

Quality of Life and Coping Strategies among Parents of Children Admitted to Thalassemia Ward

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ABSTRACT

Background: Thalassemia is a hereditary disease of defective hemoglobin synthesis. Thalassemia results from an anomaly of genes involved in the production of hemoglobin. Every year approximately 10,000 children are born with thalassemia in India. Parents of thalassemic children feel depressed, frustrated, and helpless and have numerous emotional, psychosocial, and financial sufferings.

Methods: Parent's quality of life was evaluated by a standardized WHOQOL Bref scale and coping status was assessed using the coping health inventory scale (CHIP), a sample of 100 parents of thalassemic children admitted to thalassemia ward at HSK hospital, Bagalkot was selected using purposive sampling technique, descriptive survey design was adopted. Statistical data were tested and scrutinized using descriptive and inferential analysis.

Results: Total 70% of parents experienced moderate QOL, 9% had good and 21% parents had poor QOL. The mean percentage of QOL of parents was 48.11% with a mean and SD was 63±12. Most of the parents had moderate (88%), 08% had good and 4% of parents' level of coping status was low. No association was found between QOL scores with study variables. A significant association was found among coping strategies with the type of family ($\chi^2=8.66$, $p<0.05$), previous knowledge regarding thalassemia ($\chi^2= 4.912$, $p<0.05$), relationship with the thalassemic child ($\chi^2=6.37$, $p<0.05$). A positive correlation ($r= 0.0829$ $p<0.05$) was found between QOL and coping strategies.

Conclusion: Most parents had moderate QOL and coping strategies. This study is effective to identify the QOL and coping status of parents having a child with thalassemia.

Key-words: Coping status, Level of coping, Quality of life, Thalassemia, WHOQOL Bref scale

INTRODUCTION

Thalassemia is a recessive single-gene disease, which leads to the destruction of red blood cells. Thalassemia is derived from the Greek word "thalassa" meaning "the sea" because the condition was first described in populations living near the Mediterranean Sea ^[1].

Thalassemia becomes a serious public health problem due to high incidence. Parents feel depressed, worried, frustrated, despaired, hopeless, helpless and Parents impact on child's physical, emotional, and mental well-being and affect numerous areas of a child's life including health development, academic progress, and quality of life ^[2]. Yearly 50,000 to 100,000 children die from thalassemia and nearly 7% of the world's population are movers of thalassemia ^[3], which disturbs the overall health and daily activities of children ^[4]. alpha and beta thalassemia are two types, hemoglobin electrophoresis is a test which separates different molecules in the red blood cells to identify the

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abnormal type^[3]. type and severity of the disease decide the treatment measure, treatment includes transfusion of blood, bone marrow transplant, medicines, possible surgery, iron complements, vitamins, and chelation therapy^[5]. without treatment measures, these children have severely conceded growth and a shortened life expectancy^[6].

Iron overload, growth failure, cardiac complications, infections, and endocrine diseases are complications of thalassemia^[7]. Thalassaemic children are unhealthy compare to normal children. Families without appropriate coping behaviour do not afford adequate support for their sick children and it will harm the psychological health of children^[8]. Long and undesirable treatment of thalassemia affects different aspects of the life of children^[9]. Parents are important primary caregivers of thalassaemic children. A child's quality of life depends on corresponding parents so psychological support for the caregivers is therefore central and is a vital part of inclusive treatment^[10]. In 1938 first recorded case of thalassemia was found in India on the east side of Suez in a Hindu boy aged 30 months. It was the first known case of thalassemia outside the Mediterranean region^[11].

Degree of life is accepted as vital and should consider a significant index of effective health care^[12]. Coping strategies are intellectual and social exertions to cope with traumatic circumstances and generate well-being feeling^[13]. Effective coping styles reduce the undesirable effects of stress and increase the capability to manage various stressors^[8].

MATERIALS AND METHODS

Study design and participants- The study was conducted with a descriptive survey design. 100 parents of children admitted to the thalassemia ward at HSK hospital Navanagar, Bagalkot selected for study by purposive sampling, who were ready to join in the study and parents present at the time of data collection were involved as participants.

Instruments

WHOQOL Bref scale and CHIP scale- WHOQOL Bref scale and coping health inventory scale were used to examine the standard of life and coping status. There were 26 questions on 4 aspects of QOL and 45 questions on the coping health inventory scale among parents of children admitted to the thalassemia ward at HSK hospital

Navanagar, Bagalkot. Participants were requested to use separate 5 points and 4 points Likert-type scales for QOL and CHIP respectively. The intended 'r-value after spearman brown's prophecy formula is 0.84 for the WHOQOL Bref scale and 0.79 for the coping health inventory scale, suggesting the developed tool was highly reliable.

Data collection procedures- Prior approvals were taken from pertinent organizations before starting the information assortment procedure. Partakers of the study were parents of children admitted to the thalassemia ward during the study period at HSK hospital, Bagalkot. Every parent of thalassaemic children who satisfied inclusion criteria was loomed for gathering information. Permission was attained by contestants and the Motive of the study was explicated to partakers, who asked questions in Kannada or the language coherent to them. The entire data collection was built on participants' reports.

Inclusive criteria

- aged between 25-50 years.
- able to read and speak Kannada or English.
- accessible during the period of data collection.
- enthusiastic to take part in the study.
- having children admitted to the thalassemia ward.

Exclusive criteria

- who did not have a thalassaemic child.
- unable to communicate.
- not willing to give written consent.
- sick at the time of data collection.

Statistical Analysis- Data gained were investigated in terms of the aims of the study through descriptive and inferential statistics. Participants' responses are taken into consideration and prepared a master sheet. Demographic data was examined by getting frequencies and percentages. Answered questions were calculated by average and SD. A Chi-square trial was applied to find out the association between quality of life and coping strategies with their selected socio-demographic variables accessible in tables and graphs.

Ethical Clearance- A certificate of ethical permission was obtained from the ethical committee of the institution.

RESULTS

Age-wise allocation of parents of thalassemic children revealed that a greater part of parents (34%) were belonging to 25-30 years of age, 87% were belonging to the Hindu religion, 54% were belonging to the nuclear family, 68% were residing in a rural area, 41% fathers have completed their secondary school education, 33% mothers were completed their pre-university education, 41% fathers were belonging to the category of

agriculture, 63% mothers were housewives, 35% of parents' monthly income was 50001-10000, 87% parents were not having previous knowledge regarding thalassemia, parents source of information about the thalassemia 62% were health professionals, 97% parents were not having a family history of thalassemia, relationship with thalassemic child depicts that, majority of parents (55%) were mothers (Table 1).

Table 1: Percentage-wise majority of the distribution of parents according to sample characteristics

Sample characteristics	Category	Percentage (%)
Age	25-30 years	34
Gender	Females	68
Religion	Hindu	87
Type of family	Nuclear family	54
Area of residence	Rural area	68
Father's education	Secondary school education	41
Mother's education	Pre-university education	33
Father's occupation	Agriculture	41
Mother's occupation	Housewife	63
Family monthly income	50001-10000 Rs	35
Previous knowledge regarding thalassemia	No	87
Source of information about thalassemia	Health professionals	62
Family history of thalassemia	No	97
Relation with thalassemic child	Mothers	55

A higher percentage of parents of thalassemic children had a Moderate Quality of life (70%), some parents had a good quality of life (09%) and the remaining parents had poor quality of life (21%) and there were no parents of very good and very poor quality of life. coping strategies

among Parents of thalassemic children where data reveals that most of the Parents of thalassemic children (88%) had Moderate levels of coping strategies, (08%) had a good level of coping strategies and (4%) had Low level of coping strategies (Table 2).

Table 2: Evaluation of QOL and coping strategies midst parents of thalassemic children

Degree of QOL	Frequency	Ratio (%)
Very good QOL	00	0
Good QOL	9	9
Moderate QOL	70	70
Poor QOL	21	21
Very poor QOL	0	0

Degree of coping strategies	Frequency	Percentage (%)
Good	8	8
Moderate	88	88
Low	4	4

The higher percentage of parents of thalassaemic children had a Moderate Quality of life 70% of parents had a moderate quality of life, 9% of parents had a good quality of life and 21% of parents had poor quality of life and there were no parents of very good and very poor quality

of life (Fig. 1). Total 88% of parents had a moderate level of coping strategies, 08% had a good level of coping strategies and 4% had a low level of coping strategies (Fig. 2).

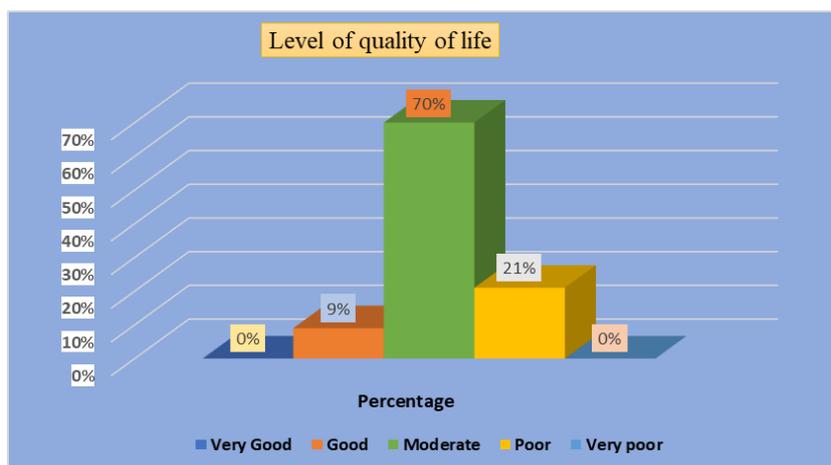


Fig. 1: Percentage-wise dispersal of QOL amongst parents of children suffering from thalassaemia

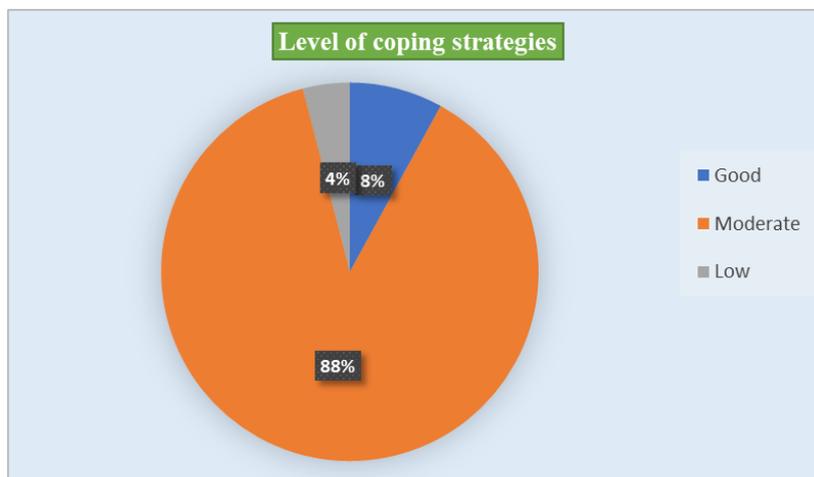


Fig. 2: Percentage-wise distribution of coping status amongst parents of children diagnosed with thalassaemia

The highest mean percentage of parents of thalassaemic children (49.73%) was found for the social domain with mean and SD (7.46) and (1.76), followed by the physical domain (48.85%) with mean and SD (17.1) and (3.537), Environmental domain (48.27%) with mean and SD (19.31) and (4.126), psychological domain (47.2%) with mean and SD (14.16) and (3.356), and overall (45.2%) with mean and SD (4.52) and (1.507) (Table 3). Findings regarding the correlation between the quality of life and

coping strategies among parents of thalassaemic children show that there is a positive correlation (0.082) exists between the quality of life and coping strategies among parents of children admitted in the thalassaemia ward. ($r=0.082$; $p>0.05$) (Table 4).

Findings regarding the association between quality-of-life scores with their socio-demographic variables show that there was no significant association ($p<0.05$) found between the quality-of-life scores with their selected socio-demographic variables (Table 5).



Table 3: Assessment of average, standard deviation and mean percentage of the quality-of-life score and coping strategies amongst parents of children having thalassemia

Variables	Maximum score	Mean	Sd	Mean (%)
Overall QOL	10	4.52	1.50	45.2
Psychological domain	30	14.16	3.35	47.2
Physical domain	35	17.1	3.53	48.85
Social Domain	15	7.46	1.76	49.73
Environmental domain	40	19.31	4.12	48.27
Total QOL	130	63	12	48.115
Coping strategies	135	73	13	53.77

Table 4: Correlation between quality of life and scores of coping strategies midst parents of thalassemic children

Correlation between quality of life and coping strategies		
	Overall QOL	0.586*
	Physical domain	0.53*
Correlation between quality of life and coping strategies	Psychological domain	0.5666*
	Social Domain	0.38*
	Environmental domain	0.4788*
	Total QOL	0.0829*

*= Positive correlation

Table 5: Relationship between scores of quality of life with their research variables

Research Variables	Df	Chi-square Value	Table Value
Parents age	1	3.332	3.84
Gender of parents	1	0.0239	3.84
Religion of parents	1	0.2046	3.84
Type of family	1	2.4784	3.84
Area of living	1	0.5075	3.84
Educational status of Father	1	1.1393	3.84
Educational status of Mother	1	0.5409	3.84
Occupation of father	1	0.017	3.84
Occupation of mother	1	3.0899	3.84



Monthly family income	1	0.0434	3.84
Previous knowledge Regarding thalassemia	1	0.6091	3.84
Base of information About thalassemia	1	0.0015	3.84
Family history of thalassemia	1	0.005	3.84
Relationship with thalassemic child	1	0.0583	3.84

There was a significant association found between the type of family ($\chi^2=8.66, p>0.05$) previous knowledge regarding thalassemia ($\chi^2=4.912, p>0.05$), relationship with the thalassemic child ($\chi^2=6.37, p>0.05$) (Table 6).

Table 6: Association between coping strategies among parents with their research variables

Research variables	Df	Chi-squarevalue	Table value
Parents age	1	0.016	3.84
Gender of parents	1	0.066	3.84
Religion of parents	1	0.472	3.84
Type of family	1	8.66	3.84
Area of living	1	0.717	3.84
Educational status of the father	1	0.020	3.84
Educational status of the mother	1	1.515	3.84
Occupation of father	1	1.086	3.84
Occupation of mother	1	0.315	3.84
Monthly family income	1	0.614	3.84
Previous knowledge regarding thalassemia	1	4.912	3.84
Base of information About thalassemia	1	0.049	3.84
Family history of Thalassemia	1	1.84	3.84
Relationship with child	1	6.37	3.84

DISCUSSION

This section deliberates the key findings of the study and evaluations findings from outcomes of other studies. A study was conducted to measure the degree of life and coping status among parents of thalassemic children. To accomplish the purposes of the study, the descriptive survey research design was adopted. By using the purposive sampling technique 100 parents were chosen as participants.

Percentage-wise distribution of parents according to their age depicted that, the majority of parents (34%) were belonging to 25-30 years of age, 26% of parents were 31-35 years, 23% were 36-40 years, 13% were 41-45 years and 4% were belonging to 46-50 years of age. The results of the present study were reliable and supported by a previous study conducted by Arulmani *et al.* [14] results displayed that mainstream parents of children were belonging to the age of 25-30 years.

The majority of parents (68%) were females and 32% were males. The present study is steady and reinforced by another study by Pruthi *et al.* [15] results showed that the majority of parents were female. The educational qualification of the most of participants was graduation. The majority of parents (87%) were from the Hindu religion, 11% were Muslim, 1% were Christian and 1% were belonging to other religions. The study was similar and conducted by Biswas *et al.* [16] results disclosed that a greater part of parents was from the Hindu religion.

Most of the parents (54%) were from the nuclear family and 46% were from joint families. Most of the parents of thalassaemic children (68%) were residing in a rural area, 24% were in an urban area and 8% were living in a semi-urban area. The majority of fathers (41%) completed their secondary school education, 22% completed pre-university education, 16% completed primary school education, 15% completed a degree and above and 6% of fathers were illiterates. Most of the mothers (33%) completed pre-university education, 25% completed secondary school education, 16% were illiterate, 15% completed primary school education and 11% of mothers completed a degree and above. This study is supported by another study conducted by Othman *et al.* [17] results revealed that the majority of parents had completed secondary schooling, most of the parents were employed 60.3% and from a socioeconomic perspective, middle- and high-income groups outnumbered the low-income group by 38.2%. The majority of fathers (41%) were belonging to the category of agriculture, 22% were private employees, 18% were businessmen, 14% were working for daily wages and 5% were government employees. Most mothers (63%) were housewives, 27% were daily wagers, 5% were private employees and 5% were government employees. The majority (35%) of parents' family monthly income was 50001-10000, 33% of parents were having family monthly income of 10001-20000, 16% of parents' monthly income was 20001 and above and 16% of parents' family monthly income was below 5000. The study was similar to the previous study by Gavneet *et al.* [15] revealed that the monthly income of the majority of participants falls in the category of 8000–15000.

A total of 87% of Parents were not having previous knowledge regarding thalassaemia and 13% of parents

were having previous knowledge of thalassaemia. The study is braced on a previous study led by Biswas *et al.* [18] results showed that 52.7% of them had satisfactory knowledge regarding the disease. The majority of parents (62%) source of information about thalassaemia was from health professionals, 18% were from mass media, 14% were from friends and 6% were from relatives. A total of 97% of parents was not partaking a family history of thalassaemia and 3% were having a family history. The study is consistent and reinforced by another study conducted by Goyal *et al.* [19] results showed that 8.18% were having a family history of thalassaemia.

The majority of parents (55%) were mothers, 30% were fathers, 12% were grandparents and 3% were siblings. Findings linked to the investigation of the degree of life amongst parents showed that a higher percentage of parents had moderate QOL (70%), 9% of parents had good QOL and the remaining parents (21%) had poor QOL. The study was sustained by a study directed by Pruthi [15] results indicated that parents in the thalassaemia group experienced poor QOL as compared to the control group.

Outcomes related to the analysis of average, standard deviation, and mean percentage of total QOL illustrate that, the total mean percentage of total QOL of parents was 48.11% with mean and SD (63±12). The study was reinforced by a similar study led by Padma *et al.* [20] results exhibited that the total average and SD score of QOL was (67.76±17.28). Most parents had moderate QOL 25 (58.1%), 14 (32.6%) had poor QOL and fewer parents had a good quality of life 4 (9.3%).

Findings related to the assessment of domain-wise mean, SD and mean% of total QOL among parents of thalassaemic children revealed that the highest mean percentage of parents (248.66%) was found for a social domain with mean and SD (7.46±1.76), followed by the physical domain (244.28%) with mean and SD (17.1±3.53), environmental domain (241.37%) with mean and SD (19.31±4.12), psychological domain (236%) with mean and SD (14.16±3.35), and overall (226%) with mean and SD (4.52±1.50). This study was supported by the study conducted by Daliya *et al.* [21] results revealed that the mean score of total QOL was 78.57 ±9.8.

Assessment of the degree of coping status among parents revealed that mainstream 88% of parents

had moderate coping strategies, 08% had good and 4% had low coping strategies. Study results were reinforced by a descriptive study led by Sandra *et al.* [22] results showed that 74% of parents experienced severe financial stress and 57% of parents were effectively using coping mechanisms.

Findings regarding the correlation between scores of QOL and coping strategies among parents of children with thalassemia showed a positive correlation between the quality of life and coping strategies (positive correlation $r=0.0829$ $p>0.01$) amongst parents of children admitted in the thalassemia ward. This study was supported by a study conducted by Dadipoor *et al.* [23] results revealed that there was a positive correlation exist between the quality of mental health and coping strategies.

Findings regarding the association between scores of the degree of life of parents with their study variables showed that there was no association exist amongst the quality-of-life scores with study variables. Findings regarding the association of coping strategies among parents with study variables showed that there was a significant association found with the type of family ($\chi^2=8.66$, $p>0.05$), previous knowledge regarding thalassemia ($\chi^2=4.912$, $p>0.05$), relationship with the thalassaemic child ($\chi^2=6.37$, $p>0.05$). this study is supported by another study conducted by Kermansaravi *et al.* [24] results revealed that there was no significant relationship between the demographic data and the total score of coping behaviours of the parents.

CONCLUSIONS

Along with medical management of thalassemia parent's psychological status is also taken care of. Continuous care of children put caregivers under a moderate level of burden. There is a great need to plan and implement health awareness programs for these caregivers. The stress experienced by caregivers is due to a lack of caregivers' knowledge regarding available support systems in the family and society. It is the nurse's role to help caregivers cope with their family and hospital environment by providing satisfactory health education and guiding necessary possessions for the caregivers.

The study is helpful to estimate the quality of life and coping status midst parents of children with thalassemia and future research can investigate the effective coping strategies to deal with thalassaemic children and improve the overall quality of life of parents. The improved

mental health of parents will ensure restorative care of the child and guarantee better adherence to the treatment.

CONTRIBUTION OF AUTHORS

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Final approval- Dr. Deelip S. Natekar

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