

Original Article

Depression, Anxiety and Stress among Primary Caregivers of Thalassemia Patients in Hyderabad

Aatir H. Rajput<sup>1</sup>, Faris Nadeem<sup>2</sup> & Vikram Kumar<sup>2</sup>.

1-LUMHS Research Forum

2-Liaquat University of Medical & Health Sciences, Jamshoro

aatirh.rajput@gmail.com

Abstract

A chronic genetic disorder; Thalassemia major is a disease, characterized by continuing and severe anemia, bone deformities, hepato-splenomegally and growth retardation. It is a potentially life threatening and serious life-limiting disease that brings about considerable disturbance in all aspects of life. Therapies such as transfusion of blood have enhanced the physical health status of the thalassemia major patients but numerous treatment sessions and alteration in physical appearance effects on the quality of life of the patients and their families. Depression while battling surviving thalassemia is increasingly accepted, globally. But we hypothesized that psychiatric morbidities aren't limited to the patient, in fact they extend to the caregivers as well. Our study screens the primary caregivers for Depression, Anxiety and Stress which more often than not are the parents. This observational study encompassed all 3 major thalassemia centers in Hyderabad namely; Fatimid foundation, Zainabia center and Saharo human aid center. The city-wide survey included 79 caregivers presenting at these centers (via convenience sampling) from 1st Dec 2014 to 10th February 2015. Data was collected using interview based structured questionnaire which included the 42 point DAS scale approved by Australian Center for Posttraumatic Mental Health. The data was analyzed in SPSS v. 19.0 and Ms. Excel 2013. Moderate levels of Depression (16.06), Anxiety (10.44) and Stress (19.11) were all unearthed in the caregivers. Majority of the sample comprised of male (60.8%), educated respondents (78.5%) living in joint families (57%). The caregivers mainly belonged to lower (35.4%) and middle (54.5%) economic class and were forced to miss an average of 2-3 days of work per week. The unending therapeutic process of thalassemia, its cost and impending health problems have adverse effects not only on the patients but on the caregivers as well who spend their time struggling and praying for the patients' health. The mental health of the caregivers should be taken into account and psychiatric consultations should be provided to the caregivers so they may be better able to tend to the patients.

Keywords

β-Thalassemia, Depression, Anxiety, Stress, Primary caregivers, Blood Transfusion, Chronic Illness.

Introduction

β-Thalassemia major, an ailment largely associated with excessive breakage of red blood cells and malproduction of hemoglobin. Hemoglobin (Hb) is comprised 4 protein subunits, 2 alpha and 2 beta units. Mutations in the gene coding for the protein β subunits, leads to a lessened or totally missing ability to synthesize the globin β-chains, leading to absence of the synthesis of β hemoglobin or, in less severe cases, to abnormal hemoglobin This error leads to anemia often stemming from the abnormal synthesis of red blood cells, which is the hallmark of thalassemia. Mediterranean region is plagued with a high prevalence of thalassemia; the highest incidence is reported in Italy, the Greek islands and in Asia, where the peak prevalence of the genetic mutations underlying thalassemia is reported in the Maldives (Pignatti BC, 2004). The conventional treatment comprises of repeated transfusions of blood that may lead to overload of iron in the tissues. Younglings on hyper-transfusion regimens will continue to grow normally probably till puberty. An estimate of the body iron is derived from serum ferritin; levels exceeding 2500 mg/l for over 15 year are thought as a factor increasing the risk for cardiac disease (Pignatti

BC, 2004). The concept of health, as explained by WHO, "a state of complete physical, mental, and social well-being, not merely the absence of disease" states clearly importance of mental health. Similar to other long term illnesses, beta-thalassemia burdens not only the individual patient but the entire family which includes (but is not limited to) social and psychological consequences which ultimately affects the wellbeing of the patient (Porter J, 2002). So it is imperative to study the psychological factors which incorporate, add to distress of the family alongside other factors. Previous studies focused on these points have shown improvement in the quality of life of such patients and their ability to integrate well into their society (Porter J, 2002).. Parents of children suffering from thalassemia not only worry regarding their children's standard of life, goals and their expectations but, also the influence of the constant realization of disease, repeated treatment visits to the morbid environment of the hospital on family dynamics and the family's financial, psychological and social stability. Major concerns of the parents regarding the disease are related to the physical outlook of their child, short stature, bone deformities, poor self-image, and hampered fertility, absent or delayed absent sexual

development and other such complications; infections, diabetes, bone and heart disease (Mazzone L, 2009). If viewed from the patient’s perspective, it is a worrying and scary experience where they have no choice but to face the mentally tiresome psychosocial aspects of thalassemia. In addition to that, their regular visits to the thalassemia centers for blood transfusions and blood tests with iron chelation therapy too are mentally and physically exhaustive. Parents of patients suffering from  $\beta$ -thalassemia have to battle a significant psychological influence, leading to hopelessness, emotional burden and difficulty with social accommodation. They often experience adverse thoughts about their life, heightened anxiety, guilt and lessened self-esteem. If the ability to cope up with painful situations abandons them, they are prey to severe psychosocial problems. On one or more account, souring of relationship amongst family members, heightened isolation and marginalization too are persistent problems faced by many. Our study aims to focus mental health in particular and studies the parents of thalassemic patients. This will help us gain insight into the pain and the impaired domains of life (physical health, psychological health and quality of life). Our study screens the caregivers for Depression, Anxiety and Stress.

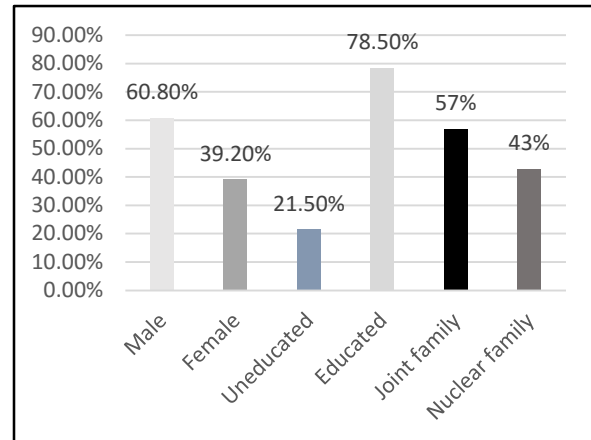
**Methodology**

This observational, cross-sectional study encompassed all 3 major thalassemia centers in Hyderabad namely; Fatimid foundation, Zainabia center and Saharo human aid center. The city-wide survey included 79 caregivers presenting at these centers (via convenience sampling) from 1st Dec 2014 to 10th February 2015. Data was collected using interview based structured questionnaires which included the 42 point DAS scale approved by Australian Center for Posttraumatic Mental Health. After obtaining verbal informed consent, respondents were requested to fill the proforma’s at the clinic. The data was analyzed in SPSS v. 19.0 and Ms Excel 2013.

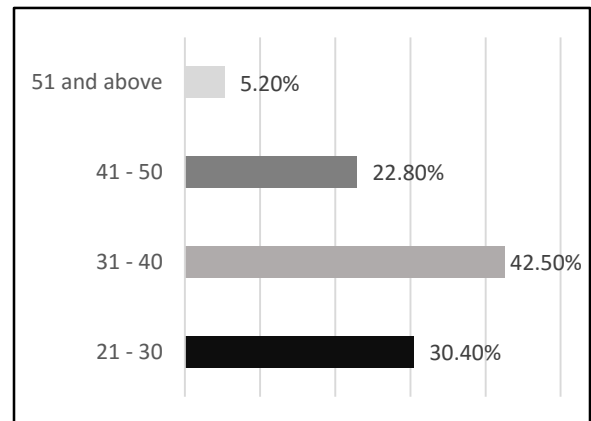
**Results**

The sample population belonged mainly to different localities of Hyderabad representing different gender, ethnic, socio-economic, educational and age groups. A few of these demographics along with the family structure of the respondents is depicted in the Figure 1.

Figure 1: Majority of the caregivers visiting the thalassemia clinic were males (60.8%) owing to our conservative societal values and traditions. Another aspect that can be attributed to our societal trends and traditions is the family structure. 57% of the respondents were a part of joint family set-up while only 43% belonged to nuclear family set-up. However, a finding defying perceived societal statistical norms



is the educational status of the respondents. A vast majority (78.5%) of the respondents were educated while only a meagre 21.5% were uneducated. Care givers of thalassemic patients poured in at the transfusion centres from varied self-defined age group. The decade long groups started from 21 ears and went



above 51 years. Figure 2 below further explains the age dynamics in detail.

Figure 2: The greatest proportion (42.5%) of the respondents fell within the age group from 31 to 40 years. The second most common age group, attracting 30.4% of the sample, was 21 to 30 years. The remaining two age groups 41 to 50 years and 51 and above years each contained 22.8% and 5.2% of the sample respectively. The age classification serves as a testimony to the primary assumption that primary care givers are parents since the respondent and early parental age coincide strongly.

Depression, Anxiety and Stress were all unearthed in the caregivers. The values are a mean of the values of

all respondents. Further detail can be derived from Figure 3.

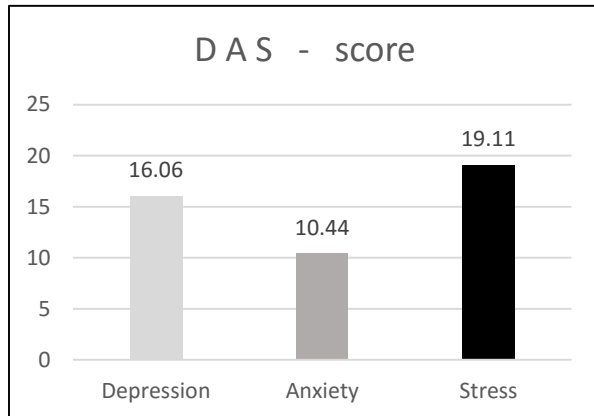


Figure 3: The height of the bars indicate individual levels only and no comparison can be drawn with each other since the standard scales and values differ for each. Depression level falls within the moderate range (14-20). Anxiety falls within the moderate range (10-14) and Stress too falls within the moderate range (19-25) defined by the DASS scoring manual.

The origins of depression, anxiety and stress aren't always psychological and emotional in origin. We believe that in our modern society, depression, anxiety and stress are often materialistic and financial in origin. The Figure 4 below sheds light on the economic class of the patients and their primary caregivers presenting at the thalassemia centers.

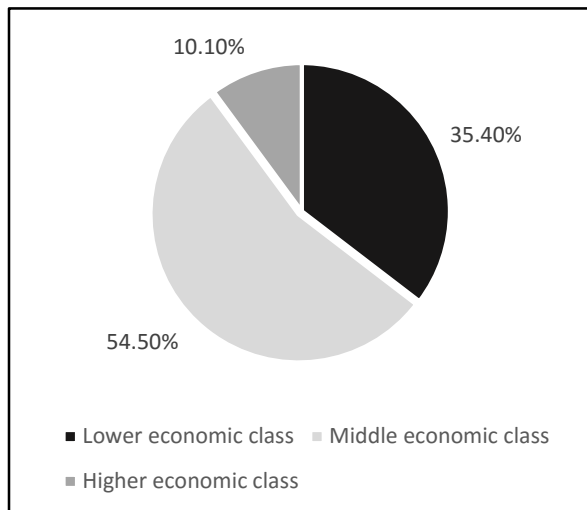


Figure 4: Majority of the respondents belonged to the middle socioeconomic class (54.5%), shortly followed by the lower socioeconomic class (35.4%). Only a small minority of the respondents belonged to the higher socioeconomic class (10.1%). The

socioeconomic distribution of synonymous with the national demographics of 2013.

As a consequence of the disease, debility is seen in not only the patients but indirectly in the caregiver as well. Many of whom were forced to miss their work. Figure 5 describes the phenomenon further below.

### Discussion

Individuals (children especially) suffering from thalassemia are battling a severe chronic hemolytic anemia that requires transfusions as the sole mode of survival. The long-term illness not only induces psychological distress among the children but their families as well. This often leads to numerous adverse types of behavioral patterns and emotional responses in the family, which influences the relationships of family members with each other and with their surroundings. Long-term diseases of childhood affect the daily life and routine of the patients parents the most and that too at several levels (cognitive levels, emotional level) (Monastero R, 2000).

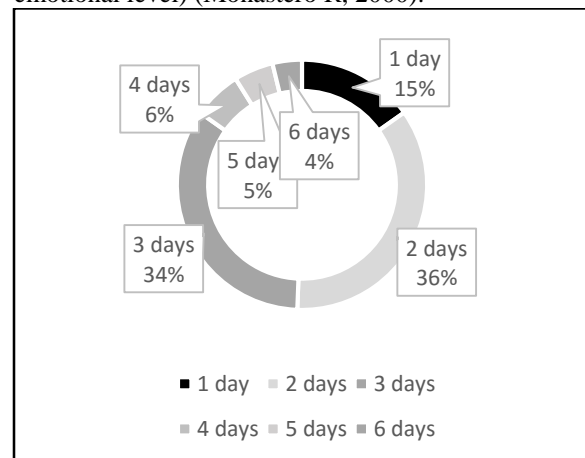


Figure 5: On average, the respondents missed 2 – 3 days of work per week owing to their responsibility of caring for the patient. On extremes, 15% of the respondents needed miss only 1 work day while 4% of them missed the entire week of work.

The battle with beta thalassemia is an unending sojourn and leads to heightened psychological burden to the patients and their families. On numerous accounts. Rao P, Pradhan PV has claimed that the incidence of psychopathological disorders is higher in parents of children with disabling and chronic illnesses (thalassemia) as compared to the normal population (Economou M, 2006). It is claimed by Deepika Shaligram that 57% of the caregivers were troubled with psychological distress and had a lessened Quality of Life in as much as 50% of the studied population. Existing literature also claims that caregivers of thalassemia patients are faced with higher incidence of developing psychological distress as compared to healthy children (Zafeiriou DI, 2006). This rate of

psychological distress leading to parental stress is higher due to the multiple problems which parents have to tackle while their children undergo the difficult and painful treatment procedures of thalassemia. Parents are troubled with issues such as the difficulty of psychosocial adjustment of the child, financial woes, treatment provision, travelling and other social problems. Existence of long-lasting diseases in children especially those that do not have complete cures is a situation which causes stress for mothers and can rile them with against life situations and make them more prone to suffer from depressive disorders (Sharghi A, 2006).

Medical centers tending to chronically/seriously ill children, should additionally provide psychiatric consultation in an attempt to monitor and control depressive disorders plaguing mothers. This can hopefully aid mothers get through the child's disease in a healthier manner and allow them care for their ill child, and their family, effectively and efficiently.

Low educational status in caregivers may lead to lesser realization of the nature of illness and consequently greater propensity of tumbling into psychological distress. It is likely that the traits of harsher diseases (younger age of onset, frequent transfusions and behavioral problems in the young patient) prompted more apprehensions and psychiatric morbidity in the caregiver. Also, the buffering effect of the nuclear family setup against psychiatric troubles may be because of the protection from societal troubles in ways that are not available to the joint/extended family systems. (Shaligram D, 2007)

#### Conclusion

Briefly, this study concludes that the caregivers' concerns pertaining to thalassaemia and their own psychiatric problems are worryingly high. The study helped bring to light multiple aspects of psychological distress which might facilitate in designing intervention strategies. The psychological troubles of the caregiver influence many facets of the lives of the caregiver including work. Thus support for the caregiver in the form of mental health intervention, self-help groups and education and medicine should be an essential part of managing thalassaemia in order to improve outcomes. Further research in this area with a control group, vaster sample size and repeated evaluations would offer better understanding of the problems that the caregivers are faced with and strengthen the case for an cohesive management approach.

#### Conflict of Interest

All the authors disclosed that there is no Conflict of interest associated in the preparation of this article.

#### Acknowledgment

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