-being. Additionally, iron overload and endocrine dysfunction contribute to bone demineralization and increased fracture risk.[32,37]

2.2.7. Infections:

Iron overload and splenic dysfunction increase the susceptibility to bacterial infections, particularly from encapsulated organisms such as *Streptococcus pneumoniae*. Individuals with BTM are at increased risk of sepsis, pneumonia, and osteomyelitis[38].

2.2.8. Psychosocial Impact

The psychological and social impact of thalassemia major significantly affects the quality of life and well-being of patients. Thalassemia major not only poses physical health issues such as damage to the heart, liver, lungs, and endocrine organs due to anaemia and iron accumulation but also leads to mental and social problems due to the congenital nature of the disease and its lifelong duration.

The thalassemia major experience a range of psychosocial challenges, including difficulties in coping with the chronicity of the disease, the need for lifelong blood transfusions, body image disorders, social stigmatization, high treatment costs, educational and employment challenges, and the impact on family dynamics. These psychosocial problems can significantly impact the mental health and overall quality of life of individuals living with thalassemia major. Moreover, the psychosocial impact extends beyond the patients themselves to their caregivers, who also face emotional challenges and stress. Factors such as lower academic achievement, economic resources, and the need for specific medications can increase the vulnerability to depression among individuals with beta-thalassemia.

Living with a chronic condition such as beta thalassemia major can have significant psychosocial consequences, including anxiety, depression, social isolation, and impaired quality of life. Psychological support and counselling are essential components of comprehensive care for individuals with BTM[13].

2.2.9. Transfusion-Related Complications

Transfusions pose hazards and problems. Thalassemia patients who rely on blood transfusions face hazards such as iron overload and accompanying endocrine issues, erythrocyte alloimmunization, transfusion reactions, and infections (such as hepatitis B,

hepatitis C, and HIV), and transfusion reactions.[39,40] These complications are mostly avoidable. Patients who understand their own transfusion histories and are aware of critical clinical practice recommendations can contribute to lowering their complication risk through their actions and conversations with clinicians[41].

2.2.10. Complications of Chelation Therapy

Iron chelation therapy is used to alleviate iron excess caused by its accumulation in various organs such as the liver and heart following regular transfusions. The iron burden in the body can be evaluated using serum ferritin, iron, and TIBC levels., By monitor both iron toxicity and the effects of excessive chelation, iron overload in thalassemia can be effectively treated.[42] The serum ferritin level is the most often used test to assess iron overload in Beta Thalassemia Major. A target ferritin level of around 1000 mg/l is widely suggested as standard practice in thalassemia major (TIF Guidelines, 2000) and other forms of iron overload caused by blood transfusion. When the serum ferritin level hits 1000 ng/l (usually after the tenth or twelfth transfusion), iron chelation therapy is typically initiated[27]. Orally administered chelating drugs, such as D-penicillamine or triethylene tetramine to mobilize copper and deferiprone and/or deferasirox to mobilize iron, can save lives[43]. Chelation therapy can lead to adverse effects such as gastrointestinal disturbances, renal dysfunction, and hypersensitivity reactions[44]

2.2.11. Other Complications

Additional complications associated with beta thalassemia major include thrombophilia, pseudoxanthoma elasticum, and an increased risk of infections due to asplenia or iron overload. These complications highlight the diverse range of health issues that individuals with beta thalassemia major may face over the long term, necessitating comprehensive medical care and management[37].

2.3. *Psychological Health*

The burden of living with a chronic illness such as BTM extends beyond the physical symptoms and treatment regimens. Children with BTM often face numerous psychosocial stressors, including frequent hospitalizations, painful medical procedures, and limitations in physical activities. Additionally, the necessity of adhering to a complex treatment regimen, including regular blood transfusions and iron chelation therapy, can contribute to emotional distress and disrupt daily life routines. These factors underscore the importance of addressing the psychological well-being of pediatric patients with BTM.

Children between the ages of 8 and 18 years with Beta Thalassemia Major may face various psychological challenges due to the chronic nature of the condition. Living with a chronic condition like Beta Thalassemia Major can lead to emotional challenges such as anxiety, depression, or feelings of isolation. They may face limitations in participating in certain physical activities or spending extended periods of time away from home due to medical treatments. This could result in social isolation and difficulties in forming and maintaining peer relationships. Due to the visible symptoms of the condition, children may experience stigma or discrimination from their peers, which can negatively impact their self-esteem and overall well-being. Frequent medical appointments and treatments can lead to missed school days, potentially affecting academic performance and social integration at school. Learning difficulties may arise due to the impact of the condition on cognitive functions. Psychosocial maladjustment affected 80% of patients with thalassemia major. Patients may encounter a wide range of emotional, psychological, and behavioral issues throughout their lives[13].

Managing a chronic illness can be overwhelming for children, and they may struggle with accepting their condition. Developing effective coping mechanisms is crucial for their mental health. Parents may experience stress and anxiety related to their child's health, which

can indirectly affect the child's psychological well-being. Support for both the child and their family is essential.

Bone growth causes typical mongoloid looks. This bone disease combined with iron overload and anemia in thalassemia adolescents frequently results in reduced height as well as late puberty. These characteristics raise adolescents' sense of oddness, which leads to worry, tension, low self-esteem, emotions of difference, poor self-image, and dependence, all of which contribute to social isolation and depression. Illness often causes pain and frustration, leading to suffering and anxiety. More importantly, people with chronic illnesses sometimes think that they will never recover. They are convinced that this ailment will always be with them because it is a part of them. As a result, teenagers with thalassemia were not permitted to play or participate in all of the typical activities in which their peers of the same age participated. As a result, people form a negative self-image and have low self-esteem. They avoid discussing their disease with friends for fear of being rejected or treated differently. Adolescents with low self-esteem and a devalued sense often seek praise and acceptance from others, leading them to accept things they loathe. All of these variables contribute to increased stress, anxiety, and depression in such teenagers with low self-esteem[45].

Psychological support, including counseling, peer support groups, and education about the condition, can play a crucial role in helping children navigate these challenges and improve their overall quality of life. Consulting with healthcare professionals, including psychologists and social workers, can also provide personalized strategies for addressing the psychological aspects of living with Beta Thalassemia Major

2.4. Prevalence of Depression and Anxiety

According to the Centre for Disease Control and Prevention (CDC), roughly 4.4% of children aged 3-17 years have been diagnosed with depression, while 9.4% have been diagnosed with anxiety[46]. Studies have indicated a higher prevalence of depression and anxiety among BTM patients, ranging from 12% to 60% and up to 54%, respectively [47,48]. The prevalence of depression and anxiety is significantly higher in BTM children compared to healthy children. The chronic nature of BTM can lead to increased stress, anxiety, and depression in children. The ongoing treatment and care requirements for BTM can contribute to feelings of isolation, social stigma, and emotional distress. The disease can significantly impact daily life, including school performance, social activities, and overall well-being, leading to increased mental health issues[47,49,50].

Studies examining the prevalence of depression and anxiety in children with BTM have reported varying rates, highlighting the heterogeneity of psychological experiences within this population. The children with BTM may be at increased risk of experiencing symptoms of depression and anxiety compared to their healthy peers. These symptoms can manifest as persistent sadness, feelings of hopelessness, irritability, and excessive worry or fear, adversely impacting their overall quality of life and functioning.

Rajput and colleagues (2015)[51] studied about the psychological challenges faced by primary caregivers of individuals with thalassemia in Hyderabad. The research aimed to assess the levels of depression, anxiety, and stress among these caregivers, shedding light on the mental health burden associated with caring for thalassemia patients. The study revealed moderate levels of depression (16.06%), anxiety (10.44%), and stress (19.11%) among primary caregivers of thalassemia patients in Hyderabad. Recommendations included the establishment of social and professional networks for psychosocial support, self-help groups, and counselling services to alleviate caregiver burden and provide holistic care.

Mugali *et al.* 2017[52] investigated anxiety levels in adolescents with thalassemia major. The study explored the prevalence of anxiety and its impact on the psychological well-being of adolescents affected by thalassemia major. The prevalence of anxiety was 38.71%, with the majority exhibiting mild intensity. Factors such as disease severity, treatment regimen, and psychosocial support have been considered in evaluating anxiety levels in this specific patient population.

Shukla and Dhaneria, 2022 [53] investigated the prevalence of behavioral problems in Thalassemia children aged 6 to 18 years and identified the factors influencing these issues. The study has utilized the Child Behavior Checklist (CBCL) to evaluate behavioral and emotional problems in the participants. Factors such as the duration of illness, parental attitudes, systemic complications of Thalassemia, and educational background of parents have been explored as potential contributors to behavioral problems in these children.

The study by Narula *et al.* 2022[54] aimed to evaluate levels of anxiety in chronically transfused Thalassemia children (8-18 years) and their parents in Amritsar, India. The results of the study have revealed insights into the anxiety prevalence among chronically transfused Thalassemia patients and the potential psychological burden associated with managing this chronic condition. Among adolescent children with thalassemia, 26% showed anxiety, with varying degrees of severity. By focusing on anxiety levels in both patients and their parents, the study likely aimed to provide a comprehensive understanding of the psychosocial aspects of thalassemia and the challenges faced by individuals undergoing long-term transfusion therapy.

Khadiya *et al.* 2023 [55] explored the mental health challenges faced by caregivers of children with β-thalassemia major. The research aimed to assess the prevalence of depression, anxiety, and the burden of care experienced by these caregivers. The findings likely revealed

that caring for children with β-Thalassemia major not only affects the children's well-being but also significantly impacts the mental health of their caregivers. The caregivers of children with β-Thalassemia major experience elevated levels of depression (35%) and anxiety (14%), in addition to bearing a substantial burden of care associated with managing the condition.

The study by Sahu *et al.,* 2023[56] sheds light on the psychological challenges faced by children with thalassemia and the burden experienced by their caregivers. The study involved children with transfusion-dependent thalassemia and their caregivers, assessing psychiatric morbidity and caregiver burden. Results showed that more than 32 children exhibited psychosocial problems, emphasizing the need for mental health support in thalassemic children. Caregivers experienced moderate burden in various domains such as general strain, isolation, disappointment, emotional involvement, and environment. A high percentage of children (65.3%) and parents (62.7%) were diagnosed with psychiatric problems, indicating the significant psychological impact of thalassemia on both patients and caregivers. Among over all children, 19.6% and 15.2% children exhibited anxiety and depression respectively.

Khoury *et al.* (2012)[57] found that the majority of individuals with β-thalassemia major were depressed. Yengil *et al.* (2014)[58] found that patients with Beta thalassemia major and their caregivers in Turkey experience higher rates of depression, stress, and anxiety, negatively impacting both physical and mental quality of life. Researchers, Khamoushi *et al.* (2015)[59] found that major thalassemia patients in Kermanshah county experienced severe anxiety, depression, and stress.

Behdani *et al.,* 2015[60] explored the psychological impact of thalassemia on young individuals in Iran. The study assessed psychological aspects in Iranian children and adolescents with thalassemia major compared to healthy subjects. Children with thalassemia major exhibited higher rates of depression (31%), anxiety (26.7%), and behavioral problems,

indicating a greater psychological burden in this patient group. Additionally, thalassemia patients had lower QOL scores compared to their healthy peers, highlighting the negative impact of the condition on their overall well-being.

Maheri et al. (2018)[61] conducted a study on depression, anxiety, and perceived social support among people with Beta-thalassemia major in Iran, and discovered that adolescents thalassemia major have greater psychological issues than healthier ones.

Venty *et al.,* 2018[62] focused on investigating the prevalence of depression among children with thalassemia major and identifying the factors that contribute to this mental health condition. The study aimed to determine the prevalence of depression in children with thalassemia major and explore the factors that may influence the development of depression in this population. The findings likely revealed a significant prevalence of depression (34.4%) among children with thalassemia major, highlighting the psychological challenges faced by these young patients. Factors such as the impact of chronic illness, treatment burden, physical health status, and psychosocial factors may have been investigated to understand their association with depression in children with thalassemia major.

Zoalyl *et al.,* 2020[47] assessed the prevalence of depression, anxiety, and stress (DAS) symptoms in individuals with BTM in Saudi Arabia. The study included adolescents and adults with BTM and discovered that depression symptoms were present in 60% of patients, anxiety symptoms in 50% of the group, and stress symptoms in 38.7% individuals. There was statically significant positive correlation among DAS and the total DASS score, highlighting the co-occurrence of these psychological symptoms in BTM patients. Factors such as age, patient's educational level, parent's employment, and medical care satisfaction were found to have a statistically significant impact on the scores of DAS symptoms. The study's conclusions emphasized that BTM patients are vulnerable to developing psychological

disorders, which can influence the progression of the disease. The DAS symptoms prevalence in BTM patients in Saudi Arabia was comparable to Arab population and international studies indicating a significant psychological burden in this patient group. The study highlighted the high prevalence of depression (34.4%), anxiety (23%), and stress symptoms in individuals with BTM in Almadinah Almunawwarah, Saudi Arabia.

El-said *et al.,* 2021[45] investigated the psychological impact of Thalassemia on adolescents. The research assessed the prevalence of anxiety, stress and depression in Thalassemia adolescents. The study highlighted that individuals with thalassemia are exposed to higher levels of emotional distress due to their symptoms, potentially affecting adolescents and adults. Findings from the study indicated that a significant proportion of thalassemia patients experienced clinical levels of depression, emphasizing the psychological challenges faced by this population. The study revealed that factors such as heart failure, frequent hospitalization, diabetes mellitus, short stature, and delayed puberty were associated with depression symptoms in individuals with thalassemia.

Overall summary of studies discussed above are tabulated in the Table 1 below

Table 1: Summary of studies on anxiety and depression in children with beta Thalassemia

Author and year	Sample size	Age range	Country	Prevalence (%)	
				Anxiety	Depression
Rajput *et al.,* 2015[51]*	79	--	India	16.6	10.44
Mugali *et al.* 2017[52]	31	10-18	India	38.71	--
Shukla and Dhaneria, 2022 [53]	180	6-18	India	--	--
Narula *et al.* 2022[54]	100	8-18	India	26	--
Khadiya *et al.* 2023[55]	100	8-18	India	14	35
Sahu *et al,* 2023[56]	46	4-16	India	19.6	15.2
Yahia *et al.,*2013			Egypt		32.1
Yengil *et al.,* 2014[58]	88	14-41	Turkey	38.6	20.5

Khamoushi *et al.*, 2015[59]	64	14-58	Iran	60.9	59.4
Adib-Hajbaghery et al., 2015[63]	198	12-18 and ≥19	Iran	58.4	58.4
Behdani *et al.*, 2015[60]	60	7-18	Iran	30	26.7
Zolaly *et al.*, 2020[47]	31	14-	Saudi Arabia	50	60
El-said *et al.*, 2021[45]	112	10-19	Egypt	54.5	23.5

*study on caregivers alone

Patients with thalassemia have a lower quality of life than their peers, and they are more likely to experience despair, anxiety, and stress than healthy individuals. As a result, efforts should be made to develop and test a variety of interventions, including those for health education and promotion, in order to reduce depression and anxiety among these patients. This is obvious that adolescents suffering from thalassemia are susceptible to many health problems, particularly those connected to psychological, mental, and emotional dimensions indicated by severe depression, anxiety, and stress.[45]

2.5. Sleep Habits in children with Beta Thalassemia Major

Sleep habits in children with beta thalassemia major have been found to be significantly disrupted compared to those of healthy children. Several studies have reported that children with beta thalassemia major experience more sleep disturbances, including night waking, sleep disordered breathing, and daytime sleepiness[64–66].

Children with beta thalassemia major have been found to have impaired sleep function, which is partially related to periodic limb movements and arousals, leading to daytime sleepiness[64,65]. Parents of children with beta thalassemia major reported more night waking compared to healthy children[65]. Higher prevalence rates of obstructive sleep apnea (OSA) have been observed in children with severe beta thalassemia. Children with beta thalassemia major have been found to have increased daytime sleepiness, which may be related to the

sleep disruptions they experience[64,65]. Sleep anxiety is also more common in children with beta thalassemia major[66].

One study found that parents of children with beta-thalassemia major reported higher rates of sleep problems, including night waking and sleep-disordered breathing, compared to healthy children[66]. Another study used the Children's Sleep Habits Questionnaire(CSHQ) to compare sleep habits between children with beta-thalassemia major and healthy controls, finding significant differences in total scores, bedtime resistance, and night waking subscores[65].

The CSHQ has been used in various studies to assess sleep problems in children with thalassemia major, and its results have been found to be consistent with the literature on sleep disturbances in this population[65–67]. The questionnaire is a useful tool for healthcare providers to identify and address sleep issues in children with thalassemia major, which can have significant impacts on their overall quality of life.

It is essential to evaluate sleep disturbances in children with beta thalassemia major during routine clinical appointments to identify and address these issues. Cooperating with parents to create a more suitable sleep environment, such as a quieter environment, can improve sleep efficiency and quality. Educating parents and children about efficient sleep and the importance of bedtime routines can increase sleep efficacy. Addressing sleep problems in children with beta thalassemia major is crucial for improving their overall daily functioning, development, and ability to cope with the symptoms of the disease [65].

2.6. Quality of life of parents of children with Beta Thalassemia Major

The quality of life (QoL) of parents of children with beta thalassemia major is significantly impacted due to the chronic nature of the disease and the continuous stress and strain they face in providing care for their children[13]. Several studies have reported that

parents of children with beta thalassemia major experience a range of negative effects on their QOL.

The ongoing treatment, frequent hospitalizations, and medical follow-ups can lead to significant financial strain on the family. Parents of children with beta thalassemia major often experience high levels of emotional stress, anxiety, and depression due to the constant worry about their child's health and the impact on their own well-being[68,69]. Sleep disruptions are common among parents of children with beta thalassemia major, which can further exacerbate their emotional and physical well-being[68]. The constant need for medical care and the stigma associated with the disease can lead to social isolation and feelings of loneliness among parents. The care requirements of children with beta thalassemia major can significantly impact the daily lives of parents, including their work and social activities [69].

The WHOQOL-BREF is a widely used, standardized questionnaire to evaluate quality of life across various dimensions, including physical health, psychological health, social relationships, and environmental factors. Several studies have utilized the WHOQOL-BREF to assess quality of life in patients with thalassemia major, including both adults and children. A large study involving 250 thalassemia major patients and 51 healthy controls found that thalassemia patients had significantly lower quality of life scores across all 6 dimensions measured by the WHOQOL-BREF compared to the control group. It was found that factors associated with better quality of life scores in thalassemia patients included higher education level, lower ferritin levels, and use of oral iron chelators. Comorbidities like cardiac disease, hepatitis C, and psychiatric disorders were linked to poorer quality of life[70].

A study focused specifically on children with thalassemia major over 7 years of age found that their quality of life was above average in the physical health, psychological

health, and environmental health domains, but below average in the social relationships domain[71].

A study on children with Thalassemia aged 8 to 18 years highlighted the importance of assessing quality of life in children with chronic illnesses like thalassemia. The study utilized the WHOQOL-BREF questionnaire tool to evaluate quality of life in thalassemic children. The study revealed that Thalassemia Major affects school-age children's quality of life. 30% of children reported good QOL scores, compared to 35% from parents. Emotional functioning scored the lowest. 91% received regular transfusions; 81% were compliant with iron chelation[72].

2.7. Thalassemia and its association with anxiety and depression

The potential association with the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) criteria for depression and anxiety disorders in children aged 8-18 years with Beta thalassemia major (BTM) is a significant area of interest. Understanding how the DSM-5 criteria for depression and anxiety apply to paediatric patients with BTM can provide valuable insights into the mental health challenges faced by this specific population.

The Diagnostic and Statistical Manual of Mental Disorders, or "DSM," is a reference book for mental health and brain-related illnesses and disorders. This book was written, edited, reviewed, and published by the American Psychiatric Association (APA). The DSM-5 provides a standardized framework for the diagnosis and classification of mental health disorders, including depression and anxiety disorders, based on specific criteria[73]. While BTM itself is not listed as a psychiatric disorder in the DSM-5, the psychological symptoms experienced by children with BTM may align with the diagnostic criteria outlined in the manual. For example, symptoms such as depressed mood, loss of interest or pleasure, fatigue, and difficulty concentrating may meet criteria for major depressive disorder, while excessive

worry, restlessness, muscle tension, and irritability may be indicative of generalized anxiety disorder.

Research suggests that children with chronic illnesses like BTM may be at a higher risk of developing depression and anxiety disorders due to the physical and emotional burden of their condition. Factors such as chronic pain, frequent medical interventions, and limitations in daily activities can contribute to psychological distress in children with BTM. By examining how the DSM-5 criteria for depression and anxiety disorders manifest in this context, healthcare providers can better identify, assess, and address the mental health needs of these young patients. Early detection and intervention based on the DSM-5 criteria can lead to improved outcomes and quality of life for children with BTM who may be struggling with depression and anxiety.

The DSM-5 criteria for anxiety disorders include symptoms such as restlessness, feeling keyed up or on edge, being easily fatigued, and difficulty concentrating. These criteria help clinicians identify different types of anxiety disorders and provide a common language for diagnosing and treating these conditions[74].

The DSM-5 diagnostic criteria for depression, also known as major depressive disorder, outline the symptoms and duration required for a diagnosis. Meeting specific criteria for the duration and intensity of these symptoms is essential for diagnosing depression according to the DSM-5 guidelines[75].By adhering to the DSM-5 criteria for anxiety and depression, healthcare professionals can accurately assess, diagnose, and treat individuals experiencing these mental health conditions. The criteria serve as a valuable tool for ensuring consistency in diagnosis, facilitating communication among clinicians, and guiding appropriate treatment interventions tailored to the specific needs of individuals with anxiety and depression.

The management of beta thalassemia major requires a multidisciplinary approach aimed at preventing and managing these long-term complications while optimizing the individual's quality of life. Regular monitoring, comprehensive medical care, adherence to treatment regimens, and psychosocial support are essential components of care for individuals with beta thalassemia major.

These findings underscore the importance of addressing the psychological well-being of children with Beta Thalassemia Major due to the high prevalence of depression and anxiety within this population. Early detection and appropriate management strategies are crucial for improving the quality of life for these individuals. Understanding the association between depression and anxiety in children with BTM and the DSM-5 criteria is essential for accurate identification, diagnosis, and treatment of psychological distress in this population. By elucidating the prevalence, risk factors, and impact of depression and anxiety in children with BTM, healthcare providers can implement targeted interventions to address the unique psychosocial needs of these patients. Future research should focus on longitudinal studies to explore the trajectory of psychological symptoms over time and evaluate the effectiveness of interventions tailored to the specific needs of children with BTM. Ultimately, by integrating psychological support into comprehensive care models, healthcare providers can enhance the overall well-being and resilience of children living with BTM.

3. AIMS AND OBJECTIVES

Main aim of this study was:

"To study the prevalence of depression and anxiety in children between 8-18years with beta thalassemia major"

Objectives of the current study were

1. To study the quality of life in parents of children suffering from beta thalassemia major

2. To study the sleep pattern of children suffering from beta thalassemia major

4. MATERIALS AND METHODOLOGY

Data was collected from all the registered outpatient cases diagnosed of Beta Thalassemia Major of age group 8-18years visiting the Department of Paediatrics, KLE'S Dr Prabhakar Kore Hospital & Medical Research Centre, Belagavi, Karnataka.

Methods of Collection of Data:

The study design is a cross sectional type of descriptive study where the data was collected over a period of 1 year (January 2023 to January 2024) at KLE'S Dr Prabhakar Kore Hospital and Medical Research Centre, Belagavi, Karnataka

SAMPLE SIZE:

The sample size for the current study was calculated using following equation[76]

$$n = \frac{Z^2 P(1 - P)}{d^2}$$

Where n= sample size

Z= Z statistic for a level of confidence levelat = 1.960

P= Prevalence (67%)

Q= 100-P

d = precession (8.5%)

The prevalence of depression and anxiety in children between 8-18years with beta thalassemia major found to be 67% as per the study by Shaligram *et al.,*[77] Therefore with p = 67% at 95% confidence with 90 % power, the calculated sample size was 95. Hence total 100 patients (5% attrition rate 5 more added to 95) were included in the current study according to inclusion criteria.

A. Sampling technique

Purposive sampling was opted for sampling in the current study as the technique is intentional selection of informants. It is based on their ability to elucidate a specific theme, concept, or phenomenon. As utilized in qualitative and mixed methods research, purposive sampling involves an iterative process of selecting research subjects rather than starting with a predetermined sampling frame. The selection process involves identifying themes, concepts, and indicators through observation and reflection researchers often utilize a purposeful sampling technique to select informants based on their particular knowledge of, and/or experience with, the focus of empirical purposive sampling was chosen for the current investigation because it involves the intentional selection of informants. It depends on their capacity to explain a given theme, concept, or phenomenon. Purposive sampling, as used in qualitative and mixed methods research, is an iterative process of selecting study subjects rather than beginning with a fixed sampling framework. The selection process includes finding themes, concepts, and indicators through observation and contemplation. Researchers frequently use a purposive sampling strategy to select informants based on their specific understanding of, and/or experience with, the topic of empirical investigation.

B. INCLUSION CRITERIA

All the patients (both male and female) 8-18 age who were diagnosed of thalassemia major in the Department of Paediatrics, KLE's Dr Prabhakar Kore Hospital were included in the study**.** All the patients who had received blood transfusions and admitted in hospital at two to four weeks intervals with or without iron chelation therapy and gave informed consent were considered in the current study along with their parents.

C. EXCLUSION CRITERIA

Patients who were not willing to give consent, aged >18 years, and known cases of other types of anaemia requiring repeated blood transfusions or hospital admissions were excluded from the study. Patients with intellectual disability and other neurological illnesses were excluded from the study.

D. METHODOLOGY

The study was a Hospital based cross sectional study carried out in KLE’s Dr Prabhakar Kore Hospital from January 2023 to January 2024. After obtaining approval and clearance from the institutional ethics committee, the patients fulfilling the inclusion criteria were enrolled for the study after obtaining informed consent (Annexure - 1) after explaining to them the plan and intention of the study in the language they understand.

Demographic and clinical details of the children were collected using a semi-structured proforma that was developed for study (Annexure -2). The patients' anxiety and depression levels were examined using the Revised Child Anxiety and Depression Scale (RCADS Child). It is a 47-item questionnaire for measuring depression and anxiety symptoms in children and adolescents aged 8 to 18.

Validity and Reliability of the Scale:

Chorpita and colleagues (2000) developed the RCADS-Child, which they validated with a community sample of 1641 children and adolescents. Six indicators were identified, which are congruent with the DMS-IV illnesses of anxiety and depression. It was validated and approved by ICHOM (International Consortium for Health Outcomes Measurement). The RCADS-Child was also validated in an Australian population sample of children and adolescents aged 8 to 18 (N = 405). The sample was divided into two age groups, 8-12 years and 13-18 years old, and is used to derive percentile scores.[78]

The approved English questionnaire was translated into Kannada, Hindi, and Marathi and utilized to improve children's understanding. A Total Anxiety Scale score (total of the five anxiety subscales) and a Total Internalizing Scale score (sum of all six subscales) were calculated, with higher scores indicating more severe symptoms. In addition, scores for each of the six subscales were provided. The anxiety disorders interview schedule for DSM-IV, child and parent versions[79] was used as a comparison to establish the 'clinical thresholds' for the overall score.[80] The sub-scale criteria were determined using normative data. A t-score of 65 indicates that the score is roughly in the top 7% of scores of un-referred young people of the same age (described as borderline clinical by the developer), while a score of 70 indicates that the score is roughly in the top 2% of scores of un-referred young people of the same age (described as clinical threshold by the developer). Sub-scales were calculated by adding Separation Anxiety, Social Phobia, Generalized Anxiety, Panic Disorder, Obsessive-Compulsive Disorder, and Major Depression.

The WHOQOL-BREF is a 26-item instrument consisting of four domains(Annexure 3). This was used to assess the quality of life of the parents. The WHOQOL-BREF questionnaire is a self-administered tool developed by the World Health Organization (WHO) to measure the quality of life of individuals and populations. It consists of 26 questions that assess an individual's perceptions of their health and well-being over the previous two weeks. The questionnaire covers four domains: physical health, psychological well-being, social relationships, and environment, each with specific facets like activities of daily living, self-esteem, social support, and living environment. Responses are recorded on a 1-5 Likert scale, with 1 indicating "disagree" or "not at all" and 5 indicating "completely agree" or "extremely"[81–84]. The WHOQOL-BREF has been extensively researched and validated for reliability, validity, and cross-cultural applicability, making it a valuable tool for assessing quality of life in various populations and settings.

The Assessment of sleep pattern of children was done using The Children's Sleep Habits Questionnaire (Annexure 4). The Children's Sleep Habits Questionnaire (CSHQ) is a widely used tool to assess sleep problems in children and adolescents, including those with thalassemia major. The CSHQ is a 45-item parent-report questionnaire that evaluates various aspects of sleep, including bedtime resistance, sleep onset delay, night waking, sleep anxiety, daytime sleepiness, parasomnias, and sleep-disordered breathing[65–67]. But here we have used an abbreviated version of sleep pattern questionnaire.

Total 100 patients were included in the current study. The socio-demographic information, clinical characteristics of patients and other required information were collected. Every piece of information was meticulously entered into an excel spread sheet and used for statistical analysis.

STATISTICAL ANALYSIS:

Continuous variables were compared using independent T-test/ or a Kruskal-Wallis test, and categorical variables were compared using a $\chi 2$ test or fisher's exact test to test for differences across groups. Continuous variables are represented as mean ± SD (standard deviation) whereas categorical variable are presented as frequency and percentages (n(%)).P-values < 0.05 were considered statistically significant. To investigate the relationship between the explanatory and outcome variables, a univariate binary logistic regression analysis was used. The unadjusted odds ratio is shown, along with the 95% confidence interval. Variables having p-values less than 0.25 in univariate analysis were used to calculate multivariate regression analysis. The adjusted odds ratio, together with its 95% confidence interval, is shown. IBM, SPSS statistics software 23.0 Version and R version 4.2.2 statistical software was used for the statistical analyses. Microsoft word and Excel was used to generate graphs, tables etc wherever required.

5. RESULTS

The aim was to study the prevalence of depression and anxiety in children between 8-18years with beta thalassemia major, to study the sleep pattern of children suffering from beta thalassemia major along with the quality of life in parents of children suffering from the same. This hospital-based cross-sectional study was conducted for one year on all registered outpatient cases diagnosed with Beta Thalassemia Major of age group 8-18years who visited the Department of Paediatrics, at Dr Prabhakar Kore Hospital & Medical Research Centre, Belagavi, Karnataka between January 2023 and January 2024. After obtaining approval and clearance from the institutional ethics committee, 100 patients with Beta Thalassemia Major fulfilling the inclusion criteria were enrolled for the study after obtaining informed consent from their parents and ascent from the children.

Distribution of the study participants based on the Socio-demographic characteristics is tabulated in Table 2. Out of the enrolled 100 participants, 48% were male and 52% were female with mean age of 12.23±2.81 years. It was found that 55 study participants belonged to the age group of 8 to 12 years and 45 participants belonged to the age group of 12 to 18 years. There were total of 96 participants in the study group had schooling, with majority of them attending high school (44%) and higher primary school (35%). Figure 1 graphically represents the distribution of participants based on their socio demographic characteristics.

Table 2: Socio demographic characteristics of study participants (n=100)

Variables		Distribution (n=100)
Gender	Male	48
	Female	52
Age (years), mean ±SD		12.23±2.81
Age group	8 to 12 years	55
	12 to 18 years	45
Currently schooling	Yes	96
	No	4
Level of education	Lower primary	16
	Higher Primary	35
	High School	44
	+2/PUC	5

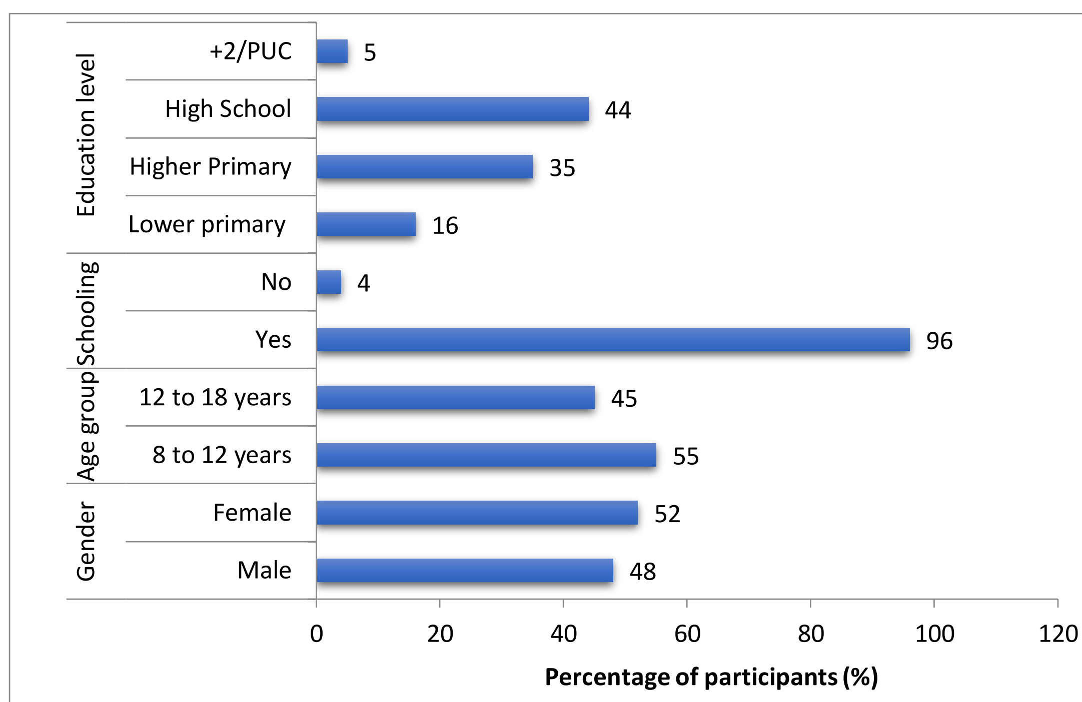

Figure 1: Bar graphs showing distribution of participants based on socio demographics characteristics

In the current study, family characteristics like number of siblings, number of family members, type of family, parents age and education were recorded (Table 3). Majority of the study participants had single sibling (50%) followed by 2 siblings (25%). In the study population, 46% participants had <5 members in the family and 45% participants had 5-8 members in the family, 79% participants belonged to nuclear families and only 15% belonged to joint families. Mean age of mothers and fathers of the participants was calculated to be 34.53 ±5.91 and 41.9 ± 7.48 years respectively. Majority of the mothers had education up to high school (47%) followed by primary school (26%) and there were 13% mothers who did not have any formal education. Among fathers, 16% did not have formal education, 30% educated up to high school and 24% till senior secondary school. Bar graph in Figure 2 shows the distribution of participants based on their family characteristics

Table 3: Family characteristics of study participants (n=100)

Variables		Distribution (n=100)
Number of siblings, n (%)	0	9
	1	50
	2	25
	>2	16
Number of family members, n (%)	< 5	46
	5-8	45
	>8	9
Type of family, n (%)	Nuclear	79
	Joint	15
	Extended	6
Parents' Age (years) Mean ± SD	Mother	34.53 ±5.91
	Father	41.9 ± 7.48
Education level of mother, n (%)	No formal education	13
	Pre Primary	1
	Primary	26
	High school	47
	Senior secondary	7
	Graduate	5
	Post graduate	1
Education level of father, n (%)	No formal education	16
	Pre Primary	1
	Primary	16
	High school	30
	Senior secondary	24
	Graduate	12
	Post graduate	1

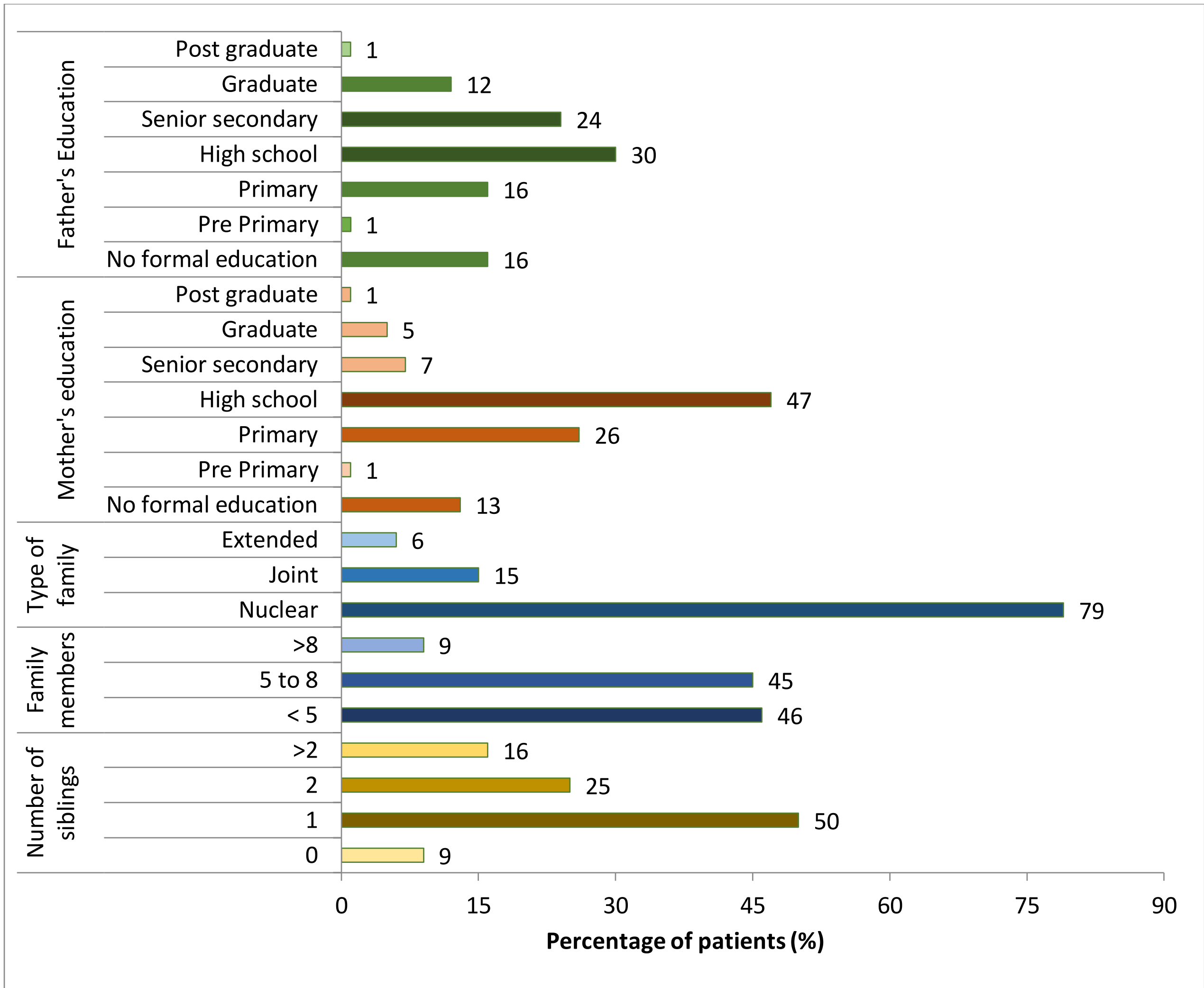

Figure 2: Family characteristics of the study participants

Illness parameters of the participants are shown in Table 3. Maximum participants of 60% were found to take a single drug. 6% of participants were taking hydroxyurea as extra drug. 43% patients had more than 25 times blood transfusion till now, 30% transfused between 20-25 times and 27% transfused < 20 times till now. Only in 9% of patients underwent splenectomy. Majority of the patients (98%) did not show any developmental delays where as 1 participant each had hearing loss and seizure episodes. Consanguinity was found in 44% of the participants. 27% patients had a family history of Thalassemia. Pictorial representation of distribution of participants with respect to illness parameters are shown in Figure 3

Table 4: Illness parameters of the participants

Variables		Distribution (n=100)
Number of drug taken (%)	1	60
	2	40
Extra drug taken (f any)	No	94
	Hydroxyurea	6
Total Blood Transfusion(%)	<20 times	27
	20-25 times	30
	>25 times	43
Splenectomy, (%)	Yes	9
	No	91
Developmental delay, (%)	None	98
	Hearing loss	1
	Seizure episodes	1
Consanguinity	Yes	44
	No	66
Family history of Thalassemia, n (%)	Yes	27
	No	73

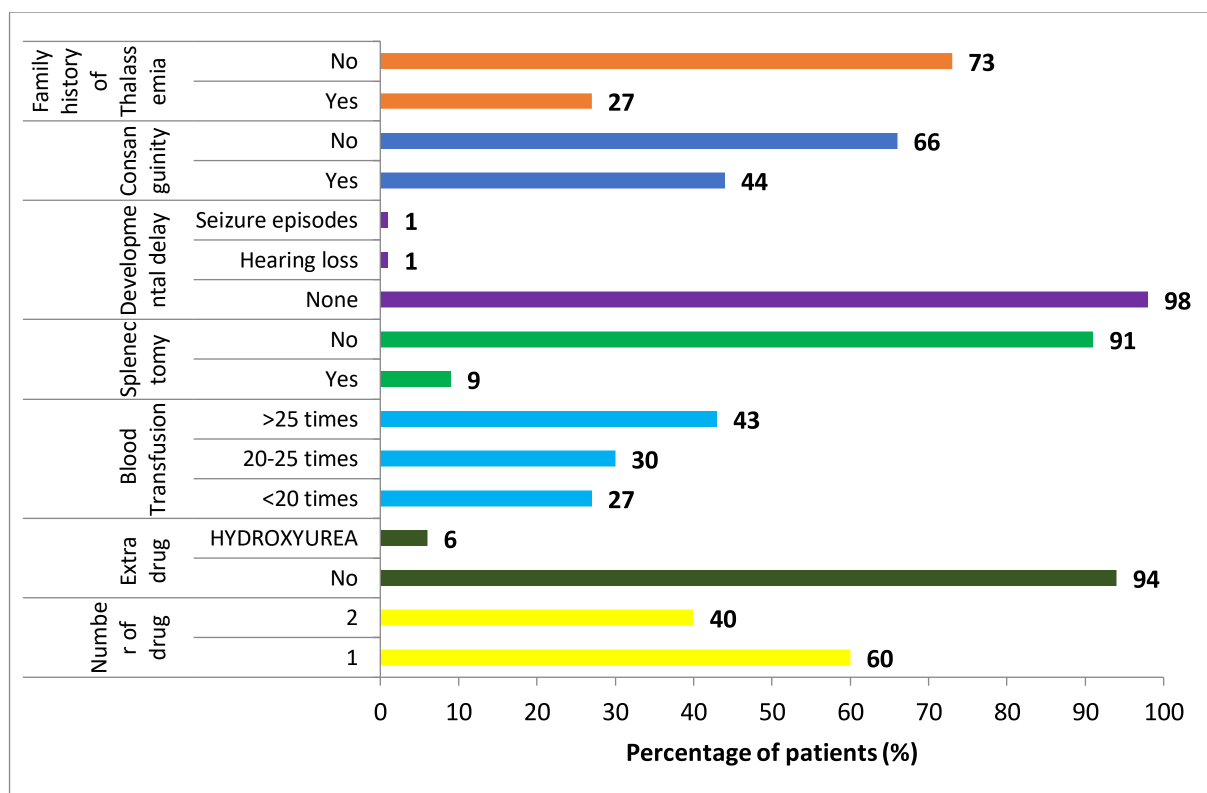

Figure 3: Distribution of participants based on illness parameters

Mean values for serum ferritin, pre and post transfusion haemoglobin were calculated to be 3261 ±2567.23mg/mL, 8.85 ± 1.22g/dL and 12.02±1.25g/dL (Table 4). Mean number of blood transfusion was found to be 12.02±1.25 times.

Table 5: Distribution of serum ferritin, pre and post haemoglobin

Variable	mean ±SD
Serum Ferritin(ng/mL)	3261 ±2567.23
Pre transfusion Haemoglobin(g/dL)	8.85 ± 1.22
Post transfusion Haemoglobin(g/dL)	12.02±1.25
Number of blood transfusion	23.00± 6.00

RCADS AND ITS INTERPRETATION:

Mean RCADS Raw score of patients 13.53±14.27 with minimum and maximum was 0 and 56 respectively. The Table 5 provides the Revised Child Anxiety and Depression Scale (RCADS) scores for 100 children with thalassemia major. The RCADS scores are used to assess various dimensions of anxiety and depression. The Table 6 shows the mean scores, standard deviations (SD), and the number of study participants with scores below and above the clinically significant threshold of 65. Mean score for separation anxiety T Score was 47.13 ± 10.48. A significant percentage of children (35%) have clinically significant separation anxiety, indicating that separation anxiety is a common issue in this group. Mean generalized anxiety disorder (GAD) T Score was 33.84 ± 7.14 and almost all children (99%) had non-clinically significant levels of generalized anxiety, suggesting that GAD is not a major concern for most children in this group. According to Panic T Score distribution, Panic symptoms are not significantly prevalent in the majority of children, with only 6% experiencing clinically significant panic symptoms and the mean value was 41.32 ± 6.23. None of the children exhibit clinically significant levels of social phobia or OCD symptoms. Mean Social Phobia T Score and Obsessive-Compulsive Disorder (OCD) T Score was 35.04 ± 10.13 and 35.27 ± 4.23 respectively. Similarly depression and anxiety were not clinically significant in any of the children with respective mean value for Depression T Score and Anxiety T Score was 35.6 ± 5.99 and 34.75 ± 8.67. The mean Total Anxiety and Depression T Score of 33.86 ± 8.44 with no children above 65 score indicated overall low levels of these symptoms. The RCADS scores suggest that most children with thalassemia major in this

study do not exhibit clinically significant levels of anxiety or depression. 35% of the children show clinically significant symptoms of separation anxiety. Other areas, such as GAD, panic, social phobia, OCD, depression, and combined anxiety and depression, show very low levels of clinical significance. This indicates that while separation anxiety is a concern, other forms of anxiety and depression are not major issues in this population.

Table 6: RCADS parameters of the study participants

T Scores	Mean ± SD	Number of respondents	
		Scores < 65 (clinically not significant)	Scores ≥ 65 (clinically significant)
Separation Anxiety	47.13±10.48	65	**35**
GAD	33.84±7.14	99	1
PANIC	41.32±6.23	94	**6**
Social phobia	35.04±10.13	100	0
OCD score	35.27±4.23	100	0
Depression	35.6±5.99	100	0
Anxiety	34.75±8.67	100	0
Total Anxiety and Depression	33.86±8.44	100	0

SLEEP PATTERN IN PATIENTS:

It was found that, the mean sleep time of study participants was 9.61±1.50 hours with minimum of 7hours and maximum of 12hours. To understand the sleep pattern of participants, they were subjected for answering a set of questionnaire to know bed time, sleep, wake up during night and, morning wake up behaviour (Table 6). It was found that 27% always maintain a consistent bedtime, 32% usually maintain a consistent bedtime, while 37% sometimes maintain, indicating a fairly consistent bedtime routine. 31% always fall asleep quickly (within 20 minutes), 30% usually do, and 30% sometimes do, and 9 % rarely do suggesting that most children fell asleep relatively quick. 30% study participants always fell asleep alone in their own bed, while 26% rarely and 24% never do which indicates that a significant number of children need someone else to fall asleep. 32% children in the study always fell asleep in parent's or sibling's bed and 16% never do, indicating that co-sleeping is

common. 86% of study participants never fell asleep with rocking or rhythmic movements. 84% never need a special object to fall asleep do, suggesting that most children do not rely on objects to fall asleep. 6% usually need parent in the room to fall asleep and 70% never need, indicating most children do not need a parent present when they sleep. 80% never resist to going to bed at bedtime, indicating minimal bedtime resistance.77% are never afraid of sleeping in the dark, showing most children are comfortable sleeping in the dark. 22% children sleep always the same amount each day, 38% usually do, and 40% sometimes do, indicating fairly consistent sleep durations. 83% children are never restless and do not move a lot during sleep suggesting most children have calm sleep. 86% never move to someone else's bed during the night indicating stable sleeping locations. 89% never grind their teeth during sleep suggesting low incidence of teeth grinding. 89% children never snore loudly, indicating snoring is uncommon among these study participants. 88% children are never awake during the night sweating, screaming, and inconsolable cry, indicating these disturbances are rare.70% children never nap during the day, showing most children do not nap in the day. 54% children rarely wake up once during the night and 33% never wake up, indicating minimal night time awakening. 99% children never wake up more than once during the night, suggesting very less frequently the child is awake multiple times at night. 18% children always wake up by themselves, 26% usually wake up and 46% sometimes wake up on their own, showing a good level of independent awaking. 54% children wake up very early in the morning sometimes, indicating a trend of early waking in some children. 52% children are rarely tired during the day and 29% are never tired, suggesting most children are not excessively tired. 48% children rarely fall asleep while involved in activities, and 31% never fall asleep, indicating falling asleep while involved in activities is uncommon.

Table 7: Sleep pattern in the study participants

Questionnaires		Always (7times a week)	Usually (5-6times a week)	Sometimes (2-4times a week)	Rarely (once a week)	Never (zero times per week)
Bed Time	1. Child goes bed at the same time at night	27	32	37	4	0
	2. Child falls asleep within 20 minutes after going to bed	31	30	30	9	0
	3. Child falls asleep alone in own bed	30	3	17	26	24
	4. Child fall asleep in parent's or sibling's bed	32	18	8	26	16
	5. Child fall asleep with rocking or rhythmic movements	0	0	0	14	86
	6. Child needs special object to fall asleep (doll, special blanket, stuffed animal etc.	0	0	0	16	84
	7. Child needs parent in the room to fall asleep	0	6	9	15	70
	8. Child resists going to bed at bedtime	0	0	13	7	80
	9. Child is afraid of sleeping in the dark	0	0	2	21	77
Sleep behaviour	10. Child sleeps about the same amount each day	22	38	40	0	00
	11. Child is restless and moves a lot during sleep	0	0	5	12	83
	12. Child moves to someone else's bed during the night(parent, sibling etc.)	0	0	6	8	86
	13. Child grinds teeth during sleep (your dentist may have told you this)	0	0	0	11	89
	14. Child snores loudly	0	0	0	11	89
	15. Child awakens during the night and is sweating, screaming	0	0	0	12	88

	and inconsolable					
	16. Child naps during the day	0	0	24	6	70
Wake up during night questionnaire	17. Child wakes up once during the night	0	12	1	54	33
	18. Child wakes up more than once during the night	0	0	0	1	99
Morning wake up questionnaire	19. Child wakes up by him/herself	18	26	46	10	00
	20. Child wakes up very early in the morning (or, earlier than necessary or desired)	8	11	54	15	12
	21. Child seems tired during day time	5	0	14	52	29
	22. Child falls asleep while involved in activities	12	0	9	48	31

The Table 8 presents the association of RCADS (Revised Children's Anxiety and Depression Scale) scores with various parameters among 100 children with thalassemia major. The median RCADS score across all participants is 11, with the middle 50% of scores ranging from 0 to 23. There is no significant association between RCADS scores and the number of drugs, the use of Hydroxyurea, family history of thalassemia, or the educational level of either parent. The only significant factor is the number of siblings, with children having no siblings showing significantly higher RCADS scores. Other factors such as consanguinity, number of blood transfusions, and splenectomy status do not show significant associations with RCADS scores.

Table 8: Association RCADS score with different variables

Variables		Median (lower quartile-upper quartile)	P value*
Over all (n=100)		11.00(0.00-23.00)	---
Number of drugs	1 (n=60)	11(0-23)	0.922
	2 (n=40)	8.5(0-24.8)	
Extra drug	Hydroxyurea (n=6)	14.5(12.5-17.2)	0.730
	No(n=94)	11(0-23)	
Family history of Thalassemia	No (n=73)	11(0-23)	0.502

	Yes (n=27)	8(0-18)	
Mother’s education	No formal education (n=13)	18(8-29)	0.619
	Pre Primary (n=1)	8(8-8)	
	Primary (n=26)	11.5(0-26.8)	
	High school (n=47)	11(0-23)	
	Senior secondary (n=7)	14(9.5-16.5)	
	Graduate (n=5)	0(0-14)	
	Post graduate (n=1)	0(0-0)	
Father’s education	No formal education (n=16)	3(0-23)	0.852
	Pre Primary (n=1)	0(0-0)	
	Primary (n=16)	8.5(0-24.8)	
	High school (n=30)	11.5(0-26.8)	
	Senior secondary (n=24)	11(0-20)	
	Graduate (n=12)	0(0-0)	
	Post graduate (n=1)	14.5(0-23)	
Consanguinity	Yes (n=56)	10(0-23)	0.459
	No (n=44)	10(0-23)	
Number of siblings	0 (n=9)	30(18-32)	**0.034**
	1-2 (n=75)	9(0-23)	
	>2 (n=16)	11(0-24.2)	
Number of blood transfusion	<20 times (n=27)	15(0-23)	0.394
	20-25 times (n=40)	8(0-18)	
	>25 times (n=23)	11(0-23)	
Splenectomy	Yes (n=9)	15(0-23)	0.663
	No (n=91)	11(0-29)	

*statistically significant if P value < 0.05

The Table 9 presents the correlation between RCADS (Revised Children's Anxiety and Depression Scale) scores and three blood parameters: serum ferritin, pre-transfusion haemoglobin (Hb), and post-transfusion hemoglobin (Hb). The correlation between serum ferritin levels and RCADS scores is very weak and not statistically significant. A correlation coefficient of -0.04 indicates a near-zero correlation, suggesting that serum ferritin levels do not have a meaningful relationship with the RCADS scores in these children. The correlation between pre-transfusion hemoglobin levels and RCADS scores is weak and not statistically significant. A correlation coefficient of -0.13 suggests a slight negative relationship, but this is not strong enough to infer a significant impact of pre-transfusion hemoglobin levels on RCADS scores. The correlation between post-transfusion hemoglobin levels and RCADS scores is also weak and not statistically significant. A correlation coefficient of -0.12 indicates a minor negative relationship, but again, it is not significant enough to suggest a real impact of post-transfusion hemoglobin levels on RCADS scores.

Table 9: Correlation of RCADS score and Serum Ferritin, Pre transfusion Hb, Post transfusion Hb

Correlation	Correlation coefficient	P value*
Serum Ferritin Vs RCADS score	-04(-0.24- 0.16)	0.674
Pre transfusion Hb Vs RCADS score	-0.13(-0.32-0.07)	0.208
Post transfusion Hb Vs RCADS score	-0.12(-0.31-0.08)	0.244

*statistically significant if P value < 0.05 for Pearson's correlation test

The Table 9 provides Quality of Life (QOL) scores for the primary caregivers of 100 children with thalassemia major. These scores are divided into four parameters: Physical Health, Psychological Health, Social Relationships, and Environment. The mean scores and standard deviations (SD) for each parameter are provided. The physical health score indicates a moderate level of physical well-being among the primary caregivers. With a mean score of 64.26 ± 15.83, caregivers may experience some physical health challenges, likely influenced by the demands of caring for a child with a chronic condition. The psychological score reflects a moderate level of psychological well-being, with caregivers experiencing some degree of stress or emotional strain. The mean score of 61.01 ± 15.23 indicates that psychological challenges are present but not overwhelming for most caregivers. The social relationships score is relatively low, with a mean of 10.19 ± 1.46. This indicates significant challenges in social interactions and support systems for caregivers. The environment score, with a mean of 25.22 ± 4.74, suggests a moderate level of satisfaction with the caregiving environment. This score reflects factors such as safety, accessibility to healthcare, and living conditions.

Table 10: QOL of the primary caregiver of the study participants

QOL parameters	Scores, Mean ± SD
Physical health score	64.26±15.83
Psychological score	61.01±15.23
Social relationships score	10.19±1.46
Environment scores	25.22±4.74

6. DISCUSSION

Thalassemia major (BTM) is a severe, chronic hematologic disorder characterized by a need for lifelong treatment, including regular blood transfusions and iron chelation therapy. The burden of managing such a chronic condition extends beyond the physical health of patients to encompass significant psychological and social challenges. Notably, studies indicate a high prevalence of depression among thalassemia patients, ranging from 11% to 62%[62]. This high incidence of depression is linked to increased morbidity and mortality, highlighting the critical need for comprehensive care that addresses both the physical and mental health of these patients. Identifying and managing these psychological issues early is crucial for improving both immediate and long-term health outcomes for these children[47]. In addition to the patients themselves, the parents and primary caregivers of children with BTM experience considerable stress and challenges. The quality of life (QOL) for these caregivers can be significantly impacted by the demands of continuous care and the emotional strain of managing a child with a chronic illness. Previous research has highlighted the need for support systems and interventions that can alleviate the psychological and social burden on these families[56]. Therefore the current study titled "Prevalence of Depression and Anxiety in Children between 8-18years with Beta Thalassemia Major: An Observational Study for a Period of 1 Year" was carried out at KLEH Dr. Prabhakar Kore Hospital, Belgaum, Karnataka from January 2023 to January 2024 to study the prevalence of depression and anxiety in children between 8-18years with beta thalassemia major, along with the quality of life in parents of children suffering from beta thalassemia major, and to study the sleep pattern of children suffering from beta thalassemia major.

In this hospital based cross sectional study, we examined the prevalence of depression and anxiety in children with beta thalassemia major (BTM) and assessed the quality of life in

their parents, as well as the sleep patterns of the affected children. A total of 100 children aged 8-18 years with BTM were included, with a near-equal gender distribution of 48% male and 52% female, and a mean age of 12.23±2.81 years. The balanced gender distribution observed in our study is noteworthy. It suggests that BTM and its associated psychological conditions, such as depression and anxiety, affect both genders equally. This finding aligns with studies conducted in the Middle East, Mediterranean, and Western regions, which also report no significant gender disparity in the incidence of BTM[85–89]. Contrarily, many studies from India have documented a male preponderance[56]. This discrepancy is often attributed to gender bias rather than an actual higher incidence of the disease among boys. In many parts of India, male children are more likely to receive medical attention and be brought to healthcare facilities than female children, potentially skewing prevalence data[87].

Notably, 96% of the participants were enrolled in school, with the majority attending high school (44%) and higher primary school (35%). This rate of school attendance is significantly higher compared to previous studies, where only 67% to 80% of children with BTM were reported to have schooling. Ismail *et al* reported of 67%[89], Mediani *et al*[90] reported of 80% and Elalfy *et al*[91] reported of 76% beta thalessamia major children who attended school. The high rate of having attended the school is observed in our study is a positive indicator which could be owing to the absence of obvious disease effects at a young age, resulting in a lessened sense of stigmatization. This is contrasts with earlier studies that showed a significant drop in school attendance among children with BTM compared to healthy controls highlighting the educational disruptions caused by the disease[89–91]. The lower school attendance rates in previous studies can be attributed to the chronic nature of BTM and its demanding treatment regimen, which includes frequent hospital visits for blood transfusions and iron chelation therapy. These medical requirements can result in children feeling weak and fatigued, making it difficult for them to keep up with school activities and

attend regularly. Furthermore, periods of illness or hospitalization further disrupt their educational experiences[90].

The sleep patterns and behavior analysis of participants in our study reveal that most children with beta thalassemia major have relatively stable and consistent bedtime routines with average sleep of 9.61 ± 1.50 hours. These children generally fall asleep quickly, sleep in their own beds without needing special objects or the presence of their parents, and experience minimal night time disturbances. Restlessness, moving to other beds, and loud snoring are rare. Additionally, most children do not nap during the day, experience minimal night awakenings, and show a good degree of independence in waking up in the morning, without appearing excessively tired during the day. These observations suggest relatively healthy sleep behaviors among the children in our study, with some common variations typical of childhood. However, this finding contrasts with the broader literature, which indicates that children with BTM often experience significantly disrupted sleep patterns compared to their healthy peers. Previous studies have reported higher incidences of sleep disturbances, including night waking, sleep-disordered breathing, and daytime sleepiness in children with BTM. Specifically, children with BTM have been found to suffer from impaired sleep function, partially due to periodic limb movements and arousals that contribute to daytime sleepiness[64,65]. Parents of children with BTM have also reported more frequent night waking compared to parents of healthy children[65]. Moreover, a higher prevalence of obstructive sleep apnea (OSA) has been observed in children with severe BTM, which is associated with increased daytime sleepiness[64,65]. Sleep anxiety is also more common in children with BTM, further complicating their sleep patterns[1]. The discrepancies between our findings and those of previous studies could be due to various factors, such as differences in study populations, methodologies, or the severity of the condition in the children studied. Our study participants might represent a subset of children with BTM who

have relatively better-managed symptoms or receive more comprehensive care, leading to healthier sleep patterns.

In this study, the mean RCADS total score for children with beta thalassemia major (BTM) was 13.53 ± 14.27, with a range from 0 to 56. This indicates that most children in our sample did not exhibit clinically significant levels of anxiety or depression, except for separation anxiety, where 35% of the children showed clinically significant symptoms. This finding is notable because it contrasts with existing literature, which suggests a higher prevalence of depression and anxiety among BTM patients. According to the Centre for Disease Control and Prevention (CDC), approximately 4.4% of children aged 3-17 years are diagnosed with depression, while 9.4% are diagnosed with anxiety[46]. Studies specific to BTM have reported a significantly higher prevalence of these conditions. For instance, one study found depression rates ranging from 12% to 60% and anxiety rates up to 54% among BTM patients[47,48]. The chronic nature of BTM, along with its demanding treatment regimen, contributes to these elevated rates of mental health issues. Our findings, however, show much lower rates of clinical anxiety and depression, with the exception of separation anxiety. This discrepancy could be attributed to several factors, including differences in psychosocial support, healthcare access, and cultural perceptions of mental health between populations. Additionally, the low RCADS scores observed in our study suggest that factors like the number of drugs taken, use of hydroxyurea, family history of thalassemia, and parental education levels did not significantly influence the children's anxiety and depression levels. Interestingly, the number of siblings was the only significant factor associated with RCADS scores. Children without siblings showed higher RCADS scores, indicating greater anxiety and depression. This finding aligns with the idea that social support from siblings may play a crucial role in mitigating psychological distress in children with chronic illnesses like BTM.

Contrary to our findings, Mugali *et al.*[52]reported a 38.71% prevalence of anxiety among adolescents with BTM, with most cases being of mild intensity. The study highlighted the impact of disease severity, treatment regimen, and psychosocial support on anxiety levels. Similarly, Shukla and Dhaneria[53] identified behavioral problems in children with thalassemia, influenced by factors such as the duration of illness and parental attitudes. Narula *et al.*[54] found that 26% of chronically transfused BTM patients showed anxiety, emphasizing the psychological burden of long-term transfusion therapy. Moreover, Sahu *et al.,*[56] emphasized the psychological challenges faced by children with transfusion-dependent thalassemia and their caregivers, with a significant portion of children (19.6%) exhibiting anxiety and 15.2% exhibiting depression. Behdani *et al.*[60] and Maheri *et al.*[61] similarly reported higher rates of depression and anxiety in BTM patients compared to healthy peers, indicating a greater psychological burden in this patient group. The variation in our study's findings compared to previous reports could be due to differences in study design, population characteristics, and the tools used for assessing mental health. For example, the use of the RCADS in our study might have captured different aspects of anxiety and depression compared to other tools like the Child Behavior Checklist (CBCL) used in other studies.

While our study found relatively low levels of anxiety and depression among children with BTM, with separation anxiety being a notable exception, it is crucial to recognize the psychological impact of BTM as highlighted by previous research. Continuous monitoring and providing comprehensive psychosocial support are essential to address the mental health needs of children with BTM and their families. Further research with larger sample sizes and diverse populations is needed to better understand the psychological challenges faced by BTM patients and to develop targeted interventions to improve their quality of life.

The Quality of Life (QOL) scores for the primary caregivers of children with beta thalassemia major in this study highlight significant challenges in various aspects of their

well-being. The mean scores for physical health, psychological health, social relationships, and environment provide a comprehensive overview of the impact of caregiving on these individuals. The physical health score of 64.26 ± 15.83 indicates a moderate level of physical well-being among caregivers. This suggests that while caregivers manage to maintain a reasonable level of physical health, they may still experience challenges, likely due to the demanding nature of caring for a child with a chronic condition. The continuous care requirements and frequent medical visits can lead to physical exhaustion and other health issues, as supported by previous studies that show parents of children with BTM often face significant physical strain[70]. Psychological well-being, with a mean score of 61.01 ± 15.23, also falls within a moderate range, indicating that caregivers experience some degree of stress and emotional strain. This is consistent with previous literature reporting high levels of emotional stress, anxiety, and depression among parents of children with BTM. The social relationships score is notably low at 10.19 ± 1.46, indicating significant difficulties in maintaining social interactions and support systems. This finding aligns with the literature that suggests social isolation and feelings of loneliness are common among parents of children with BTM due to the stigma associated with the disease and the demanding care requirements. The impact on social life is substantial, often limiting the parents' ability to engage in social activities and maintain relationships[13,92].The environmental score of 25.22 ± 4.74 reflects a moderate level of satisfaction with the caregiving environment, encompassing factors such as safety, accessibility to healthcare, and living conditions. Comparing these findings to Ansari et al.'s study, where the physical health, psychological health, social relationships, and environment scores were slightly different, it is evident that the challenges faced by caregivers are consistent across different populations. Ansari *et al.* reported scores of 64.54 ± 19.03, 55.14 ± 18.77, 59.61 ± 21.17, and 55.84 ± 18.95, respectively, for caregivers of thalassemia patients, all of which were significantly lower than the control

group(71.90±15.374, 63.06±20.24, 67.69±18.47, and 65.00±16.68 respectively)[70]. Several studies have emphasized the substantial impact of caregiving on parents' quality of life. The financial strain due to ongoing treatments and frequent hospitalizations, coupled with emotional stress and disrupted sleep, significantly affects their well-being . Furthermore, studies utilizing the WHOQOL-BREF questionnaire consistently show lower quality of life scores in thalassemia patients and their caregivers compared to healthy controls, highlighting the pervasive impact of the disease on daily life[68,69].

The QOL scores in this study reveal moderate physical and psychological health but significant challenges in social relationships for caregivers of children with BTM. These findings underscore the need for comprehensive support systems, including psychosocial interventions and resources to alleviate the burden on caregivers. Addressing these needs can potentially improve their overall quality of life, enabling them to provide better care for their children.

The study has its limitations in the small sample size and hence the results cannot be generalised for the greater population. Majority of the population was in the age group of less than 12 years and hence the significant understanding of the disease process and its complications were poorly interpreted by the study population. Follow up and required psychiatric and psychological help can be made accessible after eliciting the data on the percentage of anxiety and depression so that there is early intervention, reduction in stigma, improvement in quality of life among the peers living with thalassemia and the parents who take care of them.

7. CONCLUSION

The current study conducted at KLEH Dr. Prabhakar Kore Hospital, Belgaum, Karnataka, provides significant insights into the psychological well-being of children with Beta Thalassemia Major (BTM) and their primary caregivers.

Our findings indicate a relatively low prevalence of clinical anxiety and depression among children with BTM, with the exception of separation anxiety, which affected 35% of the participants. The high school attendance rate of 96% among the children in our study is a positive indicator, suggesting that despite the chronic nature of BTM, many children manage to continue their education, potentially benefiting from better-managed symptoms or comprehensive care.

The study also sheds light on the quality of life (QOL) of caregivers. Caregivers experience moderate physical and psychological health but face significant challenges in social relationships. The mean physical health score of 64.26 ± 15.83 reflects moderate physical well-being, while the psychological health score of 61.01 ± 15.23 indicates some level of emotional strain. The notably low social relationships score of 10.19 ± 1.46 underscores the social isolation and difficulties in maintaining support systems, a common issue highlighted in previous research. The environmental score of 25.22 ± 4.74 suggests moderate satisfaction with factors such as safety and access to healthcare.

These findings emphasize the need for holistic care approaches that address both the physical and mental health of children with BTM and their caregivers. Comprehensive support systems, including psychosocial interventions and resources, are crucial to alleviate the burden on families. Continuous monitoring and tailored interventions can improve the overall quality of life for these children and their families, helping them manage the psychological and social challenges associated with BTM.

Future research should focus on larger, more diverse populations to better understand the psychological impact of BTM and develop targeted strategies to support both patients and their caregivers. This study contributes to the growing body of evidence that highlights the critical need for integrated care models that encompass both physical and mental health support for individuals affected by chronic conditions like Beta Thalassemia Major.

8. SUMMARY

- **INTRODUCTION:** This hospital based cross sectional study conducted at KLEH Dr. Prabhakar Kore Hospital, Belgaum, Karnataka, from January 2023 to January 2024, investigated the prevalence of depression and anxiety in 100 children aged 8-18 years with beta thalassemia major over one year.
- **AIMS AND OBJECTIVES:** Main aim of this study was to study the prevalence of depression and anxiety in children between 8-18years with beta thalassemia major patients and the secondary objectives of the current study were to study the quality of life in parents of children suffering from beta thalassemia major and to study the sleep pattern of children suffering from beta thalassemia major
- **RESULTS:**

1. Demographics and Family Characteristics: The study included 48% male and 52% female participants with a mean age of 12.23 ± 2.81 years. Participants were divided into two age groups: 55 children aged 8-12 years and 45 children aged 12-18 years. 96% of participants were attending school, with 44% in high school and 35% in higher primary school.

i. 50% of children had one sibling, 25% had two siblings

ii. 46% of families had fewer than 5 members, and 45% had 5-8 members

iii. 79% of participants came from nuclear families, and 15% from joint families

iv. The mean age of mothers was 34.53 ± 5.91 years, and fathers was 41.9 ± 7.48 years

v. 46% of mothers and 30% of fathers had education up to high school

vi. 13% of mothers and 16% of fathers had no formal education.

2. Medication and Treatment:

i. 60% of participants were taking a single drug, with only 6% taking hydroxyurea

ii. 9% had undergone splenectomy

iii. 98% showed no developmental delays; one participant each had hearing loss and seizure episodes

iv. Consanguinity was present in 44% of participants.

v. 27% had a family history of thalassemia

3. Mental Health (RCADS Scores)

i General Findings -The mean RCADS score was 13.53 ± 14.27

ii Separation Anxiety - 35% had clinically significant separation anxiety

iii Generalized Anxiety Disorder - Only 1% had clinically significant levels

iv Panic Disorder**: 6% had clinically significant levels

v Social Phobia, OCD, Depression, and Total Anxiety and Depression**: None of the children had clinically significant levels.

4. Sleep Patterns

i. Mean sleep time was 9.61 ± 1.50 hours, ranging from 7 to 12 hours

ii. 27% always maintained a consistent bedtime, 32% usually did, and 37% sometimes did

iii. Most children fell asleep quickly, with 31% always, 30% usually, and 30% sometimes doing so

iv. Co-sleeping: 32% always fell asleep in a parent's or sibling's bed, while 16% never did

v. Night Awakenings: 54% rarely woke up once during the night, and 33% never did. Only 1% woke up more than once

vi. Morning Wake Up**: 18% always woke up by themselves, 26% usually did, and 46% sometimes did.

9. Quality of Life (QOL) of Caregivers

i Physical Health - Mean score 64.26 ± 15.83, indicating moderate physical health

ii Psychological Health - Mean score 61.01 ± 15.23, indicating moderate psychological well-being

iii Social Relationships - Mean score 10.19 ± 1.46, indicating significant challenges in social interactions

iv Environment - Mean score 25.22 ± 4.74, indicating moderate satisfaction with the environment.

- **CONCLUSION:** Overall, the study found that separation anxiety is a common issue among children with thalassemia major, while other forms of anxiety and depression are less prevalent. The mental health of these children is generally not significantly correlated with their serum ferritin levels or hemoglobin levels. Caregivers experience moderate physical and psychological health challenges, and social support is a significant area of need.

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10. ANNEXURE

ANNEXURE I - CONSENT FORM

K.L.E. ACADEMY OF HIGHER EDUCATION AND RESEARCH

J.N. Medical College, Belagavi

Department of Paediarics

"PREVALENCE OF DEPRESSION AND ANXIETY IN CHILDREN BETWEEN 8-18YEARS WITH BETA THALASSEMIA MAJOR: AN OBSERVATIONAL STUDY FOR A PERIOD OF 1 YEAR."

Principal Investigator: PG Student **REG NO: BM0121015**

Co – investigator: GUIDE

Professor, Department of Paediatrics, J.N. Medical College, Belagavi

Introduction: You are being invited to participate in this study to find out the prevalence of anxiety and depression in thalassemia major patients of age group 8 -18 years. Participation of your child will help us to know the prevalence of anxiety and depression in thalassemia major patients of that specific age group. Affected children face many stresses in their whole life. These include: frequent blood samplings for laboratory tests, multiple transfusions and frequent subcutaneous injections and oral therapy of iron chelator drugs. They altogether make the patient susceptible to psychiatric burden namely depression and anxiety. These always induce stress leading to sickness absenteeism and poor academic school performance. Very limited research has been conducted in the field of psychiatric illness in Beta thalassemia major patients in India. There is a scope for diagnosis and once done can be followed by appropriate evaluation in the form of medication and counselling by the child psychiatrist. Hence the present study is undertaken. Participation in this study is completely voluntary.

Explanation of procedures: In this study, you will have to answer a few prepared questions regarding your personal experience with handling the

disease and its complications especially the psychological burden. If you agree to participate, then only questions will be asked to you. At any moment, you can withdraw from the study. Information will be collected using pre-tested-designed questionnaire both for you and your child.

Possible Benefits: The complications and the disease burden can be assessed. If there is any possible sign of depression or anxiety in you or your child, psychiatric assessment will be advised both in the form of counselling as well as pharmacological therapy if required.

Possible Risks: There is no risk involved in this study

Benefits from the study: We will know the compliance of the patients to blood transfusion. If there is any possible sign of depression or anxiety in you or your child, psychiatric assessment will be advised both in the form of counselling as well as pharmacological therapy if required

Confidentiality: All the data collected will remain confidential and only aggregated data will be published. Your personal identity will not be revealed.

Withdrawal: Your participation in this study is purely voluntary. You may decide to participate or not. Even though you decide not to participate, you will not be deprived of the benefits of this study.

Costs of Participation: It is a complete questionnaire-based study. There will be no additional cost to you for participating in this study.

Payment of Participation: There will be no incentives to you for participating in this study.

Questions: If you have any questions regarding the study, you should contact Principal Investigator REGISTRATION NUMBER: BM0121015, PG 2021 MD

admission batch, Department of Paediatrics. J. N. Medical College, Belagavi, 590010, Ph. No - 7005318255

Guide: Professor, Department of Paediatrics, J. N. Medical College, Belagavi, 590010.

If you have any questions about your rights as a study participant, you may contact **Dr.Roopa Bellad**, Chairman, Institutional Ethics Committee on Human Subjects' Research, J.N. Medical College, Belagavi -590010, Ph. No 0831-2473777, Extn 4052, 4057.

Legal Rights: By signing this consent form; you are not waiving any of your Legal rights.

Consent statement:

"I volunteer and consent to participate in the study. I have read (or it has been read to me in the language known to me) the information sheet thoroughly. Full opportunity was given to me to ask questions. I am fully satisfied with the answers to the questions I wanted to ask. I hereby voluntarily agree to participate in this research project".

______________________	______________________
Name of the Participant	Signature of the participant or Left-Hand Thumb impression
______________________	______________________
Name of Investigator	Signature of investigator
______________________	______________________
Name of Witness	Signature of Witness

Date: ______________________ Place: ______________________

Assent (<18 years)

I have read the information in this form. After understanding all details about the study, I agree to give assent to be included as a volunteer in the study titled "**PREVALENCE OF DEPRESSION** AND ANXIETY IN CHILDREN BETWEEN 8 -18YEARS WITH BETA THALASSEMIA MAJOR: AN OBSERVATIONAL **STUDY FOR A PERIOD OF 1 YEAR.**"

______________________	______________________
Name of the Participant	Signature of the participant OR Left-Hand Thumb impression
______________________	______________________
Name of the Parent	Signature of the parent
______________________	______________________
Name of Investigator	Signature of investigator
______________________	______________________
Name of Witness	Signature of Witness

Date: ________________ Place: ________________

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"गोबीय वोमुक्त प्रचतयषा योग के चरए स्क्रीचनोग भें गबचनार यक्त चनयऩेष चरम्पोवाइट गणना की उऩमोचगता"

प्रधान अन्लेऴक का नाभ: डॉ. ओचरव्हशमा दावगुप्ता, ऩीजी वलद्याथी

वश अन्लेऴकों का नाभ: डॉ. सानेळ डी के

ऩरयिम:

आऩको इव अध्ममन भें बाग रेने के चरए आभॊवत्रत ककमा जा यशा शै ताकक मश ऩता रगामा जा वके कक 8-18 लऴच के आमु लगच के थैरेवीचभमा प्रभुख योचगमों भें चिॊता औय अलवाद की हमाऩकता क्मा शै। आऩके फच्िे की बागीदायी वे शभें उव वलचळष्ट आमु लगच के थैरेवीचभमा प्रभुख योचगमों भें चिॊता औय अलवाद की हमाऩकता जानने भें भदद चभरेगी। प्रबावलत फच्िे अऩने नूये जीलन भें कई तनालों का वाभना कयते शैं। इनभें ळाचभर शैं: प्रमोगळारा ऩयीषणों के चरए फाय-फाय यक्त के नभूने, कई आधान औय फाय-फाय िभडे के नीिे के इॊजेक्ळन औय आमयन के रेटय दलाओॊ की भौक्खक चिककत्वा। ले नूयी
तयश वे योगी को भानचवक फोझ अथाचत ्अलवाद औय चिॊता के प्रचत वॊलेदनळीर फनाते शैं। मे शभेळा तनाल को प्रेरयत कयते शैं ज्जववे फीभायी की अनुऩज्स्थचत औय खयाफ ळैषज्णक स्कू र का प्रदळचन शोता शै। बायत भें फीटा थैरेवीचभमा प्रभुख योचगमों भें भानचवक फीभायी के षेत्र भें फशुत वीचभत ळोध ककमा गमा शै। चनदान के चरए एक गॊजाइळ शै औय एक फाय फाय भनोचिककत्वक द्वाया दला औय ऩयाभळच के रूऩ भें उचित भूलमॊकन के फाद ककमा जा वकता शै। इवचरए लतचभान अध्ममन ककमा जाता शै। इव अध्ममन भें बाग रेना नूणचत् स्वैच्छिक शै।

प्रकरमा की हमाख्मा:

इव अध्ममन भें, आऩको फीभायी औय इवकी जकटरताओॊ, वलळेऴ रूऩ वे भनोलैसाचनक फोझ वे चनऩटने के अऩने हमवक्तगत अनुबल के फाये भें कु ि तैमाय प्रश्नों के उत्तय देने शोंगे। मकद आऩ बाग रेने के चरए वशभत शैं, तो आऩवे के लर प्रश्न नूिे जाएॊगे। आऩ ककवी बी वभम अध्ममन वे नीिे शट वकते शैं। आऩके औय आऩके फच्िे दोनों के चरए नूलच-ऩयीक्षत-कडजाइन की गई प्रश्नालरी का उऩमोग कयके जानकायी एकत्र की जाएगी।

वॊबावलत राब:

जकटरताओॊ औय फीभायी के फोझ का आकरन ककमा जा वकता शै। मकद आऩ मा आऩके फच्िे भें अलवाद मा चिॊता का कोई वॊबावलत वके त शै, तो भनोलैसाचनक भूलमॊकन की वराश ऩयाभळच के वाथ-वाथ मकद आलश्मक शो तो औऴधीम चिककत्वा दोनों के रूऩ भें दी जाएगी।

वॊबावलत जोक्खभ: इव अध्ममन भें कोई जोक्खभ ळाचभर नशीॊ शै।

अध्ममन वे राब :

शभ यक्त आधान के चरए योचगमों के अनुन्नारन के फाये भें जानेंगे। मकद आन्न मा आन्नके फच्िि भें अलवाद मा चिौता का कोई वॊबावलत वके त शै, तो भनोलैसाचनक भूलमॊकन की वराश न्नयाभळच के वाथ-वाथ मकद आलश्मक शो तो औऴधीम चिककत्वा दोनों के रून्न भें दी जाएगी।

गोन्ननीमता :

एकत्र ककमा गमा वबी डेटा गोन्ननीम यशेगा औय के लर एकवत्रत डेटा प्रकाचळत ककमा जाएगा। आन्नकी हमवक्तगत न्नशिान उजागय नशीीं की जाएगी।

चनकावी :

इव अध्ममन भें आन्नकी बागीदायी वलळुद्ध रून्न वे स्वैच्छ्िक शै। आन्न बाग रेने मा न कयने का चनणचम रे वकते शैं। बरे शी आन्न बाग न रेने का चनणचम रेते शैं, कपय बी आन्न इव अध्ममन के राबों वे लॊचित नशीीं यशेंगे।

बागीदायी की रागत :

मश एक नूणच प्रश्नालरी आधारयत अध्ममन शै। इव अध्ममन भें बाग रेने के चरए आन्नवे कोई अचतरयक्त ळुलक नशीीं चरमा जाएगा।

बागीदायी का बुगतान : इव अध्ममन भें बाग रेने के चरए आन्नको कोई प्रोत्वाशन नशीीं कदमा जाएगा।

प्रळन :

मकद अध्ममन के वॊफॊध भें आन्नके कोई प्रश्न शैं, तो आन्नको प्रधान अन्लेऴक डॉ ओचरवलमा दावगुप्ता, न्नीजी 2021 एभडी प्रलेळ फैि, फार योग वलबाग, जे एन भेकडकर कॉरेज, फेरगाली, 590010, वे वन्नकच कयना िाकशए। पोन। न.- 7005318255 भागचदळचक: डॉ सानेळ डी के, प्रोपे वय, फार योग वलबाग, जे.एन. भेकडकर कॉरेज, फेरगाली, 590010।

मकद आन्नके न्नाव अन्नने अचधकाय के वॊफॊध भें कोई प्रश्न मा चळकामत शै अध्ममन प्रचतबागी के रून्न भें आन्न डॉ शऴच शेगडे, अध्मष, जेएनएभवी की नैचतक वचभचत, 0831-2473777 एक्टेंळन 4052 वे वन्नकच कय वकते शैं।

कानूनी अचधकाय :

इव वशभचत पॉभच न्नय शस्ताषय कयके , शभ आन्नके ककवी बी कानूनी अचधकाय का उलरॊघन नशीीं कय यशे शैं।

वशभचत लक्तहम

"भैं स्क्लेच्िा वे अध्ममन भें बाग रेने के चरए वशभत शॊ। भैंने वूिना न्नत्र को अच्िी तयश वे न्नढ़ चरमा शै (मा भुझे उव बाऴा भें न्नढ़ा गमा शै जो भुझे सात शै)। भुझे वलार न्नूिने का न्नूया भौका कदमा गमा। भैं उन वलारों के जलाफ वे न्नूयी तयश वॊतुष्ट शॊ जो भैं न्नूिना िाशता था। भैं इवके द्वाया स्क्लेच्िा वे इव ळोध न्नरयमोजना भें बाग रेने के चरए वशभत शॊ।"

__________________________ __________________________

प्रचतबागी का नाभ | प्रचतबागी के शस्क्ताषय

मा फाएॊ शाथ के अॊगूठे का चनळान

__________________________ __________________________

अन्लेऴक का नाभ | अन्लेऴक के शस्क्ताषय

__________________________ __________________________

गलाश का नाभ | गलाश के शस्क्ताषय

कदनाॊक : ____________________ स्क्थान : ____________________________________

स्वीकृ चत (<18 लऴच)

भैंने इव पॉभ्च भें दी गई जानकायी को नढ़ चरमा शै। अध्मभन के फाये भें वबी वललयणों को वभझने के फाद, भैं व्लीऴचक लारे अध्मभन भें एक स्लमॊंवेलक के रूऩ भें व्ळाचभ्र शोने के चरए वशभचत देने के चरए वशभत शॄॊ
"गॊबीय वॊमुक्त प्रचतयषा योग के चरए स्क्रीचनॊग भें गबचनार यक्त चनयनेष चरम्पोवाइट गणना की उऩमोचगता"

___________________________ ___________________________

प्रचतबागी का नाभ प्रचतबागी के शस्ताषय

मा फाएॊ शाथ के अॊगूठे का चनळान

___________________________ ___________________________

भाता-वऩता का नाभ भाता-वऩता के शस्ताषय

___________________________ ___________________________

अन्लेऴक का नाभ अन्लेऴक के शस्ताषय

___________________________ ___________________________

गलाश का नाभ गलाश के शस्ताषय

कदनॊक : ______________ स्थान : ____

ತಿಳುವಳಿಕೆಯುಳ್ಳ ಒಪ್ಪಿಗೆ ಪತ್ರ

ಕೆ.ಎಲ್.ಇ. ಉನ್ನತ ಶಿಕ್ಷಣ ಮತ್ತು ಸಂಶೋಧನೆಯ ಅಕಾಡೆಮಿ

ಜೆ.ಎನ್. ವೈದ್ಯಕೀಯ ಕಾಲೇಜು, ಬೆಳಗಾವಿ

ಮಕ್ಕಳ ವಿಭಾಗ

"ಬೀಟಾ ಥಲಸ್ಸೆಮಿಯಾ ಮೇಜರ್‌ನೊಂದಿಗೆ 8-18 ವರ್ಷಗಳ ನಡುವಿನ ಮಕ್ಕಳಲ್ಲಿ ಖಿನ್ನತೆ ಮತ್ತು ಆತಂಕದ ಹರಡುವಿಕೆ: 1 ವರ್ಷದ ಅವಧಿಗೆ ವೀಕ್ಷಣಾ ಅಧ್ಯಯನ."

ಪ್ರಧಾನ ತನಿಖಾಧಿಕಾರಿಯ ಹೆಸರು : ಡಾ. ಒಲಿವಿಯಾ ದಾಸಗುಪ್ತಾ, ಪಿಜಿ ವಿದ್ಯಾರ್ಥಿನಿ

ಸಹ ತನಿಖಾಧಿಕಾರಿಗಳ ಹೆಸರು : ಡಾ. ಜ್ಞಾನೇಶ್ ಡಿ ಕೆ

ಮಕ್ಕಳ ವಿಭಾಗದ ಪ್ರಾಧ್ಯಾಪಕ ಜೆ.ಎನ್. ವೈದ್ಯಕೀಯ ಕಾಲೇಜು, ಬೆಳಗಾವಿ.

ಪರಿಚಯ:

8-18 ವರ್ಷ ವಯಸ್ಸಿನ ಥಲಸ್ಸೆಮಿಯಾ ಪ್ರಮುಖ ರೋಗಿಗಳಲ್ಲಿ ಆತಂಕ ಮತ್ತು ಖಿನ್ನತೆಯ ಹರಡುವಿಕೆಯನ್ನು ಕಂಡುಹಿಡಿಯಲು ಈ ಅಧ್ಯಯನದಲ್ಲಿ ಭಾಗವಹಿಸಲು ನಿಮ್ಮನ್ನು ಆಹ್ವಾನಿಸಲಾಗುತ್ತಿದೆ. ನಿಮ್ಮ ಮಗುವಿನ ಭಾಗವಹಿಸುವಿಕೆಯು ನಿರ್ದಿಷ್ಟ ವಯಸ್ಸಿನ ಥಲಸ್ಸೆಮಿಯಾ ಪ್ರಮುಖ ರೋಗಿಗಳಲ್ಲಿ ಆತಂಕ ಮತ್ತು ಖಿನ್ನತೆಯ ಪ್ರಾಮುಖ್ಯತೆಯನ್ನು ತಿಳಿಯಲು ನಮಗೆ ಸಹಾಯ ಮಾಡುತ್ತದೆ. ಬಾಧಿತ ಮಕ್ಕಳು ತಮ್ಮ ಇಡೀ ಜೀವನದಲ್ಲಿ ಅನೇಕ ಒತ್ತಡಗಳನ್ನು ಎದುರಿಸುತ್ತಾರೆ. ಅವುಗಳೆಂದರೆ: ಪ್ರಯೋಗಾಲಯ ಪರೀಕ್ಷೆಗಳಿಗೆ ಆಗಾಗ್ಗೆ ರಕ್ತದ ಮಾದರಿಗಳು, ರಕ್ತ ವರ್ಗಾವಣೆಗಳು ಮತ್ತು ಆಗಾಗ್ಗೆ ಸಬ್ಕ್ಯುಟೇನಿಯಸ್ ಚುಚ್ಚುಮದ್ದು ಮತ್ತು ಐರನ್ ಚೆಲೇಟರ್ ಔಷಧಿಗಳ ಮೌಖಿಕ ಚಿಕಿತ್ಸೆ. ಅವರು ಒಟ್ಟಾರೆಯಾಗಿ ರೋಗಿಯನ್ನು ಖಿನ್ನತೆ ಮತ್ತು ಆತಂಕದಂತಹ ಮನೋವೈದ್ಯಕೀಯ ಹೊರೆಗೆ ಗುರಿಯಾಗುವಂತೆ ಮಾಡುತ್ತಾರೆ. ಇದು ಯಾವಾಗಲೂ ಒತ್ತಡವನ್ನು ಉಂಟುಮಾಡುತ್ತದೆ, ಇದು ಅನಾರೋಗ್ಯದ ಗೈರುಹಾಜರಿ ಮತ್ತು ಕಳಪೆ ಶೈಕ್ಷಣಿಕ ಶಾಲೆಯ ಕಾರ್ಯಕ್ಷಮತೆಗೆ ಕಾರಣವಾಗುತ್ತದೆ. ಭಾರತದಲ್ಲಿ ಬೀಟಾ ಥಲಸ್ಸೆಮಿಯಾ ಪ್ರಮುಖ ರೋಗಿಗಳಲ್ಲಿ ಮನೋವೈದ್ಯಕೀಯ ಕಾಯಿಲೆಯ ಕ್ಷೇತ್ರದಲ್ಲಿ ಬಹಳ ಸೀಮಿತ ಸಂಶೋಧನೆಯನ್ನು ನಡೆಸಲಾಗಿದೆ. ರೋಗನಿರ್ಣಯಕ್ಕೆ ಅವಕಾಶವಿದೆ ಮತ್ತು ಒಮ್ಮೆ ಮಾಡಿದ ನಂತರ ಮಕ್ಕಳ ಮನೋವೈದ್ಯರಿಂದ ಔಷಧಿ ಮತ್ತು ಸಮಾಲೋಚನೆಯ ರೂಪದಲ್ಲಿ ಸೂಕ್ತ ಮೌಲ್ಯಮಾಪನವನ್ನು ಮಾಡಬಹುದು. ಆದ್ದರಿಂದ ಪ್ರಸ್ತುತ ಅಧ್ಯಯನವನ್ನು ಕೈಗೊಳ್ಳಲಾಗಿದೆ. ಈ ಅಧ್ಯಯನದಲ್ಲಿ ಭಾಗವಹಿಸುವಿಕೆಯು ಸಂಪೂರ್ಣವಾಗಿ ಸ್ವಯಂಪ್ರೇರಿತವಾಗಿದೆ.

ಕಾರ್ಯವಿಧಾನದ ವಿವರಣೆ:

ಈ ಅಧ್ಯಯನದಲ್ಲಿ, ರೋಗ ಮತ್ತು ಅದರ ತೊಡಕುಗಳನ್ನು ವಿಶೇಷವಾಗಿ ಮಾನಸಿಕ ಹೊರೆಯನ್ನು ನಿಭಾಯಿಸುವಲ್ಲಿ ನಿಮ್ಮ ವೈಯಕ್ತಿಕ ಅನುಭವದ ಕುರಿತು ಕೆಲವು ಸಿದ್ಧಪಡಿಸಿದ ಪ್ರಶ್ನೆಗಳಿಗೆ ನೀವು ಉತ್ತರಿಸಬೇಕಾಗುತ್ತದೆ. ನೀವು ಭಾಗವಹಿಸಲು ಒಪ್ಪಿದರೆ, ನಂತರ ನಿಮಗೆ ಪ್ರಶ್ನೆಗಳನ್ನು ಮಾತ್ರ ಕೇಳಲಾಗುತ್ತದೆ. ಯಾವುದೇ ಕ್ಷಣದಲ್ಲಿ, ನೀವು ಅಧ್ಯಯನದಿಂದ ಹಿಂದೆ ಸರಿಯಬಹುದು. ನಿಮಗಾಗಿ ಮತ್ತು ನಿಮ್ಮ ಮಗುವಿಗೆ ಪೂರ್ವ-ಪರೀಕ್ಷಿತ-ವಿನ್ಯಾಸಗೊಳಿಸಿದ ಪ್ರಶ್ನಾವಳಿಯನ್ನು ಬಳಸಿಕೊಂಡು ಮಾಹಿತಿಯನ್ನು ಸಂಗ್ರಹಿಸಲಾಗುತ್ತದೆ.

ಸಂಭವನೀಯ ಪ್ರಯೋಜನಗಳು:

ತೊಡಕುಗಳು ಮತ್ತು ರೋಗದ ಹೊರೆಯನ್ನು ನಿರ್ಣಯಿಸಬಹುದು. ನಿಮ್ಮಲ್ಲಿ ಅಥವಾ ನಿಮ್ಮ ಮಗುವಿನಲ್ಲಿ ಖಿನ್ನತೆ ಅಥವಾ ಆತಂಕದ ಯಾವುದೇ ಸಂಭವನೀಯ ಚಿಹ್ನೆಗಳು ಕಂಡುಬಂದರೆ, ಮನೋವೈದ್ಯಕೀಯ ಮೌಲ್ಯಮಾಪನವನ್ನು ಸಲಹೆಯ ರೂಪದಲ್ಲಿ ಮತ್ತು ಅಗತ್ಯವಿದ್ದರೆ ಔಷಧಿಯ ಚಿಕಿತ್ಸೆಯ ರೂಪದಲ್ಲಿ ಸೂಚಿಸಲಾಗುತ್ತದೆ.

ಸಂಭವನೀಯ ಅಪಾಯಗಳು: ಈ ಅಧ್ಯಯನದಲ್ಲಿ ಯಾವುದೇ ಅಪಾಯವಿಲ್ಲ.

ಅಧ್ಯಯನದ ಪ್ರಯೋಜನಗಳು :

ರಕ್ತ ವರ್ಗಾವಣೆಗೆ ರೋಗಿಗಳ ಅನುಸರಣೆ ನಮಗೆ ತಿಳಿಯುತ್ತದೆ. ನಿಮ್ಮಲ್ಲಿ ಅಥವಾ ನಿಮ್ಮ ಮಗುವಿನಲ್ಲಿ ಖಿನ್ನತೆ ಅಥವಾ ಆತಂಕದ ಯಾವುದೇ ಸಂಭವನೀಯ ಚಿಹ್ನೆಗಳು ಕಂಡುಬಂದರೆ, ಮನೋವೈದ್ಯಕೀಯ ಮೌಲ್ಯಮಾಪನವನ್ನು ಸಲಹೆಯ ರೂಪದಲ್ಲಿ ಮತ್ತು ಅಗತ್ಯವಿದ್ದರೆ ಔಷಧೀಯ ಚಿಕಿತ್ಸೆಯ ರೂಪದಲ್ಲಿ ಸೂಚಿಸಲಾಗುತ್ತದೆ.

ಗೌಪ್ಯತೆ :

ಸಂಗ್ರಹಿಸಿದ ಎಲ್ಲಾ ಡೇಟಾ ಗೌಪ್ಯವಾಗಿ ಉಳಿಯುತ್ತದೆ ಮತ್ತು ಒಟ್ಟುಗೂಡಿದ ಡೇಟಾವನ್ನು ಮಾತ್ರ ಪ್ರಕಟಿಸಲಾಗುತ್ತದೆ. ನಿಮ್ಮ ವೈಯಕ್ತಿಕ ಗುರುತನ್ನು ಬಹಿರಂಗಪಡಿಸಲಾಗುವುದಿಲ್ಲ.

ಹಿಂತೆಗೆದುಕೊಳ್ಳುವಿಕೆ :

ಈ ಅಧ್ಯಯನದಲ್ಲಿ ನಿಮ್ಮ ಭಾಗವಹಿಸುವಿಕೆಯು ಸಂಪೂರ್ಣವಾಗಿ ಸ್ವಯಂಪ್ರೇರಿತವಾಗಿದೆ. ನೀವು ಭಾಗವಹಿಸಬೇಕೆ ಅಥವಾ ಬೇಡವೇ ಎಂಬುದನ್ನು ನಿರ್ಧರಿಸಬಹುದು. ನೀವು ಭಾಗವಹಿಸದಿರಲು ನಿರ್ಧರಿಸಿದರೂ ಸಹ, ಈ ಅಧ್ಯಯನದ ಪ್ರಯೋಜನಗಳಿಂದ ನೀವು ವಂಚಿತರಾಗುವುದಿಲ್ಲ.

ಭಾಗವಹಿಸುವಿಕೆಯ ವೆಚ್ಚಗಳು :

ಇದು ಸಂಪೂರ್ಣ ಪ್ರಶ್ನಾವಳಿ ಆಧಾರಿತ ಅಧ್ಯಯನವಾಗಿದೆ. ಈ ಅಧ್ಯಯನದಲ್ಲಿ ಭಾಗವಹಿಸಲು ನಿಮಗೆ ಯಾವುದೇ ಹೆಚ್ಚುವರಿ ವೆಚ್ಚ ಇರುವುದಿಲ್ಲ.

ಭಾಗವಹಿಸುವಿಕೆಯ ಪಾವತಿ : ಈ ಅಧ್ಯಯನದಲ್ಲಿ ಭಾಗವಹಿಸಲು ನಿಮಗೆ ಯಾವುದೇ ಪ್ರೋತ್ಸಾಹಕ ಇರುವುದಿಲ್ಲ.

ಪ್ರಶ್ನೆಗಳು

ಅಧ್ಯಯನಕ್ಕೆ ಸಂಬಂಧಿಸಿದಂತೆ ನೀವು ಯಾವುದೇ ಪ್ರಶ್ನೆಗಳನ್ನು ಹೊಂದಿದ್ದರೆ, ನೀವು ಪ್ರಿನ್ಸಿಪಾಲ್ ಇನ್ವೆಸ್ಟಿಗೇಟರ್ ಡಾ. ಒಲಿವಿಯಾ ದಾಸ್‌ಗುಪ್ತಾ, ಪಿಜಿ 2021 ಎಂ ಡಿ ಪ್ರವೇಶ ಬ್ಯಾಚ್, ಪೀಡಿಯಾಟ್ರಿಕ್ಸ್ ವಿಭಾಗ J. N. ವೈದ್ಯಕೀಯ ಕಾಲೇಜು, ಬೆಳಗಾವಿ, ಸಂಪರ್ಕಿಸಬೇಕು. 590010, ದೂರವಾಣಿ ಸಂಖ್ಯೆ 7005318253

ಮಾರ್ಗದರ್ಶಿ : ಡಾ. ಜ್ಞಾನೇಶ್ ಡಿ ಕೆ, ಪ್ರಾಧ್ಯಾಪಕರು, ಪೀಡಿಯಾಟ್ರಿಕ್ಸ್ ವಿಭಾಗ, ಜೆ.ಎನ್. ವೈದ್ಯಕೀಯ ಕಾಲೇಜು, ಬೆಳಗಾವಿ, 590010.

ನಿಮ್ಮ ಹಕ್ಕಿನ ಕುರಿತು ನೀವು ಯಾವುದೇ ಪ್ರಶ್ನೆ ಅಥವಾ ದೂರುಗಳನ್ನು ಹೊಂದಿದ್ದರೆ ಅಧ್ಯಯನದಲ್ಲಿ ಭಾಗವಹಿಸುವವರನ್ನು ನೀವು ಸಂಪರ್ಕಿಸಬಹುದು ಡಾ ಹರ್ಷ ಹೆಗಡೆ, ಅಧ್ಯಕ್ಷರು, ಜೆಎನ್‌ಎಂಸಿ ನೈತಿಕ ಸಮಿತಿ, 0831-2473777 ವಿಸ್ತರಣೆ 4052.

ಕಾನೂನು ಹಕ್ಕುಗಳು :

ಈ ಸಮ್ಮತಿಯ ನಮೂನೆಗೆ ಸಹಿ ಮಾಡುವ ಮೂಲಕ, ನಿಮ್ಮ ಯಾವುದೇ ಕಾನೂನು ಹಕ್ಕುಗಳನ್ನು ನಾವು ಕೈ ಬಿಡಿಸಿ ಕರೆಯುತ್ತಿಲ್ಲ.

ಸಮ್ಮತಿ ಹೇಳಿಕೆ

"ನಾನು ಸ್ವಯಂಸೇವಕನಾಗಿ ಮತ್ತು ಅಧ್ಯಯನದಲ್ಲಿ ಭಾಗವಹಿಸಲು ಒಪ್ಪಿಗೆ ನೀಡುತ್ತೇನೆ. ನಾನು ಮಾಹಿತಿ ಹಾಳೆಯನ್ನು ಸಂಪೂರ್ಣವಾಗಿ ಓದಿದ್ದೇನೆ (ಅಥವಾ ನನಗೆ ತಿಳಿದಿರುವ ಭಾಷೆಯಲ್ಲಿ ಅದನ್ನು ನನಗೆ ಓದಲಾಗಿದೆ). ಪ್ರಶ್ನೆಗಳನ್ನು ಕೇಳಲು ನನಗೆ ಸಂಪೂರ್ಣ ಅವಕಾಶವನ್ನು ನೀಡಲಾಯಿತು. ನಾನು ಕೇಳಲು ಬಯಸಿದ ಪ್ರಶ್ನೆಗಳಿಗೆ ಉತ್ತರಗಳಿಂದ ನಾನು ಸಂಪೂರ್ಣವಾಗಿ ತೃಪ್ತನಾಗಿದ್ದೇನೆ. ಈ ಸಂಶೋಧನಾ ಯೋಜನೆಯಲ್ಲಿ ಭಾಗವಹಿಸಲು ನಾನು ಸ್ವಯಂಪ್ರೇರಣೆಯಿಂದ ಸಮ್ಮತಿಸುತ್ತೇನೆ" .

____________________	________________
ಭಾಗವಹಿಸುವವರ ಹೆಸರು	ಭಾಗವಹಿಸುವವರ ಸಹಿ ಅಥವಾ ಎಡಗೈ ಹೆಬ್ಬೆರಳಿನ ಗುರುತು
____________________	________________
ತನಿಖಾಧಿಕಾರಿಯ ಹೆಸರು	ತನಿಖಾಧಿಕಾರಿಯ ಸಹಿ
____________________	________________
ಸಾಕ್ಷಿಯ ಹೆಸರು	ಸಾಕ್ಷಿಯ ಸಹಿ
ದಿನಾಂಕ : ____________________	ಸ್ಥಳ : __________________________

ANNEXURE II- PERFORMA

Name of the patient:

Age: Date of Birth:

Educational qualification:

Do they go to school?

Total years of schooling if not going to school currently:

Gender:

Patient hospital no: Date of Admission:

Address:

Distance from KLE Hospital:

Phone number:

Anthropometry and its interpretation:

Weight :

Height:

BMI(for children>5yrs):

Head circumference:

Chest circumference:

Midarm circumference:

Upper segment: lower segment ratio:

Date of diagnosis:

Date of enrollment in the study:

Date of first blood transfusion:

Date of last blood transfusion:

Proposed date of next blood transfusion:

Any treatment/ medication they are currently taking? If yes, elaborate:

H/o splenectomy or planned:

Investigations sent and their values:

Physical complaints (if any):

Appetite Concerns (if any)/ Dietary history:

Developmental milestones:

Birth history

Immunization status:

Demographic details of patient and family

Ethnicity:

H/o consanguinity: yes : no :

Family history of Thalassemia: yes: no:

No of siblings:

Socio economic status as per modified BG Prasad:

Type of family:

Total number of family members:

Parent's details

Mother	Father
Name:	Name:
Age :	Age:
Education:	Education:

reduced hours of job/income in either of the parents:

extra care if any for the child:

reduced sleep:

reduced income:

how much do you think your child's ill health has affected you?

QUESTIONNAIRE FOR CHILDREN

BEDTIME

Write in your child's usual bedtime: Weeknights ____:____ am/pm

Weekends ____:____ am/pm

	7 Always	5-6 Usually	2-4 Sometimes	1 Rarely	0 Never
1. Child goes to bed at the same time at night.	( )	( )	( )	( )	( )
2. Child falls asleep within 20 minutes after going to bed.	( )	( )	( )	( )	( )
3. Child falls asleep alone in own bed.	( )	( )	( )	( )	( )
4. Child falls asleep in parent's or sibling's bed.	( )	( )	( )	( )	( )
5. Child falls asleep with rocking or rhythmic movements.	( )	( )	( )	( )	( )
6. Child needs special object to fall asleep (doll, special blanket, stuffed animal, etc.).	( )	( )	( )	( )	( )
7. Child needs parent in the room to fall asleep.	( )	( )	( )	( )	( )
8. Child resists going to bed at bedtime.	( )	( )	( )	( )	( )
9. Child is afraid of sleeping in the dark.	( )	( )	( )	( )	( )

SLEEP BEHAVIOR

Write in your child's usual amount of sleep each day (combining nighttime sleep and naps): ____ hours and ____ minutes

	7 Always	5-6 Usually	2-4 Sometimes	1 Rarely	0 Never
10. Child sleeps about the same amount each day.	( )	( )	( )	( )	( )
11. Child is restless and moves a lot during sleep.	( )	( )	( )	( )	( )

	7 Always	5-6 Usually	2-4 Sometimes	1 Rarely	0 Never
12. Child moves to someone else's bed during the night (parent, sibling, etc.).	( )	( )	( )	( )	( )
13. Child grinds teeth during sleep (your dentist may have told you this).	( )	( )	( )	( )	( )
14. Child snores loudly.	( )	( )	( )	( )	( )
15. Child awakens during the night and is sweating, screaming, and inconsolable.	( )	( )	( )	( )	( )
16. Child naps during the day.	( )	( )	( )	( )	( )
Write in the number of minutes the nap usually lasts: _____ minutes					

WAKING DURING THE NIGHT

	7 Always	5-6 Usually	2-4 Sometimes	1 Rarely	0 Never
17. Child wakes up once during the night.	( )	( )	( )	( )	( )
18. Child wakes up more than once during the night.	( )	( )	( )	( )	( )

MORNING WAKE UP

Write in the time child usually wakes up in the morning: Weekdays _____:_____ am/pm

Weekends _____:_____ am/pm

	7 Always	5-6 Usually	2-4 Sometimes	1 Rarely	0 Never
19. Child wakes up by him/herself.	( )	( )	( )	( )	( )
20. Child wakes up very early in the morning (or, earlier than necessary or desired).	( )	( )	( )	( )	( )
21. Child seems tired during the daytime.	( )	( )	( )	( )	( )
22. Child falls asleep while involved in activities.	( )	( )	( )	( )	( )

		Never	Sometimes	Often	Alwa
1	I worry about things	0	1	2	3
2	I feel sad or empty	0	1	2	3
3	When I have a problem, I get a funny feeling in my stomach	0	1	2	3
4	I worry when I think I have done poorly at something	0	1	2	3
5	I would feel afraid of being on my own at home	0	1	2	3
6	Nothing is much fun anymore	0	1	2	3
7	I feel scared when I have to take a test	0	1	2	3
8	I feel worried when I think someone is angry with me	0	1	2	3
9	I worry about being away from my parents	0	1	2	3
10	I get bothered by bad or silly thoughts or pictures in my mind	0	1	2	3
11	I have trouble sleeping	0	1	2	3
12	I worry that I will do badly at my school work	0	1	2	3
13	I worry that something awful will happen to someone in my family	0	1	2	3
14	I suddenly feel as if I can't breathe when there is no reason for this	0	1	2	3
15	I have problems with my appetite	0	1	2	3
16	I have to keep checking that I have done things right (like the switch is off, or the door is locked)	0	1	2	3

		Never	Sometimes	Often	Always
17	I feel scared if I have to sleep on my own	0	1	2	3
18	I have trouble going to school in the mornings because I feel nervous or afraid	0	1	2	3
19	I have no energy for things	0	1	2	3
20	I worry I might look foolish	0	1	2	3
21	I am tired a lot	0	1	2	3
22	I worry that bad things will happen to me	0	1	2	3
23	I can't seem to get bad or silly thoughts out of my head	0	1	2	3
24	When I have a problem, my heart beats really fast	0	1	2	3
25	I cannot think clearly	0	1	2	3
26	I suddenly start to tremble or shake when there is no reason for this	0	1	2	3
27	I worry that something bad will happen to me	0	1	2	3
28	When I have a problem, I feel shaky	0	1	2	3
29	I feel worthless	0	1	2	3
30	I worry about making mistakes	0	1	2	3
31	I have to think of special thoughts (like numbers or words) to stop bad things from happening	0	1	2	3
32	I worry what other people think of me	0	1	2	3
33	I am afraid of being in crowded places (like shopping centers, the movies, buses, busy playgrounds)	0	1	2	3
34	All of a sudden I feel really scared for no reason at all	0	1	2	3
35	I worry about what is going to happen	0	1	2	3
36	I suddenly become dizzy or faint when there is no reason for this	0	1	2	3

		Never	Sometimes	Often	Always
37	I think about death	0	1	2	3
38	I feel afraid if I have to talk in front of my class	0	1	2	3
39	My heart suddenly starts to beat too quickly for no reason	0	1	2	3
40	I feel like I don't want to move	0	1	2	3
41	I worry that I will suddenly get a scared feeling when there is nothing to be afraid of	0	1	2	3
42	I have to do some things over and over again (like washing my hands, cleaning or putting things in a certain order)	0	1	2	3
43	I feel afraid that I will make a fool of myself in front of people	0	1	2	3
44	I have to do some things in just the right way to stop bad things from happening	0	1	2	3
45	I worry when I go to bed at night	0	1	2	3
46	I would feel scared if I had to stay away from home overnight	0	1	2	3
47	I feel restless	0	1	2	3

WHO Quality of Life Scale-Brief

Before we begin we would like to ask you to answer a few general questions about yourself by circling in the correct answer or by filling in the space provided.

1.	What is your gender?	Male	Female
2.	What is your date of birth?	_______ / _______ / _______ Day Month Year	
3.	What is the highest education you received?	None at all Elementary School High School College Graduate/Professional Degree	
4.	What is your marital status?	Single Married Living as Married	Separated Divorced Widowed
5.	Are you currently ill?	Yes	No
6.	If something is wrong with your health, what do you think it is?	________________	illness/problem

Instructions: This questionnaire asks how you feel about your quality of life, health, or other areas of your life. Please answer all of the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind standards, hopes, pleasures, and concerns. We ask that you think about your life in the last two weeks. For example, thinking about the last two weeks a question might ask:

Do you get the kind of support from others that you need?	*(Please circle the number)*				
	Not at all	A little	Moderately	Mostly	Completely
	1	**2**	**3**	**4**	**5**

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others.

Do you get the kind of support from others that you need?	*(Please circle the number)*				
	Not at all	A little	Moderately	Mostly	Completely
	1	**2**	**3**	**(4)**	**5**

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks.

Do you get the kind of support from others that you need?	*(Please circle the number)*				
	Not at all	A little	Moderately	Mostly	Completely
	①	2	3	4	5

Please read each question, assess your feelings, and circle the number on the scale that gives the best answer for you for each question.

1. How would you rate your quality of life?	*(Please circle the number)*				
	Very poor	Poor	Neither poor nor good	Good	Very Good
	1	2	3	4	5

2. How satisfied are you with your health?	*(Please circle the number)*				
	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

	(Please circle the number)				
	Not at all	A little	A moderate amount	Very much	An extreme amount
3. To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4. How much do you need any medical treatment to function in your life?	1	2	3	4	5
5. How much do you enjoy life?	1	2	3	4	5
6. To what extent do you feel your life to be meaningful?	1	2	3	4	5
7. How well are you able to concentrate?	1	2	3	4	5

	(Please circle the number)				
	Not at all	Slightly	A moderate amount	Very much	Extremely
8. How safe do you feel in your daily life?	1	2	3	4	5
9. How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

	(Please circle the number)				
	Not at all	A little	Moderately	Mostly	Completely
10. Do you have enough energy for everyday life?	1	2	3	4	5
11. Are you able to accept your bodily appearance?	1	2	3	4	5
12. Have you enough money to meet your needs?	1	2	3	4	5
13. How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14. To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

	(Please circle the number)				
	Very poor	Poor	Neither poor nor well	Well	Very well
15. How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good** or **satisfied** you have felt about various aspects of your life over the last two weeks.

	(Please circle the number)				
	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16. How satisfied are you with your sleep?	1	2	3	4	5
17. How satisfied are you with your ability to perform your daily living activities.	1	2	3	4	5

	(Please circle the number)				
	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
18. How satisfied are you with your capacity for work?	**1**	**2**	**3**	**4**	**5**
19. How satisfied are you with yourself?	**1**	**2**	**3**	**4**	**5**
20. How satisfied are you with your personal relationships?	**1**	**2**	**3**	**4**	**5**
21. How satisfied are you with your sex life?	**1**	**2**	**3**	**4**	**5**
22. How satisfied are you with the support you get from your friends?	**1**	**2**	**3**	**4**	**5**
23. How satisfied are you with the conditions of your living place?	**1**	**2**	**3**	**4**	**5**
24. How satisfied are you with your access to health services?	**1**	**2**	**3**	**4**	**5**
25. How satisfied are you with your mode of transportation?	**1**	**2**	**3**	**4**	**5**

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

	(Please circle the number)				
	Never	Seldom	Quite often	Very often	Always
26. How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	**1**	**2**	**3**	**4**	**5**

)id someone help you to fill out his form? *(Please circle Yes or No)* Yes No

Iow long did it take you to fill out this form? ____________minutes

ANNEXURE III – PERMISSION TO USE RCADS

Regarding the use for RCADS in the thesis of Post graduation MD paediatrics course in India

me 8 Feb 2023

to RCADS

Respected sir/ma'am

I am a Post graduate resident in the department of Paediatrics in JN medical college, Belagavi, Karnataka, India. I have my thesis on the prevalence of anxiety and depression in thalassemia major patients in KLE Prabhakar kore hospital in Belagavi. I am intend on using the RCADS scoring for the assessment of the same. Kindly let me know the procedure for procurement of the scoring tool and permission to do so.

Thanking you
Yours sincerely
REGNO: BM0121015
Paediatrics resident
JN medical college
Belagavi, Karnataka-590010
India.

Psychology RCADS 14 Feb 2023

to me

Dear **REG NO:BM0121015**

Thank you for asking permission to use the RCADS in your research project. You are welcome to do so if you follow the terms in the latest User's Guide. The User's Guide is regularly updated and located on the Child FIRST Lab website under the resources page. As a friendly reminder, use of the RCADS or its derivatives in published research should include acknowledgment of the development of the RCADS using appropriate scholarly citations. The recommended citation for use of the RCADS in any published research is as follows:

Chorpita, B. F., Yim, L. M., Moffitt, C. E., Umemoto L. A., & Francis, S. E. (2000). Assessment of symptoms of DSM-IV anxiety and depression in children: A Revised Child Anxiety and Depression Scale. Behaviour Research and Therapy, 38, 835-855.

Best of luck with your project!

Sincerely,
The Child FIRST RCADS Team

From: **REGNO: BM0121015**
Sent: Tuesday, February 7, 2023 9:27 PM
To: Psychology RCADS <RCADS@psych.ucla.edu>
Subject: Regarding the use for RCADS in the thesis of Post graduation MD paediatrics course in India

ANNEXURE IV – KEY TO MASTER CHART

Variable	Code	Key
Religion	1	Hindu
	2	Islam
	3	Christian
Extra Drugs	NA	No
	1	HYDROXYUREA
Developmental delay	X	No
	1	Hearing Loss
	2	Seizure episodes
Type of family	1	Nuclear
	2	Joint
	3	Extended
Level of education	1	No formal Education
	2	Below Primary
	3	Primary
	4	High school
	5	Secondary school
	6	Graduate
	7	Post Graduate
Questionnaire	0	Never
	1	Rarely
	2	Sometimes
	3	Usually
	4	Always

ANNEXURE IV- MASTER CHART

S.No.	AGE(years)	RELIGION	GENDER	SCHOOLING(YES/NO)	CLASS	DISTANCE FROM HOSPITAL	WT(KG)	HT(CM)	BMI	NUMBER OF DRUGS FOR CHELATION	EXTRA DRUGS	TOTAL SUPPLEMENTS	SERUM FERRITIN	PRE TRANSFUSION HB	POST TRANSFUSION HB	FREQUENCY BETWN TWO BTs	SPLENECTOMY	DEVELOPMENTAL DELAY	CONSANGUINITY	FAMILY HISTORY OF THAL	NO. OF SIBLINGS	TYPE OF FAMILY	NO. OF FAMILY MEMBERS	Mother's AGE	Mother's EDUCATION	Father's AGE	Father's EDUCATION
1	14	2	F	Y	9TH	114	40	145	19	2	NA	3	848	7.7	9	25	NO	X	NO	NO	3	1	6	36	4	48	4
2	10	1	F	Y	5TH	5.5	29.6	136	16	1	NA	3	2278	10.5	13.5	21	NO	X	NO	NO	2	1	5	33	6	40	7
3	17	1	M	Y	7TH	57	31	138	16.2	1	NA	3	2745	11	12.8	21	NO	X	NO	NO	1	1	4	35	6	45	6
4	15	1	F	Y	9TH	47	27	138	14	1	NA	3	2635	10.6	12.9	19	NO	X	YES	YES	4	1	6	40	2	45	3
5	8	2	F	Y	3RD	15	21	117	15.3	2	NA	3	5736	11	13.5	28	NO	X	NO	NO	1	1	4	26	4	31	4
6	10	2	M	Y	3RD	106	25	139	12.9	1	NA	3	1671	8.5	11.6	14	NO	X	NO	NO	1	2	8	31	6	37	6
7	10	1	F	Y	5TH	57	28	130	16.5	1	NA	3	4927	10.5	13.6	28	NO	X	YES	NO	1	3	5	29	4	35	3
8	16	2	F	Y	10TH	347	35	150	15.5	2	NA	3	1546	10.5	12.6	21	NO	X	YES	YES	5	1	8	42	4	70	1
9	14	1	F	Y	9TH	67	36	144	17.3	1	NA	3	959	7.9	11.8	35	NO	X	NO	NO	1	1	4	33	4	38	5
10	13	2	M	Y	8TH	8.1	29	132	16.6	2	NA	3	2073	8.7	11.5	15	NO	X	NO	NO	1	1	4	29	3	39	4
11	8	2	F	Y	3RD	80	19	114	14.6	2	NA	3	3315	8.5	12.6	28	NO	X	NO	NO	3	2	7	26	4	32	5
12	8	1	F	Y	3RD	88	19	111	15.4	1	NA	3	1287	10.8	13.5	33	YES	X	YES	NO	1	1	4	31	5	35	5
13	9	2	F	Y	3RD	77	29	117	15.3	1	NA	3	1675	8.4	12.2	28	NO	X	NO	NO	1	1	4	28	3	38	4

14	13	1	M	Y	7TH	80	33	136	17.8	2	NA	3	2446	9.8	13	14	NO	X	NO	NO	2	3	6	38	1	45	5
15	12	1	F	Y	5TH	46	30	138	15.7	2	NA	3	4644	10.7	13.2	23	NO	X	YES	NO	2	1	5	28	6	38	6
16	11	2	F	Y	5TH	83	24	129	14.4	1	NA	3	2155	7.4	10.2	20	NO	X	YES	YES	1	1	5	30	4	40	4
17	11	2	F	Y	5TH	110	24.9	130	14.7	1	1	3	595	6.2	9.3	28	NO	X	YES	NO	1	1	4	32	4	40	4
18	9	1	F	Y	4TH	9.7	13	105	11.7	1	NA	3	432	8.4	13.3	28	NO	X	YES	YES	2	1	5	32	4	40	4
19	8	1	M	Y	3RD	57	21	136	11.3	1	NA	3	150	6	9.8	15	NO	X	YES	YES	1	2	10	31	6	36	6
20	13	1	F	Y	7TH	68	28	140	14.2	2	NA	3	7184	9.8	12.6	28	NO	X	NO	NO	2	2	7	45	1	45	1
21	12	2	F	Y	7TH	88	27	138	14.1	1	NA	3	802	8.8	11.5	17	NO	1	YES	NO	2	1	5	35	3	45	1
22	17	1	F	NO		140	36	140	18.3	2	NA	3	10911	9.8	11.9	28	YES	X	YES	YES	1	1	4	40	3	46	5
23	13	1	F	Y	7TH	47	22	133	12.4	1	NA	3	4273	9.9	12.2	28	NO	X	YES	YES	3	2	9	38	1	50	1
24	16	1	F	Y	10TH	95	32	138	16.8	2	NA	3	5703	10	12	28	NO	X	YES	NO	3	1	6	34	3	42	6
25	10	1	M	Y	5TH	212	30	133	16.9	1	NA	3	3325	6.9	11.9	28	NO	X	YES	NO	1	1	4	32	3	38	4
26	14	1	M	Y	8TH	40	29.5	133	16.6	1	NA	3	1293	7.8	10.5	14	NO	X	NO	NO	0	1	4	37	3	47	4
27	9	2	M	Y	3RD	46	20.8	124	13.5	1	NA	3	3153	10.5	13	28	NO	X	NO	YES	1	2	14	28	3	35	5
28	14	1	M	Y	8TH	100	35	143	17.1	1	NA	3	1488	8.5	11.6	21	NO	X	YES	NO	0	1	3	35	4	43	3
29	13	1	M	Y	8TH	83	25	134	13.9	2	NA	3	4633	7.8	12.3	28	NO	X	NO	NO	1	1	4	38	4	47	5
30	16	1	M	Y	10TH	140	30	143	14.6	1	NA	3	4566	9.8	13.2	28	NO	X	NO	YES	1	1	4	38	4	42	6
31	14	1	M	Y	9TH	87	37	142	18.3	1	NA	3	1086	10	14.2	28	NO	X	YES	NO	3	1	6	38	4	40	1
32	12	2	F	NO		60	21	110	17.3	1	NA	3	1821	8.5	10.3	28	NO	2	NO	NO	1	1	4	36	4	40	4
33	9	1	M	Y	2ND	240	27	129	16.2	2	NA	3	6596	6.6	9.6	21	NO	X	YES	NO	3	3	6	40	3	45	3
34	10	1	M	Y	3RD	96	24	130	14.2	1	NA	3	2819	7	10.2	21	NO	X	NO	NO	1	1	4	42	1	53	6
35	13	1	F	Y	8TH	96	24	135	13.1	1	NA	3	1423	9.9	12.6	28	NO	X	YES	NO	0	1	3	34	5	38	6
36	14	1	F	Y	9TH	100	43	162	16.3	2	NA	3	10502	7.2	10.8	24	NO	X	NO	YES	2	1	4	35	1	40	3
37	8	2	M	Y	2ND	88	20	124	13	1	NA	3	1178	8.1	11.7	25	NO	X	NO	YES	1	2	6	30	4	40	4

38	9	1	M	Y	3RD	100	16	109	13.1	1	NA	3	1176	8	12	24	NO	X	YES	NO	1	3	6	28	3	42	4
39	11	3	F	Y	5TH	80	22	125	14.1	2	NA	3	6045	8.3	11.7	21	NO	X	YES	NO	1	1	4	31	3	41	3
40	11	2	F	Y	6TH	100	23.5	124	15.2	1	NA	3	4637	8.2	10.5	14	NO	X	NO	NO	1	3	5	32	5	40	6
41	15	2	M	Y	10TH	80	29	140	14.8	2	NA	3	4442	7.2	9.3	14	NO	X	NO	YES	1	1	4	39	4	43	4
42	16	2	F	Y	11TH	80	41	154	17.3	1	NA	3	1158	9.1	12.5	14	NO	X	NO	YES	1	1	4	39	4	43	4
43	12	2	M	Y	7TH	10	30	140	15.3	2	NA	3	3571	8.4	10.7	14	NO	X	NO	NO	1	1	4	34	5	37	4
44	14	1	F	Y	8TH	134	27	135	14.8	2	NA	3	12746	9.5	12.4	21	NO	X	NO	NO	2	2	12	37	4	48	5
45	11	2	F	Y	5TH	100	29.9	130	17.7	2	NA	3	2236	9.8	12.5	21	NO	X	YES	NO	1	2	11	35	5	41	5
46	17	1	M	Y	10TH	8.1	40	150	17.8	2	NA	3	2286	8.5	10.5	14	NO	X	NO	NO	0	3	5	38	4	45	3
47	10	1	M	Y	4TH	20	27	130	16	1	1	3	582	6.6	10	14	NO	X	YES	YES	1	1	5	40	1	50	4
48	14	1	M	Y	9TH	63	35	143	17.1	1	NA	3	4176	9.8	12.5	21	NO	X	YES	NO	3	1	6	35	4	40	5
49	11	1	F	Y	5TH	10	32	137	17	1	NA	3	1087	9.5	12.4	21	NO	X	YES	NO	1	1	4	32	3	40	3
50	15	1	F	Y	9TH	92	44	154	18.6	1	NA	3	657	8.8	12.2	21	NO	X	YES	NO	1	1	5	32	4	40	5
51	13	1	F	Y	6TH	189	50	155	20.8	1	NA	3	832	8.9	12.5	21	NO	X	YES	YES	2	2	6	35	3	40	5
52	16	1	F	Y	1OTH	134	36	151	15.8	1	NA	3	373	8.4	12.3	21	NO	X	NO	NO	3	1	5	38	4	46	5
53	15	1	M	Y	10TH	250	34	149	15.3	2	NA	3	9000	8.3	12.4	28	NO	X	YES	NO	1	1	4	35	3	38	3
54	17	1	M	NO		150	39	154	16.4	2	NA	3	6032	9	12.4	28	YES	X	YES	NO	1	1	4	35	4	43	4
55	14	1	M	Y	9TH	70	30	144	14.5	1	NA	3	2494	7.9	12	14	NO	X	YES	NO	1	1	4	32	3	37	2
56	9	1	F	Y	3RD	8.7	23	136	12.4	2	NA	3	4079	8.8	12.3	14	NO	X	YES	NO	1	1	4	28	4	32	4
57	8	1	M	Y	3RD	60	20	119	14.1	2	NA	3	4124	5.5	9	10	NO	X	NO	NO	2	1	5	28	4	30	5
58	8	1	F	Y	3RD	47	18	110	14.9	2	NA	3	4216	10	15	21	NO	X	YES	NO	1	1	4	35	4	43	5
59	16	1	F	Y	11TH	20	29	139	15	2	1	3	7143	8.5	13.5	21	NO	X	YES	NO	1	1	4	45	3	50	3
60	14	2	M	Y	9TH	347	31	134	17.3	1	NA	3	327	8.7	13	21	NO	X	YES	YES	5	1	8	42	4	70	1
61	14	1	M	Y	9TH	20	29.5	140	15.1	1	NA	3	1945	8	13.3	28	NO	X	YES	NO	1	1	4	30	5	38	5

62	10	1	F	Y	4TH	120	22.5	124	14.6	1	NA	3	1136	8.9	13	28	NO	X	NO	NO	1	1	4	32	4	42	4
63	10	1	F	Y	5TH	140	21	128	12.8	1	NA	3	4394	10.2	13	28	NO	X	NO	NO	4	1	6	40	1	45	4
64	9	1	M	Y	3RD	60	22	116	16.3	2	NA	3	3319	9.8	12.5	28	NO	X	YES	YES	2	1	5	24	4	35	4
65	8	1	M	Y	3RD	87	20	140	10.2	1	NA	3	3790	10.5	13.6	28	N0	X	NO	NO	2	1	5	29	4	32	3
66	12	1	M	Y	5TH	100	29	113	22.7	1	NA	3	5436	10.2	12.8	28	NO	X	NO	NO	5	2	10	40	4	45	5
67	10	1	M	Y	4TH	50	24	125	15.4	1	NA	3	973	9.4	10.5	14	NO	X	NO	NO	1	1	5	36	4	40	4
68	12	2	M	Y	6TH	60	30	140	15.3	2	NA	3	4436	9.8	12.3	14	NO	X	NO	NO	1	2	10	30	4	40	5
69	12	1	F	Y	5TH	140	20	125	12.8	1	NA	3	1995	10.5	13.3	28	NO	X	YES	NO	2	1	5	33	4	40	6
70	14	1	F	Y	8TH	100	24.2	132	13.9	1	NA	3	1120	10.6	13	28	NO	X	YES	NO	2	2	9	31	5	47	1
71	15	1	F	Y	8TH	100	24.6	147	11.4	2	NA	3	995	9.8	12.8	28	YES	X	YES	NO	2	1	5	55	1	60	1
72	12	1	M	Y	5TH	60	23	122	15.4	1	NA	3	1134	8.4	11.9	21	YES	X	YES	NO	2	1	4	53	1	55	1
73	16	1	M	Y	8TH	60	26	130	15.3	2	NA	3	8106	8.2	11.5	21	YES	X	NO	NO	1	1	4	37	1	56	1
74	15	1	F	Y	8TH	10	35	133	19.7	1	NA	3	5716	7.8	10.1	14	YES	X	NO	NO	3	1	6	30	1	42	1
75	16	1	F	Y	10TH	163	35	135	19.2	1	NA	3	427	10.5	14	35	NO	X	NO	NO	1	1	3	37	3	42	3
76	17	1	F	Y	10TH	87	48	150	21.3	2	NA	3	3872	9.5	11.2	28	YES	X	YES	NO	1	1	2	56	1	52	1
77	16	1	M	Y	10TH	163	36	160	14.1	1	NA	3	4775	7.5	9.5	14	NO	X	YES	NO	1	1	4	35	4	45	1
78	16	2	F	Y	10TH	347	34	149	15.3	1	NA	3	1519	9.5	11.8	28	NO	X	YES	YES	5	1	8	42	4	70	1
79	10	1	F	Y	4TH	8.1	27	132	20.4	2	NA	3	4178	8.2	11.5	14	NO	X	YES	YES	2	1	5	36	4	38	4
80	10	1	F	Y	5TH	77	26	132	14.9	1	1	3	1477	7.2	10.2	21	NO	X	NO	YES	2	1	5	32	4	38	4
81	9	1	F	Y	4TH	88	21	123	13.9	1	NA	3	1158	8.9	12.4	28	NO	X	YES	NO	1	1	4	31	4	41	5
82	11	1	M	Y	6TH	140	24	127	14.9	2	NA	3	7530	10.2	13.4	28	NO	X	YES	NO	2	1	5	30	3	35	3
83	11	1	M	Y	6TH	67	32	139	16.6	1	NA	3	5808	8.7	11.7	28	NO	X	YES	NO	1	1	4	32	4	38	4
84	9	1	M	Y	4TH	114	21	124	13.7	1	NA	3	2500	10.2	13.5	28	NO	X	YES	NO	2	1	5	28	4	36	5
85	12	1	F	Y	7TH	46	25	138	13.1	1	NA	3	1230	9.5	13.2	21	NO	X	YES	NO	0	1	3	28	3	35	5

86	15	1	F	Y	10TH	8.1	37	149	16.6	2	NA	3	3938	6.8	10.5	14	NO	X	YES	YES	2	1	5	36	4	38	4
87	11	1	F	Y	5TH	8.1	30	131	17.4	1	1	3	2829	8	10.5	21	NO	X	YES	NO	1	1	4	29	3	35	1
88	12	1	F	Y	6TH	40	28	128	17.1	1	NA	3	477	8.5	12	21	NO	X	NO	NO	3	1	7	33	3	38	3
89	17	2	F	Y	12TH	100	29.7	138	15.5	1	1	3	2278	7	11.5	14	YES	X	NO	YES	2	1	5	43	4	45	6
90	12	2	M	Y	6TH	100	25	128	15.7	1	NA	3	1408	8.5	12	14	NO	X	NO	YES	2	1	5	43	4	45	6
91	15	2	M	Y	10TH	100	38	150	16.9	2	NA	3	10394	7.9	12	14	NO	X	YES	NO	0	1	3	32	3	38	3
92	15	1	M	Y	9TH	70	32	155	13.3	1	NA	3	5300	9	12	14	NO	X	YES	NO	1	1	4	34	4	45	4
93	8	1	M	Y	3RD	50	18	122	12.1	1	NA	3	485	9.5	11.8	28	NO	X	NO	NO	1	2	8	25	4	40	4
94	9	1	M	Y	3RD	80	17	115	12.9	2	NA	3	4901	8.6	13.5	28	NO	X	NO	YES	2	1	4	35	3	39	3
95	10	1	M	Y	4TH	80	17	121	11.6	2	NA	3	3656	8.2	12.4	28	NO	X	NO	NO	0	1	3	36	3	41	5
96	10	1	M	Y	4TH	120	21	128	12.8	2	NA	3	4260	8	10.6	21	NO	X	YES	YES	1	2	11	27	4	35	5
97	12	1	M	NO		250	27	126	17	2	NA	3	2593	8.9	13.5	28	NO	X	YES	YES	1	1	4	31	3	32	4
98	8	1	M	Y	3RD	10	19	121	13	1	NA	3	1630	9.2	13.2	28	NO	X	NO	NO	0	1	3	26	7	27	5
99	16	1	F	Y	10TH	100	29	133	16.4	2	NA	3	2276	9.5	12.2	28	NO	X	YES	NO	0	1	3	39	1	43	1
100	8	1	M	Y	2ND	40	18.5	115	13.9	2	NA	3	2419	10	12.2	14	NO	X	YES	YES	2	1	5	27	3	35	4

Questionnaire

S. No.	REDUCAED SLEEP/INCOME	BEDTIME 1	BEDTIME 2	BEDTIME 3	BEDTIME 4	BEDTIME 5	BEDTIME 6	BEDTIME 7	BEDTIME 8	BEDTIME 9	TOTAL HOURS OF SLEEP	SLEEP BEHAVIOUR 1	SLEEP BEHAVIOUR 2	SLEEP BEHAVIOUR 3	SLEEP BEHAVIOUR 4	SLEEP BEHAVIOUR 5	SLEEP BEHAVIOUR 6	SLEEP BEHAVIOUR 7	WAKE UP DURING NIGHT 1	WAKE UP DURING NIGHT 2	MORNING WAKE UP 1	MORNING WAKE UP 2	MORNING WAKE UP 3	MORNING WAKE UP 4	SEPARATION ANXIETY T SCORE	GAD T SCORE	PANIC T SCORES	SOCIAL PHOBIAS T SCORES	OCD T SCORES	DEPRESSION T SCORES	TOTAL ANXIETY T SCORE	TOTAL ANXIETY AND DEPRESSION T SCORE	PHYSICAL HEALTH DOMAIN 1 T SCORE	PSYCHOLOGICAL DOMAIN 2 T SCORE	SOCIAL RELATIONSHIPS DOMAIN 3 T SCORE	ENVIRONMENT DOMAIN 4 T SCORES
1	YES	5	5	5	3	1	1	3	3	1	10.5	4	1	1	1	1	1	0	0	0	4	3	1	1	48	40	66	57	39	40	52	49	44	56	9	25
2	NO	5	5	0	5	0	0	0	0	0	10.5	5	0	0	0	0	0	3	0	0	5	0	0	5	39	27	37	24	35	30	26	25	81	75	11	29
3	YES	4	4	3	1	0	0	0	0	0	7	3	0	0	0	0	0	0	4	0	3	1	0	0	45	37	42	37	35	45	35	36	56	56	9	19
4	YES	5	5	5	3	1	1	3	3	1	10.5	4	1	1	1	1	1	0	0	0	4	3	1	1	43	27	45	28	35	35	30	30	44	56	9	25
5	YES/NO	3	3	5	1	0	0	0	0	0	9	3	0	0	0	0	0	0	1	0	3	3	1	1	39	27	37	24	35	30	26	25	81	75	11	29
6	NO	3	3	1	4	0	0	0	0	0	12:00	4	0	0	0	0	0	0	1	0	4	3	1	1	38	29	37	28	31	30	27	26	75	69	12	30
7	NO	4	4	3	1	0	0	0	0	0	7	3	0	0	0	0	0	0	4	0	3	1	0	0	51	39	42	41	34	39	39	39	56	56	9	19
8	NO	5	5	0	5	0	0	0	0	0	10.5	5	0	0	0	0	0	3	0	0	5	0	0	5	39	27	37	24	35	30	26	25	81	75	11	29
9	NO	3	5	5	0	0	0	0	0	0	8	5	0	0	0	0	0	3	1	0	3	4	3	3	44	38	36	49	35	37	39	38	81	75	11	29
10	NO	4	1	1	5	1	1	1	3	1	11	4	3	3	1	1	1	3	1	0	1	3	3	0	69	33	65	35	40	49	47	47	44	56	10	20

11	NO	3	3	5	1	0	0	0	0	0	9	3	0	0	0	0	0	0	1	0	3	3	1	1	39	27	37	24	35	30	26	25	81	75	11	29
12	NO	3	3	5	1	0	0	0	0	0	9	3	0	0	0	0	0	0	1	0	3	3	1	1	34	29	36	27	29	32	27	27	81	75	11	29
13	NO	3	3	1	4	0	0	0	0	0	12:00	4	0	0	0	0	0	0	1	0	4	3	1	1	34	29	36	27	29	32	27	27	75	69	12	30
14	NO/YES	3	5	5	0	0	0	0	0	0	8	5	0	0	0	0	0	3	1	0	3	4	3	3	45	43	45	41	38	40	40	39	75	69	12	30
15	NO	5	5	0	5	0	0	0	0	0	10.5	5	0	0	0	0	0	3	0	0	5	0	0	5	39	27	37	24	35	30	26	25	81	75	11	29
16	YES/YES	5	5	0	5	0	0	0	0	0	10.5	5	0	0	0	0	0	3	0	0	5	0	0	5	39	27	37	24	35	30	26	25	81	75	11	29
17	YES/YES	4	4	3	1	0	0	0	0	0	7	3	0	0	0	0	0	0	4	0	3	1	0	0	51	39	42	41	34	39	39	39	56	56	9	19
18	NO	3	3	1	4	0	0	0	0	0	8	3	0	0	0	0	0	0	1	0	4	3	1	1	66	48	45	59	51	46	55	53	44	56	8	18
19	NO	3	3	1	4	0	0	0	0	0	8	3	0	0	0	0	0	0	1	0	4	3	1	1	66	48	45	59	51	46	55	53	44	56	8	18
20	NO	4	4	3	1	0	0	0	0	0	7	3	0	0	0	0	0	0	4	0	3	1	0	0	51	39	42	41	34	39	39	39	56	56	9	19
21	NO	4	4	3	1	0	0	0	0	0	7	3	0	0	0	0	0	0	4	0	3	1	0	0	51	39	42	41	34	39	39	39	56	56	9	19
22	NO	4	4	1	5	0	0	4	1	0	9	4	0	0	0	0	0	1	1	0	5	3	5	1	54	65	49	34	38	56	46	48	56	50	9	27
23	YES/YES	4	4	3	1	0	0	0	0	0	7	3	0	0	0	0	0	0	4	0	3	1	0	0	51	39	42	41	34	39	39	39	56	56	9	19
24	NO	4	4	1	5	0	0	4	1	0	9	4	0	0	0	0	0	1	1	0	5	3	5	1	68	43	38	59	44	34	51	47	56	50	9	27
25	NO	3	3	3	3	0	1	1	1	1	10	3	1	0	0	0	0	0	1	0	1	3	3	3	62	39	47	47	41	39	46	44	44	44	9	15
26	NO	4	1	1	5	1	1	1	3	1	11	4	3	3	1	1	1	3	1	0	1	3	3	0	69	33	65	35	40	49	47	47	44	56	10	20
27	NO	3	3	1	4	0	0	0	0	0	12:00	4	0	0	0	0	0	0	1	0	4	3	1	1	38	29	37	28	31	30	27	26	75	69	12	30
28	NO/YES	4	1	1	5	1	1	1	3	1	11	4	3	3	1	1	1	3	1	0	1	3	3	0	69	33	65	35	40	49	47	47	44	56	10	20
29	NO	4	1	1	5	1	1	1	3	1	11	4	3	3	1	1	1	3	1	0	1	3	3	0	69	33	65	35	40	49	47	47	44	56	10	20
30	NO	1	1	5	0	0	0	0	0	0	10.5	3	0	0	0	0	0	0	1	0	3	3	1	1	38	29	37	28	31	30	27	26	81	75	11	29
31	YES	3	5	5	0	0	0	0	0	0	8	5	0	0	0	0	0	3	1	0	3	4	3	3	44	33	41	36	34	37	34	33	44	38	12	22

32	NO	4	4	3	1	0	0	0	0	0	7	3	0	0	0	0	0	0	4	0	3	1	0	0	51	39	42	41	34	39	39	39	56	56	9	19
33	YES	3	3	1	4	0	0	0	0	0	12:00	4	0	0	0	0	0	0	1	0	4	3	1	1	38	29	37	28	31	30	27	26	75	69	12	30
34	NO	3	3	1	4	0	0	0	0	0	12:00	4	0	0	0	0	0	0	1	0	4	3	1	1	38	29	37	28	31	30	27	26	75	69	12	30
35	NO	4	4	5	1	1	1	1	3	3	10	4	1	1	0	0	1	0	3	0	4	1	1	1	43	27	40	32	38	32	31	30	81	75	11	29
36	NO	5	5	5	3	1	1	3	3	1	10.5	4	1	1	1	1	1	0	0	0	4	3	1	1	43	27	45	28	35	35	30	30	44	56	9	25
37	YES/YES	3	3	1	4	0	0	0	0	0	12:00	4	0	0	0	0	0	0	1	0	4	3	1	1	38	29	37	28	31	30	27	26	75	69	12	30
38	YES/NO	3	3	1	4	0	0	0	0	0	12:00	4	0	0	0	0	0	0	1	0	4	3	1	1	38	29	37	28	31	30	27	26	75	69	12	30
39	NO/NO	5	5	0	5	0	0	0	0	0	10.5	5	0	0	0	0	0	3	0	0	5	0	0	5	39	27	37	24	35	30	26	25	81	75	11	29
40	NOYES	5	4	0	5	0	0	1	0	1	10	3	0	0	0	0	0	0	0	0	3	5	1	0	48	41	40	39	34	37	38	37	44	19	7	20
41	NO/NO	1	1	5	0	0	0	0	0	0	10.5	3	0	0	0	0	0	0	1	0	3	3	1	1	38	29	37	28	31	30	27	26	81	75	11	29
42	NO/NO	4	4	5	0	0	0	0	0	0	9.5	5	0	0	0	0	0	0	0	0	3	3	0	0	42	33	40	34	36	40	33	33	81	75	11	29
43	NO	4	4	3	1	0	0	0	0	0	7	3	0	0	0	0	0	0	4	0	3	1	0	0	45	37	42	37	35	45	35	36	56	56	9	19
44	NO/NO	5	5	5	3	1	1	3	3	1	10.5	4	1	1	1	1	1	0	0	0	4	3	1	1	43	27	45	28	35	35	30	30	44	56	9	25
45	NO/YES	4	4	3	1	0	0	0	0	0	7	3	0	0	0	0	0	0	4	0	3	1	0	0	51	39	42	41	34	39	39	39	56	56	9	19
46	NO/NO	4	4	1	5	0	0	4	1	0	9	4	0	0	0	0	0	1	1	0	5	3	5	1	68	43	38	59	44	34	51	47	56	50	9	27
47	NO	5	4	0	5	0	0	1	0	1	10	3	0	0	0	0	0	0	0	0	3	5	1	0	48	41	40	39	34	37	38	37	44	19	7	20
48	YES	3	5	5	0	0	0	0	0	0	8	5	0	0	0	0	0	3	1	0	3	4	3	3	44	33	41	36	34	37	34	33	44	38	12	22
49	NO	5	5	0	5	0	0	0	0	0	10.5	5	0	0	0	0	0	3	0	0	5	0	0	5	39	27	37	24	35	30	26	25	81	75	11	29
50	NO	5	5	5	3	1	1	3	3	1	10.5	4	1	1	1	1	1	0	0	0	4	3	1	1	43	27	45	28	35	35	30	30	44	56	9	25
51	YES/YES	5	4	0	5	0	0	1	0	1	10	3	0	0	0	0	0	0	0	0	3	5	1	0	48	41	40	39	34	37	38	37	44	19	7	20
52	YES	5	5	0	5	0	0	0	0	0	10.5	5	0	0	0	0	0	3	0	0	5	0	0	5	39	27	37	24	35	30	26	25	81	75	11	29

53	YES/YES	4	4	3	1	0	0	0	0	0	8	5	0	0	0	0	0	0	0	0	5	4	0	0	52	29	38	34	34	34	33	32	56	50	9	27
54	YES	1	1	5	0	0	0	0	0	0	10.5	3	0	0	0	0	0	0	1	0	3	3	1	1	38	29	37	28	31	30	27	26	81	75	11	29
55	NO	3	3	5	1	0	0	0	0	0	9	3	0	0	0	0	0	0	1	0	3	3	1	1	39	27	37	24	35	30	26	25	81	75	11	29
56	NO/NO	3	3	5	1	0	0	0	0	0	9	3	0	0	0	0	0	0	1	0	3	3	1	1	39	27	37	24	35	30	26	25	81	75	11	29
57	NO	3	3	1	4	0	0	0	0	0	12:00	4	0	0	0	0	0	0	1	0	4	3	1	1	38	29	37	28	31	30	27	26	75	69	12	30
58	NO	3	3	5	1	0	0	0	0	0	9	3	0	0	0	0	0	0	1	0	3	3	1	1	34	29	36	27	29	32	27	27	81	75	11	29
59	NO	4	4	5	0	0	0	0	0	0	9.5	5	0	0	0	0	0	0	0	0	3	3	0	0	42	33	40	34	36	40	33	33	81	75	11	29
60	YES	3	5	5	0	0	0	0	0	0	8	5	0	0	0	0	0	3	1	0	3	4	3	3	44	33	41	36	34	37	34	33	44	38	12	22
61	NO	3	5	5	0	0	0	0	0	0	8	5	0	0	0	0	0	3	1	0	3	4	3	3	44	33	41	36	34	37	34	33	44	38	12	22
62	YES	3	3	1	4	0	0	0	0	0	8	3	0	0	0	0	0	0	1	0	4	3	1	1	66	48	45	59	51	46	55	53	44	56	8	18
63	YES/YES	3	3	1	4	0	0	0	0	0	8	3	0	0	0	0	0	0	1	0	4	3	1	1	48	36	40	42	34	42	38	39	44	56	8	18
64	NO/NO	5	5	0	5	0	0	0	0	0	10	4	0	0	0	0	0	0	0	0	1	3	1	1	38	29	37	28	31	30	27	26	63	69	10	29
65	YES/YES	3	3	1	4	0	0	0	0	0	12:00	4	0	0	0	0	0	0	1	0	4	3	1	1	38	29	37	28	31	30	27	26	75	69	12	30
66	YES/YES	3	3	3	3	0	1	1	1	1	10	3	1	0	0	0	0	0	1	0	1	3	3	3	62	39	47	47	41	39	46	44	44	44	9	15
67	NO/NO	5	4	0	5	0	0	1	0	1	10	3	0	0	0	0	0	0	0	0	3	5	1	0	48	41	40	39	34	37	38	37	44	19	7	20
68	NO/NO	3	3	3	4	1	1	0	0	0	10	3	0	0	0	0	0	0	1	0	3	1	1	1	59	42	44	45	35	36	43	41	81	69	10	30
69	YES/YES	4	4	3	1	0	0	0	0	0	7	3	0	0	0	0	0	0	4	0	3	1	0	0	51	39	42	41	34	39	39	39	56	56	9	19
70	NO/NO	5	5	0	5	0	0	3	0	1	10	4	1	0	0	0	0	0	0	0	4	4	1	1	46	39	42	36	35	33	36	34	81	75	12	28
71	NO/NO	4	4	0	5	0	0	4	0	1	9	4	1	1	0	0	0	0	1	0	4	4	1	1	39	27	37	24	35	30	26	25	81	81	13	29
72	NO/NO	4	4	4	1	0	0	1	3	3	10	4	1	0	0	0	0	1	1	1	3	3	1	0	69	39	44	51	32	42	46	45	69	56	9	18
73	YES/YES	4	1	1	5	1	1	1	3	1	11	4	3	3	1	1	1	3	1	0	1	3	3	0	69	33	65	35	40	49	47	47	44	56	10	20

74	NO/NO	5	5	5	3	1	1	3	3	1	10.5	4	1	1	1	1	1	0	0	0	4	3	1	1	43	27	45	28	35	35	30	30	44	56	9	25
75	YES/YES	4	4	4	1	0	0	0	0	0	10.5	4	0	3	0	0	0	0	1	0	3	3	1	1	71	43	36	47	39	46	45	45	44	56	10	20
76	YES/YES	3	3	5	0	0	0	0	0	0	8	3	0	0	0	0	0	0	1	0	3	3	1	1	54	30	38	42	36	31	36	34	81	75	11	29
77	NO/NO	1	1	5	0	0	0	0	0	0	10.5	3	0	0	0	0	0	0	1	0	3	3	1	1	38	29	37	28	31	30	27	26	81	75	11	29
78	NO	5	5	0	5	0	0	0	0	0	10.5	5	0	0	0	0	0	3	0	0	5	0	0	5	39	27	37	24	35	30	26	25	81	75	11	29
79	NO/NO	4	5	0	1	0	0	3	0	0	9.5	4	0	0	0	0	0	0	0	0	3	5	1	0	39	27	37	24	35	30	26	25	81	75	11	29
80	YES/YES	3	3	4	1	0	0	0	0	0	10	3	0	0	0	0	0	0	1	0	1	3	0	0	40	34	42	33	32	39	33	33	81	75	11	29
81	NO/NO	3	3	5	1	0	0	0	0	0	9	3	0	0	0	0	0	0	1	0	3	3	1	1	39	27	37	24	35	30	26	25	81	75	11	29
82	NO/NO	4	5	0	1	0	0	3	0	0	9.5	4	0	0	0	0	0	0	0	0	3	5	1	0	39	27	37	24	35	30	26	25	81	75	11	29
83	NO/NO	5	5	0	5	0	0	0	0	0	10.5	5	0	0	0	0	0	3	0	0	5	0	0	5	39	27	37	24	35	30	26	25	81	75	11	29
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85	NO/NO	4	4	3	1	0	0	0	0	0	7	3	0	0	0	0	0	0	4	0	3	1	0	0	51	39	42	41	34	39	39	39	56	56	9	19
86	YES/YES	4	5	5	0	0	0	0	0	0	9.5	4	0	0	0	0	0	0	0	0	4	4	0	0	53	52	53	49	35	40	48	46	56	56	9	19
87	NO	5	5	0	5	0	0	0	0	0	10.5	5	0	0	0	0	0	3	0	0	5	0	0	5	39	27	37	24	35	30	26	25	81	75	11	29
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89	NO	3	3	5	0	0	0	0	0	0	8	3	0	0	0	0	0	0	1	0	3	3	1	1	54	30	38	42	36	31	36	34	81	75	11	29
90	NO	3	3	3	4	1	1	0	0	0	10	3	0	0	0	0	0	0	1	0	3	1	1	1	59	42	44	45	35	36	43	41	81	69	10	30
91	NO/NO	4	4	1	5	0	0	4	1	0	9	4	0	0	0	0	0	1	1	0	5	3	5	1	68	43	38	59	44	34	51	47	56	50	9	27
92	YES	3	5	5	0	0	0	0	0	0	8	5	0	0	0	0	0	3	1	0	3	4	3	3	44	33	41	36	34	37	34	33	44	38	12	22
93	NO	3	3	1	4	0	0	0	0	0	12:00	4	0	0	0	0	0	0	1	0	4	3	1	1	38	29	37	28	31	30	27	26	75	69	12	30
94	NO	5	5	0	5	0	0	0	0	0	10	4	0	0	0	0	0	0	0	0	1	3	1	1	38	29	37	28	31	30	27	26	63	69	10	29

95	NO	5	4	0	5	0	0	1	0	1	10	3	0	0	0	0	0	0	0	0	3	5	1	0	48	41	40	39	34	37	38	37	44	19	7	20
96	NO	5	4	0	5	0	0	1	0	1	10	3	0	0	0	0	0	0	0	0	3	5	1	0	48	41	40	39	34	37	38	37	44	19	7	20
97	NO	5	5	0	5	0	0	0	0	0	10.5	5	0	0	0	0	0	3	0	0	5	0	0	5	39	27	37	24	35	30	26	25	81	75	11	29
98	NO	3	3	1	4	0	0	0	0	0	12:00	4	0	0	0	0	0	0	1	0	4	3	1	1	38	29	37	28	31	30	27	26	75	69	12	30
99	NO	4	4	1	5	0	0	4	1	0	9	4	0	0	0	0	0	1	1	0	5	3	5	1	68	43	38	59	44	34	51	47	56	50	9	27
100	NO	3	3	1	4	0	0	0	0	0	12:00	4	0	0	0	0	0	0	1	0	4	3	1	1	38	29	37	28	31	30	27	26	75	69	12	30