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**Mausumi Digal**

M. Sc. Nursing, Child health  
Nursing, Bharati Vidyapeeth  
Deemed University, College of  
Nursing Pune, Maharashtra

**Pranalini Pardeshi**

Assistant Professor, Child  
Health Nursing, Bharati  
Vidyapeeth Deemed  
University, College of Nursing  
Pune, Maharashtra

**Shubhangi Borude**

Clinical Instructor,  
Community Health Nursing,  
Bharati Vidyapeeth Deemed  
University, College of Nursing  
Pune, Maharashtra

**Correspondence**

**Mausumi Digal**

M. Sc. Nursing, Child health  
Nursing, Bharati Vidyapeeth  
Deemed University, College of  
Nursing Pune, Maharashtra

## A descriptive study to assess the quality of life among thalassemic children residing in Pune city

**Mausumi Digal, Pranalini Pardeshi and Shubhangi Borude**

### Abstract

**Purpose** of the study was to assess the quality of life of thalassemic children residing in Pune city.

**Materials and method:** The research design was used exploratory descriptive design. The sample consists of 100 who fulfilled the inclusion criteria. The samples were selected by convenient sampling technique. Quality of life was assessed by KIDSCREEN standardized tool.

**Result:** 65% of the thalassemic children had good physical well-being, 55% of them satisfied with psychological well-being, 59% of them were satisfied with moods and emotion, 48% of them satisfied with self-perception, 68% of them satisfied with autonomy, 94% of children always satisfied with parent relations and home life, 78% of them satisfied with peer and social support, 99% of them were very poorly satisfied with social acceptance, 95% of children satisfied with school environment.

**Conclusion:** From the above findings, the study indicates that the quality of life of thalassemic children were good quality of life. The demographic variables were found no significant association with quality of life of thalassemic children.

**Keywords:** Quality of life, Thalassemic children

### Introduction

Thalassemia is a genetic blood disorder. People with Thalassemia disease are not able to make enough hemoglobin, which causes severe anemia. Hemoglobin is found in red blood cells and carries oxygen to all parts of the body. When there is not enough hemoglobin in the red blood cells, oxygen cannot get to all parts of the body. Organs then become starved for oxygen and are unable to function properly. <sup>[1]</sup>

S. Ansari (2014) this is an analytic case control study. Two hundred and fifty patients and 51 participants as controls were assessed using WHOQOL- BREF (Farsi version) questionnaire. All questions were answered based on the self-evaluated status in the past 2 weeks before enrollment and were rated on a five-point Likert scale. Therefore, the raw item score ranged from 1 to 5 and scaled in a positive direction and 6 dimensions including overall QOL, overall health, physical, psychological, social, and environmental relationship were assessed. Results showed that the QOL in all 6 dimensions was lower in patients compared to the controls ( $P < 0.05$ ). Also age, higher education level, lower ferritin level and using oral iron chelator were associated with better QOL scores. On the other hand, cardiac disease, hepatitis C and history of psychiatric disorders were associated with impaired QOL scores. <sup>[2]</sup> Kaheni & M Yaghobian (2013) conducted the cross-sectional descriptive-analytical study on 40 children over 7 years of age with thalassemia major. Tools for data collection included a demographic questionnaire and World Health Organization Quality of Life questionnaire (WHOQOL- Bref) standard questionnaire comprising 26 items to determine quality of life in patients with thalassemia. Data was analyzed using descriptive statistical tests (mean, SD, and frequency), and inferential statistical test (t-test) in SPSS software. Results showed mean score of  $70.37 \pm 9.88$  for quality of life,  $25 \pm 3.06$  for physical health,  $18.12 \pm 3.22$  for mental health,  $21.3 \pm 4.43$  for living environment, and  $5.95 \pm 1.58$  for sociability. There was no

### 2. Objectives

- To assess the quality of life of Thalassemic children.
- To associate quality of life of thalassemic children with selected demographic variables.

### 3. Conceptual Framework

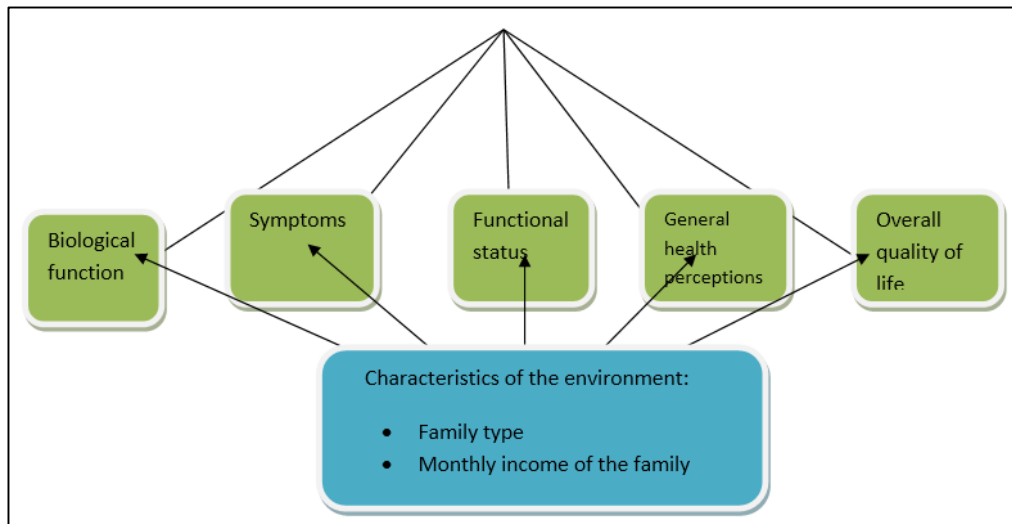


Fig 1: Wilson and Cleary health related quality of life model

### 4. Materials and Methods

#### Assumptions:

- The study assumes that the thalassemic children may have altered quality of life.

#### Methodology

The research approach adopted for the study was quantitative research approach. The research design adopted for the study was non-experimental research design. Based on the objectives of the study the major variable identified was the quality of life of thalassemic children. Sample size was 100, after obtaining administrative approval and written consent from the participants tool was administered for data collection. Data collection done in Thalassemic centre, Bharati Hospital, Kashibai Navale Hospital by using tool comprised of section I: Demographic profile consist of age, gender, marriage type of parents, family type, monthly income per year. Section II consist of item analysis of quality of life of thalassemic children and overall analysis of quality of life of thalassemic children. Section III consist of association of quality of life of thalassemic children with demographic variable

### 5. Results

#### Section- I

#### Demographic variables

##### 1. Age

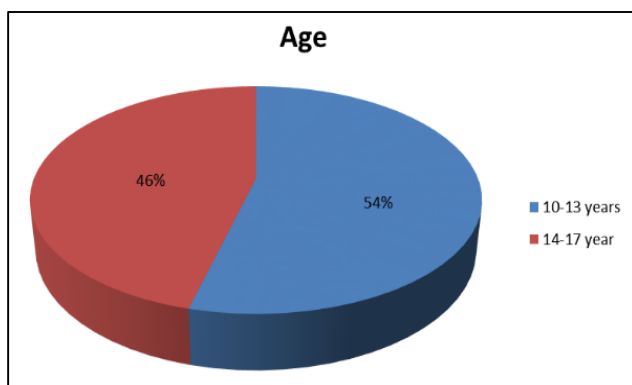


Fig 1: Distribution of samples according to Age n=100

From above diagram, we see that there were 54% thalassemia children followed ages in interval of 14 to 17 years. Remaining 46% were 10 to 13 years

##### 2. Gender

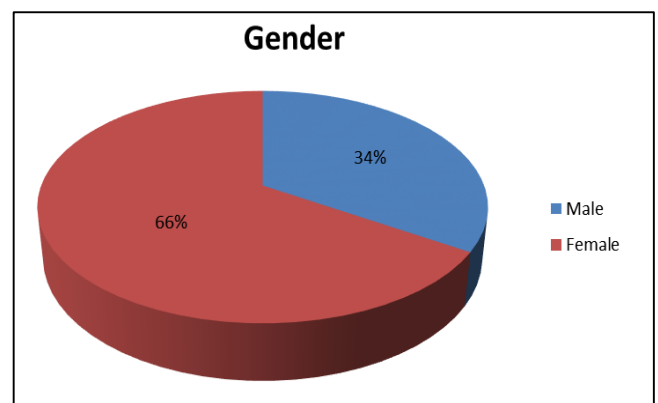


Fig 2: Distribution of samples according to gender n=100

From above diagram, we see that there were maximum i.e. 66 thalassemia children were females and remaining were male.

##### 3. Marriage type of parents

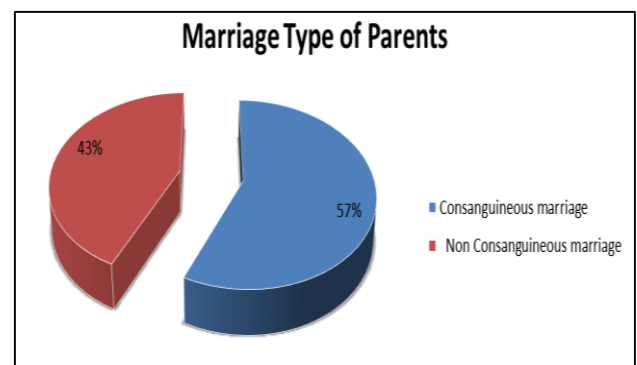
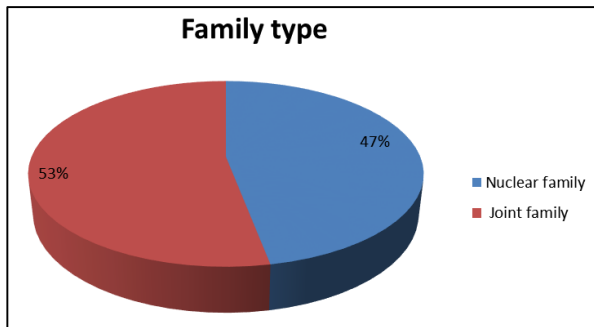


Fig 3: Distribution of samples according to marriage type of parents. n=100

From above diagram, we found that in 57% cases type of parents marriage was Consanguineous. And remaining 43% cases were Non Consanguineous.

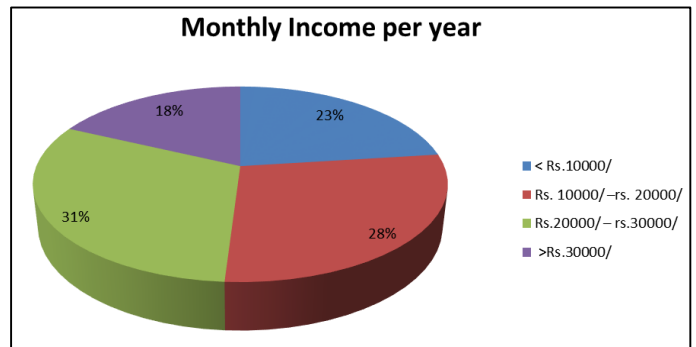
**4. Type of family**



**Fig 4:** Distribution of samples according to type of family n=100.

From above diagram, we found that 53% families was joint type family.

**5. Monthly income per year**



**Fig 5:** Distribution of samples according to monthly income of the family per year n=100

From above diagram, we found that in 31% cases income of family per month was in between rs.20000/-30000/ only.

**Section II:**

**i. Item analysis of quality of life of thalassaemic children. n=100**

| Dimensions                 | Question No | Category    | Frequency | Percentage |
|----------------------------|-------------|-------------|-----------|------------|
| 1.Physical well-being      | a.          | Poor        | 0         | 0%         |
|                            |             | Fair        | 18        | 18%        |
|                            |             | Good        | 60        | 60%        |
|                            |             | Very good   | 22        | 22%        |
|                            |             | Excellent   | 0         | 0%         |
|                            | b.          | Not at all  | 0         | 0%         |
|                            |             | Slightly    | 15        | 15%        |
|                            |             | Moderately  | 68        | 68%        |
|                            |             | Very        | 17        | 17%        |
|                            |             | Extremely   | 0         | 0          |
|                            | c.          | Not at all  | 1         | 1%         |
|                            |             | Slightly    | 24        | 24%        |
|                            |             | moderately  | 57        | 57%        |
|                            |             | Very        | 18        | 18%        |
|                            |             | Extremely   | 0         | 0%         |
| 2.Psychological well-being | a.          | Not at all  | 0         | 0%         |
|                            |             | Slightly    | 2         | 2%         |
|                            |             | Moderately  | 71        | 71%        |
|                            |             | Very        | 27        | 27%        |
|                            |             | Extremely   | 0         | 0%         |
|                            | b.          | Not at all  | 0         | 0%         |
|                            |             | Slightly    | 11        | 11%        |
|                            |             | Moderately  | 69        | 69%        |
|                            |             | Very        | 20        | 20%        |
|                            |             | Extremely   | 0         | 0%         |
| 3. moods and emotion       | c.          | Never       | 0         | 0%         |
|                            |             | Seldom      | 21        | 21%        |
|                            |             | Quite often | 51        | 51%        |
|                            |             | Very often  | 26        | 26%        |
|                            |             | Always      | 2         | 2%         |
|                            |             | Always      | 0         | 0%         |
| 3. moods and emotion       | a.          | Very often  | 10        | 10%        |
|                            |             | Quite often | 31        | 31%        |
|                            |             | Seldom      | 2         | 2%         |
|                            |             | Never       | 57        | 57%        |
|                            | b.          | Always      | 0         | 0%         |
|                            |             | Very often  | 23        | 23%        |
|                            |             | Quite often | 46        | 46%        |
|                            |             | Seldom      | 31        | 31%        |
| c.                         | Never       | 0           | 0%        |            |
|                            | Always      | 0           | 0%        |            |

|                                  |    |             |     |      |
|----------------------------------|----|-------------|-----|------|
|                                  |    | Very often  | 3   | 3%   |
|                                  |    | Quite often | 52  | 52%  |
|                                  |    | Seldom      | 27  | 27%  |
|                                  |    | Never       | 18  | 18%  |
| 4.self- perception               | a. | Always      | 0   | 0%   |
|                                  |    | Very often  | 13  | 13%  |
|                                  |    | Quite often | 47  | 47%  |
|                                  |    | Seldom      | 24  | 24%  |
|                                  |    | Never       | 16  | 16%  |
|                                  | b. | Always      | 0   | 0%   |
|                                  |    | Very often  | 28  | 28%  |
|                                  |    | Quite often | 22  | 22%  |
|                                  |    | Seldom      | 22  | 22%  |
|                                  |    | Never       | 28  | 28%  |
| 5. Autonomy                      | a. | Never       | 0   | 0%   |
|                                  |    | Seldom      | 11  | 11%  |
|                                  |    | Quite often | 14  | 14%  |
|                                  |    | Very often  | 31  | 31%  |
|                                  |    | Always      | 44  | 44%  |
|                                  | b. | Never       | 0   | 0%   |
|                                  |    | Seldom      | 0   | 0%   |
|                                  |    | Quite often | 33  | 33%  |
|                                  |    | Very often  | 53  | 53%  |
|                                  |    | Always      | 14  | 14%  |
|                                  | c. | Never       | 0   | 0%   |
|                                  |    | Seldom      | 18  | 18%  |
|                                  |    | Quite often | 26  | 26%  |
|                                  |    | Very often  | 35  | 35%  |
|                                  |    | Always      | 21  | 21%  |
|                                  | d. | Never       | 0   | 0%   |
|                                  |    | Seldom      | 23  | 23%  |
|                                  |    | Quite often | 40  | 40%  |
|                                  |    | Very often  | 25  | 25%  |
|                                  |    | Always      | 12  | 12%  |
| 6.parent relations and home life | a. | Not at all  | 0   | 0%   |
|                                  |    | Slightly    | 0   | 0%   |
|                                  |    | Moderately  | 0   | 0%   |
|                                  |    | Very        | 45  | 45%  |
|                                  |    | Extremely   | 55  | 55%  |
|                                  | b. | Not at all  | 0   | 0%   |
|                                  |    | Slightly    | 0   | 0%   |
|                                  |    | Moderately  | 0   | 0%   |
|                                  |    | Very        | 0   | 0%   |
|                                  |    | Extremely   | 100 | 100% |
|                                  | c. | Never       | 0   | 0%   |
|                                  |    | Seldom      | 0   | 0%   |
|                                  |    | Quite often | 0   | 0%   |
|                                  |    | Very often  | 0   | 0%   |
|                                  |    | always      | 100 | 100% |
|                                  | d. | Never       | 0   | 0%   |
|                                  |    | Seldom      | 0   | 0%   |
|                                  |    | Quite often | 19  | 19%  |
|                                  |    | Very often  | 47  | 47%  |
|                                  |    | Always      | 34  | 34%  |
|                                  | e. | Never       | 0   | 0%   |
|                                  |    | Seldom      | 0   | 0%   |
|                                  |    | Quite often | 34  | 34%  |
|                                  |    | Very often  | 46  | 46%  |
|                                  |    | Always      | 20  | 20%  |
| 7.peer and social support        | a. | Never       | 0   | 0%   |
|                                  |    | Seldom      | 0   | 0%   |
|                                  |    | Quite often | 53  | 53%  |
|                                  |    | Very often  | 47  | 47%  |
|                                  |    | Always      | 0   | 0%   |
|                                  | b. | Never       | 0   | 0%   |
|                                  |    | Seldom      | 0   | 0%   |
|                                  |    | Quite often | 43  | 43%  |
|                                  |    | Very often  | 47  | 47%  |

|                       |    |             |    |     |
|-----------------------|----|-------------|----|-----|
|                       |    | Always      | 10 | 10% |
|                       | c. | Never       | 0  | 0%  |
|                       |    | Seldom      | 0  | 0%  |
|                       |    | Quite often | 0  | 0%  |
|                       |    | Very often  | 60 | 60% |
|                       |    | Always      | 40 | 40% |
|                       | d. | Never       | 0  | 0%  |
|                       |    | Seldom      | 0  | 0%  |
|                       |    | Quite often | 42 | 42% |
|                       |    | Very often  | 45 | 45% |
|                       |    | Always      | 13 | 13% |
| 8. social acceptance  | a. | Always      | 0  | 0%  |
|                       |    | Very often  | 0  | 0%  |
|                       |    | Quite often | 0  | 0%  |
|                       |    | Seldom      | 30 | 30% |
|                       |    | Never       | 70 | 70% |
|                       | b. | Always      | 0  | 0%  |
|                       |    | Very often  | 0  | 0%  |
|                       |    | Quite often | 0  | 0%  |
|                       |    | Seldom      | 33 | 33% |
|                       |    | Never       | 67 | 67% |
|                       | c. | Always      | 0  | 0%  |
|                       |    | Very often  | 0  | 0%  |
|                       |    | Quite often | 0  | 0%  |
|                       |    | Seldom      | 28 | 28% |
|                       |    | Never       | 72 | 72% |
| 9. school environment | a. | Never       | 0  | 0%  |
|                       |    | Seldom      | 0  | 0%  |
|                       |    | Quite often | 0  | 0%  |
|                       |    | Very often  | 24 | 24% |
|                       |    | Always      | 76 | 76% |
|                       | b. | Never       | 0  | 0%  |
|                       |    | Seldom      | 0  | 0%  |
|                       |    | Quite often | 6  | 6%  |
|                       |    | Very often  | 69 | 69% |
|                       |    | Always      | 25 | 25% |
|                       | c. | Never       | 0  | 0%  |
|                       |    | Seldom      | 0  | 0%  |
|                       |    | Quite often | 0  | 0%  |
|                       |    | Very often  | 52 | 52% |
|                       |    | Always      | 48 | 48% |
|                       | d. | Never       | 0  | 0%  |
|                       |    | Seldom      | 0  | 0%  |
|                       |    | Quite often | 14 | 14% |
|                       |    | Very often  | 41 | 41% |
|                       |    | Always      | 45 | 45% |

**Interpretation**

In physical wellbeing, 60% of thalassemic children stated that they have felt good with their health, 68% of all respondents stated that they have felt moderately fit and well, and 57% reported that they have been moderately physically active.

In psychological well-being 71% of all respondents felt that their life has been moderately enjoyable, 69% revealed that they have moderately felt satisfied with their life, 51% reported that they have quite often had fun.

In moods and emotion 57% of all respondents reported that they have never felt that they do everything badly, 46% of all respondents stated that they have quite often felt sad, 52% revealed that they have quite often felt being under pressure.

In self -perception 47% of all respondents reported that they have quite often happy with the way they are, 28% stated that very often been worried about the way they look.

In autonomy, 44% of all respondents reported that they have always had enough time for themselves, 53% stated that

they have very often been able to do the things that they want to do in their free time, 35% stated that they had enough opportunity to be outside, 40% of them perceived that they have quite often had enough time to meet friends.

In parents and home life 55% reported that the parents have extremely understood them, 100% stated that they felt always loved by their parents, 100% were always been happy at home, 47% indicated that their parents have very often had enough time for the children, 46% perceived that they have very often able to talk with their parents when they wanted to.

In peer and social support 53% of all respondents reported that they have quite often spent time with their friends, 47% indicated that they have very often had fun with their friends, 60% reported that they and their friends very often helped each other, 45% stated that they have very often able to talk about everything with their friends.

In social acceptance 70% of all respondents reported that they never been afraid of other girls or boys, 67% stated that

other girls and boys never made fun of them, 72% perceived that other girls and boys never bullied them.

In school environment 76% of children reported that they have been extremely happy at school, 69% of them have got on well at school, 52% of them have very often been able to pay attention, 45% stated that they have always enjoyed going to school

**ii. Overall analysis of quality of life of thalassemic children**

| Study factors                  | Agreeable level of opinion | No. of Respondents | Percentage [%] |
|--------------------------------|----------------------------|--------------------|----------------|
| Physical well-being            | Very poor                  | 0                  | 0%             |
|                                | Poor                       | 2                  | 2%             |
|                                | Good                       | 65                 | 65%            |
|                                | Very good                  | 33                 | 33%            |
|                                | Excellent                  | 0                  | 0.00%          |
| Psychological well-being       | Very poor                  | 0                  | 0.00%          |
|                                | Poor                       | 0                  | 0%             |
|                                | Good                       | 55                 | 55%            |
|                                | Very good                  | 45                 | 45%            |
|                                | Excellent                  | 0                  | 0%             |
| Moods and emotions             | Excellent                  | 0                  | 0.00%          |
|                                | Very good                  | 0                  | 0%             |
|                                | Good                       | 25                 | 25%            |
|                                | Poor                       | 59                 | 59%            |
|                                | Very poor                  | 16                 | 16%            |
| Self-perception                | Excellent                  | 0                  | 0.00%          |
|                                | Very good                  | 4                  | 4%             |
|                                | Good                       | 38                 | 38%            |
|                                | Poor                       | 48                 | 48%            |
|                                | Very poor                  | 10                 | 10%            |
| Autonomy                       | Very poor                  | 0                  | 0.00%          |
|                                | Poor                       | 0                  | 0%             |
|                                | Good                       | 14                 | 14%            |
|                                | Very good                  | 68                 | 68%            |
|                                | Excellent                  | 18                 | 18%            |
| Parent relations and home life | Very poor                  | 0                  | 0.00%          |
|                                | Poor                       | 0                  | 0.00%          |
|                                | Good                       | 0                  | 0%             |
|                                | Very good                  | 6                  | 6%             |
|                                | Excellent                  | 94                 | 94%            |
| Peer and social support        | Very poor                  | 0                  | 0.00%          |
|                                | Poor                       | 0                  | 0.00%          |
|                                | Good                       | 1                  | 1%             |
|                                | Very good                  | 78                 | 78%            |
|                                | Excellent                  | 22                 | 22%            |
| Social acceptance/Bullying     | Excellent                  | 0                  | 0.00%          |
|                                | Very good                  | 0                  | 0.00%          |
|                                | Good                       | 0                  | 0%             |
|                                | Poor                       | 1                  | 1%             |
|                                | Very poor                  | 99                 | 99%            |
| School Environment             | Very poor                  | 0                  | 0%             |
|                                | Poor                       | 0                  | 0%             |
|                                | Good                       | 0                  | 0%             |
|                                | Very good                  | 95                 | 95%            |
|                                | Excellent                  | 5                  | 5%             |

**Interpretation**

From above table 65% of the thalassemic children had good physical well-being (no. of respondents are 65), 55% of them satisfied with psychological well-being, 59% of them were satisfied with moods and emotion, 48% of them satisfied with self –perception, 68% of them satisfied with autonomy, 94% of children always satisfied with parent

relations and home life, 78% of them satisfied with peer and social support, 99% of them were very poorly satisfied with social acceptance, 95% of children satisfied with school environment.

**Section III: Association of quality of life of thalassemic children with demographic variable.**

| Demographic variable     | Calculated value | P value | Interpretation    |                |
|--------------------------|------------------|---------|-------------------|----------------|
| Age                      | 2.3794           | 0.4974  | Greater than 0.05 | No association |
| Sex                      | 1.9997           | 1       | Greater than 0.05 | No association |
| Marriage type of parents | 1.693            | 0.6383  | Greater than 0.05 | No association |
| Family type              | 3.7              | 0.2     | Greater than 0.05 | No association |
| Family income            | 1.0514           | 0.5911  | Greater than 0.05 | No association |

**Interpretation**

Since the p-value is larger (greater than 0.05), none of the demographic variable was found to have significant association with quality of life of thalassemic children except Physical well-being (p- value is 0) in family type.

**6. Discussion**

Findings of the study were based on the objectives of the study. Analysis of demographic profile 54% children were between the age group of 10-13 and 46% were between 14-17 years in the group.66% children were females and 34% were males in the group.57% children were from consanguineous marriage of parents and 43% of children were from non-consanguineous marriage of parents. 53% children were from joint family and 47% children from nuclear family. 31% children whose family income were rs.20, 000/ to 30,000/. 28% children whose family income were rs.10, 000/ to 20,000/. 23% of children whose family income were < rs.10, 000/. 18% children whose family income were >rs.30, 000/.

In physical wellbeing, 60% of thalassemic children stated that they have felt good with their health, 68% of all respondents stated that they have felt moderately fit and well, and 57% reported that they have been moderately physically active.

In psychological well-being 71% of all respondents felt that their life has been moderately enjoyable, 69% revealed that they have moderately felt satisfied with their life, 51% reported that they have quite often had fun.

In moods and emotion 57% of all respondents reported that they have never felt that they do everything badly, 46% of all respondents stated that they have quite often felt sad, 52% revealed that they have quite often felt being under pressure.

In self -perception 47% of all respondents reported that they have quite often happy with the way they are, 28% stated that very often been worried about the way they look.

In autonomy, 44% of all respondents reported that they have always had enough time for themselves, 53% stated that they have very often been able to do the things that they want to do in their free time, 35% stated that they had enough opportunity to be outside, 40% of them perceived that they have quite often had enough time to meet friends.

In parents and home life 55% reported that the parents have extremely understood them, 100% stated that they felt

always loved by their parents, 100% were always been happy at home, 47% indicated that their parents have very often had enough time for the children, 46% perceived that they have very often able to talk with their parents when they wanted to.

In peer and social support 53% of all respondents reported that they have quite often spent time with their friends, 47% indicated that they have very often had fun with their friends, 60% reported that they and their friends very often helped each other, 45% stated that they have very often able to talk about everything with their friends.

In social acceptance 70% of all respondents reported that they never been afraid of other girls or boys, 67% stated that other girls and boys never made fun of them, 72% perceived that other girls and boys never bullied them.

In school environment 76% of children reported that they have been extremely happy at school, 69% of them have got on well at school, 52% of them have very often been able to pay attention, 45% stated that they have always enjoyed going to school.

To associate the findings of quality of life with selected demographic variables researcher used chi-square test and since table values corresponding to demographic variables such as age, gender, marriage type of parents, type of family, monthly income per year of the family, they were found to have there is no significant association of quality of life of thalassemic children.

## 7. Conclusion

On the basis of the findings of the present study, there is no any association of quality of life of thalassemic children with their demographic variables.

## 8. Recommendations

Keeping in view the findings of the study, the following recommendations are made.

- It is suggested that the study may be replicated using a larger population of children admitted or come for transfusions of more number of hospital.
- Study can be done to compare the quality of life between a healthy child and hospitalized child who is having thalassemia.

## 9. Limitations

- This study is limited to 100 children. This limits the generalization of the findings.
- Data collection period was only for one month.
- The study was limited to the experience level of the researcher.

## 10. Acknowledgement

We express our appreciation to the respected officials of Bharati Vidyapeeth Deemed University, College of Nursing, Pune for cooperation with us for executing this research. The author would like to thank Mrs. Pranalini Pardeshi and Mrs. Shubhangi Borude for their constant encouragement, detailed and constructive comments. The author also thankful to all participants the participants in the study and those who helped directly or indirectly in successfully completing the research.

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