

## Health Related Quality of Life in Patients with Transfusion-dependent Thalassemia

Patients with transfusion-dependent thalassemia are expected to have an unfavorable quality of life due to multiple factors. We studied the quality of life in 72 patients (age 5-39 y) with transfusion-dependent thalassemia in the era of improved care, and assessed different parameters affecting it.

**Keywords:** *Beta-thalassemia, Blood transfusion, Outcome.*

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**T**ransfusion-dependent thalassemia has a negative impact on the quality of life (QoL) because of the disease, and its treatment [1]. Recent advances in management such as access to safer blood and oral chelation are expected to improve QoL in these patients [2]. We aimed to study the QoL of transfusion-dependent thalassemia patients and evaluate the effect of multiple variables on different domains of QoL.

This study was conducted at a day-care center of a hospital, and an outreach clinic for patients with limited resources. Patients over the age of five were enrolled in the study. QoL of thalassemia patients was measured using the PedsQL Version 4.0 [3]. A structured questionnaire was developed for collecting information after pilot testing. Children who were unable to read or write were interviewed. Data were collected regarding the socioeconomic status (SES), mean pre-transfusion hemoglobin, frequency of blood transfusions, mode of chelation, adequacy of chelation and presence of complications. The PedsQL version 4.0 was used to calculate the QoL in 4 domains: physical, emotional, social, and school functioning. For older patients, we modified school functioning as work functioning to make the results comparable.

Seventy-two patients (20 females) between the ages 5 to 39 years were included with mean (SD) age of 14.6 (7.6) years. Nearly half (48.6%) of the patients maintained their pre-transfusion hemoglobin above 9 g/dL. The majority (72.2%) received oral deferasirox for chelation. Mean serum ferritin over the preceding one year was calculated, and 19.4% had a level of less than 1000 µg/mL, 48.7% had

a level between 1000-2500 µg/mL, and 31.9% had a ferritin level above 2500 µg/mL. We found that 20.8% of patients had liver dysfunction due to viral hepatitis or iron overload, 23.6% had growth failure, 4.1% had osteoporosis, and 16.6% had multiple complications (endocrinopathy along with above listed complications).

The mean (SD) QoL scores for physical functioning was 83.1 (16.6), emotional functioning was 78.8 (18.5), social functioning was 88.6 (20.3), and school functioning was 82.8 (17.8). We found a negative correlation between age and social functioning ( $P=0.02$ ). A significant difference was observed in levels of school functioning between patients without any complication when compared to the ones with liver dysfunction ( $P=0.048$ ). We found no statistical difference in QoL amongst patients receiving treatments in the two setups.

Previous studies using PedsQL have shown mean QoL scores for physical functioning, emotional functioning, social functioning and school functioning between 68.4-69.1, 68.1-76.9, 74.3-83.7, and 60.1-69.4, respectively. Our results show a higher QoL for patients of transfusion-dependent thalassemia [4-6]. The higher QoL in our patients can be attributed to optimal chelation, easy access to safe blood products, flexible timing of transfusion, regular counseling and patient support.

We found that older patients had poorer social functioning; this could be because of increased awareness about the impact of the disease on finding gainful employment, marriage, and parenthood. Liver dysfunction was seen to have more detrimental effect on the functional status of patients than any other complication attributable to thalassemia.

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## Iodine Deficiency in School Children in Aligarh District, India

We carried out this study to assess iodine deficiency disorders among school children of 6-12 years age group in Aligarh district of India. The prevalence of goiter was 5.2%. Median Urinary Iodine Excretion level was 150  $\mu\text{g/L}$ ; 22.5% of students had biochemical iodine deficiency. 50.4% households were consuming adequately iodized salt.

**Keywords:** Goiter, Iodine deficiency disorders (IDD), Median Urinary Iodine Excretion, Prevalence.

Iodine deficiency disorders (IDD) affect all age groups [1]. In India, 263 districts are endemic for IDD [2]. Apart from goiter, WHO has also recommended the Median Urinary Iodine Excretion (MUIE) in school children as the main indicator for assessing IDD [3]. Very few studies have been carried out in the Aligarh for assessment of IDD. In view of this, a study was planned to find out the Goiter prevalence in school children aged 6–12 years in Aligarh, to determine MUIE in children, and to assess the level of iodine in salt samples at household levels.

The EPI-30 cluster sampling method as recommended by WHO/UNICEF/ICCIDD was followed [3]. The study was done in field practice areas of Department of Community Medicine, JNMC, AMU, Aligarh. The study spanned over a period of one year in 2012. A sample size of 790 was selected assuming goiter prevalence of 30.2% (as seen previously in Aligarh) at confidence level of 95%, margin of error at 15%, and design effect of 2 [4]. Twenty seven students of each school were studied using random sampling. On-spot urine samples were collected from 132 children using systematic random sampling. Samples were tested in Department of Gastroenterology and Human Nutrition, AIIMS, New Delhi. UIE levels were analyzed using wet digestion method of the Sandell-Kolthoff [5]. One

hundred twenty-one salt samples were checked in school with a MIB kit provided by UNICEF, and iodine concentration was recorded as 0, <15 and  $\geq 15$  ppm [3].

Only 40 children were having Grade I goiter (thyroid palpable but not visible) giving prevalence rate of 5.2%. Not a single student had Grade 2 goiter (thyroid visible with neck in normal position). The prevalence of goiter was significantly higher in females than in males (6.9% vs 3.4%) and higher in 10- to 12-year-old children than in younger children (**Web Table I**). The MUIE was 150  $\mu\text{g/L}$ . The proportion of students having normal range of UIE ( $\geq 100 \mu\text{g/L}$ ) was 77.5%. 22.5% of students had biochemical iodine deficiency (<100  $\mu\text{g/L}$ ) (**Web Table II**) [3].

Only 50.4% households were consuming adequately iodized salt ( $\geq 15$  ppm). Nearly 55% of households consume powdered salt, rest consumed crystalline salt. 91% samples of the powdered salt had adequate iodine ( $\geq 15$  ppm) while iodine level was nil in all samples of crystalline salt.

Our result is similar to goiter prevalence of 4.78% reported by Toteja, *et al*. [6] in 15 districts of 10 states. Like NFHS-3, higher goiter prevalence was observed in girls and older children [7]. The MUIE was 150  $\mu\text{g/L}$  suggesting adequate iodine intake ( $>100 \mu\text{g/L}$ ) [3]. Studies elsewhere have also shown similar results [8,9]. A recent study done by Kapil, *et al*. [10] had shown that in India 86% of districts had a MUIE above 100  $\mu\text{g/L}$ .

Only 50.4% households were consuming adequately iodized salt ( $\geq 15$  ppm), similar NFHS-3 data [10].

Our area is far from the goal of 90% in terms of proportion of household using adequately iodized salt. This may pose a future risk of iodine deficiency. We should create awareness among community to consume only powdered packeted iodized salt.

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