ORIGINAL RESEARCH

Stress, Anxiety, Depression and Burden in caregivers of Beta thalassemia Major

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ABSTRACT

Background: Thalassemia is haemoglobinopathy characterized by a decrease or an absence of synthesis of synthesis of normal globin chains. The disease itself has high morbidity and mortality which is augmented by the high frequency of treatment. The complexity of the problem in patients with thalassemia is related not only to biological aspects but also to psychological, social and spiritual aspects both in patients and their caregivers.

Objectives: This study was conducted to determine the Stress, Anxiety, Depression and Burden in caregivers of Beta thalassemia Major

Materials and methods: The study was conducted in OPD and day-care center for thalassemia patients of Guru Nanak Dev Hospital Amritsar. Fifty Caregivers of children with Thalassemia Major were interviewedThree proformas were used. One for general information (Socio Demographic Performa), and the others were the DASS-21 and the Zarit Burden Interview scale.

Conclusion: Patients with Beta Thalassemia Major expose to intensive and serious medical therapies and their complications lifelong. Thus, psychological status of these patients has important effects on their caregivers. It leads an increase in the frequency of depression and anxiety in both patients and their caregivers. This increase results in negative effects on physical and mental health and increases burden on their caregivers.

INTRODUCTION

Thalassemia is a component of haemoglobinopathy, a haemoglobin disorder caused due to changes in the composition of amino acids that form globin chains, which are characterised by a decrease or an absence of synthesis of normal globin chains[1]. Thalassemia is primarily inherited as a recessive trait. As an autosomal recessive condition, heterozygotes with either alpha or beta thalassemia are generally asymptomatic and do not require treatment. The WHO has estimated that 7% of the world's population are carriers of haemoglobinopathy and an estimated 300,000-400,000 babies born will be affected by this disease each year[2]·More than 95% of these births occur in Asia, India and the Middle East. Nowadays, it spreads across the Mediterranean and Middle East regions, Southeast Asia and from southwestern Europe to the Far East. It is seen in large parts of Africa[3,4].

The disease itself has high morbidity and mortality which is augmented by the high frequency of treatment. Prevalence of complications is: Heart Failure 6-8%, Arrhythmias 5-7%, Hypogonadism 54.7%, Hypothyroidism 10.8%, Diabetes 6.4%, HIV infection 1.7% and

thrombosis 1.1%[5]. Another study in Northern Taiwan showed that among living patients over 15 years of age Hypogonadotropic hypogonadism, HCV infection, diabetes, heart failure and arrhythmias are common complications whereas the main causes of death are Heart disease, Bone Marrow Transplant related death and infections[6].

The complexity of the problem in patients with thalassemia is related not only to biological aspects but also to psychological, social, and spiritual aspects both in patients and their caregivers. Qualitative studies with a phenomenological approach have shown that the bio-psycho socio-spiritual aspects are extremely important and interrelated in the adjustment of the life of patients with thalassemia and their families. Case studies have reported that the factors that influence the bio-psycho socio-spiritual adjustment of caregivers with thalassemia include parental knowledge and parenting and family support. Therefore, patients with thalassemia and their families must have good adaptability to survive[7]. Children with major thalassemia require serious attention, commitment, and struggle of family members to care for them hence is a burden on their family members. A mother who has a child suffering from thalassemia must be able to accept it by adjusting to the situation and condition of the child[8]. This study was conducted to determine the Stress, Anxiety, Depression and Burden in caregivers of Beta thalassemia Major

METHODOLOGY

It was a cross sectional interview based study. Minimum of Fifty Caregivers of children with Thalassemia Major presenting to OPD and day-care centre for thalassemia patients of Guru Nanak Dev Hospital Amritsar were interviewed. Three proformas were used. One for general information (Socio Demographic Performa), and the others were the DASS-21 and the Zarit Burden Interview scale.

INCLUSION CRITERIA FOR KEY CAREGIVERS/RELATIVES

1. Identified current caregivers of patients should be aged more than 18 years
2. Caring and living with patient for more than 1 year
3. Not suffering from any chronic illness since last 1 year (medical/psychiatric)
4. Agreed to give informed consent

EXCLUSION CRITERIA

1. Caregivers who had a cognitive impairment or an intellectual disability
2. Children and young people <18 years
3. Caregivers not giving consent
4. Uncooperative caregiver

The study sample was assessed using following documents:

Self-structured Sociodemographic proforma – to analyse the sociodemographic profile of the caregivers.

DASS-21 questionnare[9]: The Depression, Anxiety, and stress scale-21 Items (DASS-21) is a set of three self-report scales designed to measure the emotionally states of depression, anxiety, and stress. Each of the three DASS-21 scales contains 7items, divided into subscales with similar content.

Zarit burden Interview scale[10]: It is a popular caregiver self-report measure used by many aging agencies. The revised version contains 22 items and each item on interview is a statement which caregiver is asked to endorse using a 5- point scale.

RESULTS

The study included 50 patients of thalassemia and their key care givers. Of the 50 patients 26(52%) were boys and 24(48%) were girls. Only 5(10%) patients had family history of

hematological disorderand 2(4%) had history of death due to hematological disease in the family. It was found that maximum number of patients 26(52%) had blood transfusion once per two weeks,14(28%) had blood transfusion once per month followed by 6(12%) once per three weeks and 4(8%) once per week. 39(78%) patients had good adherence to treatment and 11(22%) had poor adherence to treatment. No patient had history of stem cell transplantation.

Category	Variables	Frequency	Percentage (%)
Gender	male	26	52
	female	24	48
	other	00	00
Family history of hematological disorder	Present	05	10
	absent	45	90
History to death due to hematological disease in family	present	02	04
	absent	48	96
Transfusion frequency	Once/week	4	08
	Once/2weeks	26	52
	Once/3weeks	6	12
	Once/4weeks	14	28
Adherence to therapy	Good	39	78
	Poor	11	22
History of Stem cell transplantation	present	00	00
	absent	50	100

The caregivers of thalassemia patients were distributed over a range of demographic subgroups. 52% of the caregivers are males. Majority of caregivers belong to 38-47years age group followed by 48-57years age group. Maximum of the caregivers i.e.,88% of caregivers were married, 58% of them were from rural background and 42% were urban. On questioning about the faith/religion,

It was found that 58% were Sikhs followed by 40% Hindus. It was found that 38 % of them were educated till higher secondary followed by 22% who were graduates. Maximum number of them were housewives, 30% were employed followed by 16% self-employed and 12% were unemployed. It was found that 62% of caregivers had income between 5000-10000 rupees followed by 36% having income more than 10000rupees. On enquiring about relation with the patient, it was found that 84% ofcaregivers were parents followed by siblings which were 8%. Itwas also noted that 4% of patients had history of tobacco use and only 2% had history of psychiatric illness.

Category	Variables	Frequency	Percentage (%)
Gender	Males	26	52
	Females	24	48
	Others	00	00
Age	18-27years	1	2
	28-37 years	08	16
	38-47 years	21	42
	48-57 years	19	38
	>57 years	1	2
Religion	Sikh	29	58
	Hindu	20	40
	Other	01	02
Area	Rural	29	58
	Urban	21	42

Marital Status	Never Married	03	06
	Married	44	88
	Divorced	03	06
Education	Illiterate	06	12
	Primary (upto 5^{th})	06	12
	Middle (upto 8^{th})	08	16
	Upto 10^{th} and 12^{th}	19	38
	Graduation	11	22
	Post Graduate	0	0
Employment	Employed	21	42
	Unemployed	06	12
	Student	1	2
	Housewife	15	30
Income	<5000	1	2
	5000-10000	31	62
	>10000	18	38
Relation to patient	Father	20	40
	Mother	22	44
	Siblings	02	04
	Others	06	12
History of substance use	Present	00	00
	Absent	50	100
History of tobacco use/smoking	Present	04	08
	Absent	46	92
History of psychiatric illness	Present	01	02
	Absent	49	98
Suicidal ideation	Present	00	00
	Absent	50	100

On measuring the depression, anxiety, and stress on DASS 21 it was found that 28% of caregivers had mild depression and 06% had moderate depression, 18% had mild anxiety and 30% had moderate anxiety, and 2% had mild Stress.

Depression	Normal	33	6626
	Mild	14	282
	Moderate	3	6
Anxiety	Normal	26	52
	Mild	9	18
	Moderate	15	30
Stress	Normal	49	98
	Mild	1	2

On assessing the burden among the caregivers, it was found that 38% of caregivers had moderate to severe burden and 18% had mild to moderate burden.

Burden	No burden	22	44
	Mild to moderate	9	18
	Moderate to severe	19	38

DISCUSSION

Changes in mental health and health related quality of life in patients and family members of chronically ill patients were well established previously. Our research shows that the family members of the thalassaemic children have a higher level of psychosocial problems than the family members of normal children and their siblings. Numerous studies have confirmed and reported that the caregivers of patients with thalassemia have psychosocial disorders; this may be due to the chronic nature of thalassemia, medical costs and the expectation of premature death. They need treatment, psychological counselling and further intellectual and social supports[11]. The results of these studies also indicate the necessity of screening programs for early diagnosis and treatment of psychosocial disorders in caregivers of thalassemia patients as well as the use of knowledge and expertise of psychiatrists and clinical psychologists in thalassemia centres[12]. Our study was aimed to collect information about the history of the same disease in families with thalassemia to construct a complex medical and psychosocial relationships diagram as a part of a family genogram. Some researchers have also proven that a three-generation pedigree can identify a thalassemia career higher than other approaches[13]. This screening is also appropriate for regions that have very large populations and lack health infrastructure to support large-scale screening. Families with a history or family members who have thalassemia tend to be more afraid of getting thalassemia, so family members will easily getthemselves screenedto understand whether they are carriers or not. Therefore, after the index case is identified, cascade screening is more cost effective.

In our study though 52% of caregiver were males but female respondents who had a parental relationship with the child were also large (48%) and most of the caregivers (84%) were parents. This finding may be attributed to the Asian culture of parenting in which mothers tend to stay at home and take care of their child. A weak association was found between sex and caregiverpsychopathology in this study, which is consistent with previous findings[14].

The caregivers of thalassemia patients were distributed over a range of demographic subgroups. 52% of the caregivers are males. majority of caregivers belong to 38-47years age group followed by 48-57years age group. Maximum of the caregivers i.e., 88% of caregivers were married, 58% of them were from rural background and 42% were urban, which is consistent with demographic profile of the region.

In our study it was found that 28% of caregivers had mild depression and 06% had moderate depression, 18% had mild anxiety and 30% had moderate depression, and 2% had mild stress. Furthermore,it was found that 38% of caregivers had moderate to severe burden and 18% had mild to moderate burden. This is consistent with the studies of Beutel et al.[15,16]. Caregivers of children with thalassemia did not plan their unemployment. Their unemployment was undesired and beyond their control because of the impact from having children with thalassemia[17,18]. Meanwhile, caregivers with psychopathological symptoms may show reduced quality of care to the patient, which can decrease the patient's survival rate[19,20]. Therefore, it is important to provide psychosocial intervention for caregivers of children with thalassemia, as well as those with other chronic diseases.

CONCLUSION

Patients with Beta Thalassemia Major expose to intensive and serious medical therapies and their complications lifelong. Thus, psychological status of these patients has important effects on their caregivers.It leads an increase in the frequency of depression and anxiety in both patients and their caregivers. This increase results in negative effects on physical and mental health and increases burden on their caregivers. Therefore, it is important for physicians to provide health care management not only to the patients but also to their caregivers.

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