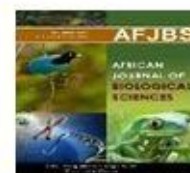




African Journal of Biological Sciences



Research Paper

Open Access

Assessment of quality of life and coping strategies among school going children with thalassemia attending selected hospital, West Bengal

Anima Sarkar Biswas¹, Soma Bhattacharya², Papri Das³

¹Assistant Professor, Institute of Nursing, Brainware University.

²Associate Professor, Institute of Nursing, Brainware University.

³Professor, Institute of Nursing, Brainware University.

Corresponding author: Anima Sarkar Biswas

Article History

Volume 6, Issue 14, August 2024

Received: 09 June 2024

Accepted: 11 July 2024

Published: 26 August 2024

doi: [10.48047/AFJBS.6.14.2024.9610-9620](https://doi.org/10.48047/AFJBS.6.14.2024.9610-9620)

Abstract

The investigator conducted a descriptive survey with the objectives to assess the quality of life to identify coping strategies adopted by the school going children, and to determine relationship between quality of life and coping strategies adopted by the school going children with thalassemia attending in selected hospital, West Bengal. The conceptual framework of the study was based on sister Callista Roy's Adaptation Model (1976). Non-probability convenience sampling technique was adopted to select 100 participants. An un-structured interview schedule for demographic characteristics, standardized Pediatric Quality of Life Inventory TM Version 4.0 used to measure quality of life and standardized Kid COPE used to determine the coping strategies.

The findings of the study revealed that among 100 respondents, 50% respondents had favourable quality of life and 50% respondents had unfavourable quality of life. Domain wise unfavourable quality of life was in physical domain 55%, in emotional domain 45%, in social domain 49% and in school domain 36% whereas favourable quality of life was in physical domain 45%, in emotional domain 55%, in social domain 51% and in school domain 64%. The majority (66%) respondents adopted moderate coping strategies, 14% adopted high coping strategies and only 20% respondents adopted low coping strategies. A significant association was found between quality of life and selected demographic variables like age ($\chi^2 = 8.04$), educational qualification ($\chi^2 = 6.28$) and blood transfusion ($\chi^2 = 7.70$) with school domain.

The study has several implications in the field of nursing practice, education, administration and research. The study was conducted with the recommendations for conducting with larger samples for better generalization of findings.

Key words: Quality of life, coping strategies, school going children, thalassemia.

INTRODUCTION:

Children are very significant and important group of the community as well as society. To have a healthy society, healthy child is required as they are the future of the mankind. Any disease may be environmental or genetic, effect badly on child's health and consequences hamper normal growth and development of this group which is very important for the future generation. Likewise, Thalassemia is a heterogeneous genetic disorder of blood, inherited to offspring autosomal recessively. Globally, 15 million people are suffering from clinically thalassemia disorders apparently [1]. Worldwide 270 million people are reported as β -thalassemia carrier, and 10,000 to 15,000 children with thalassemia are born each year,

among them 3.3% live in India. Thalassemia is a chronic disease, where cure is not attainable due to limited resource and treatment may be prolonged, unpleasant and repetitive; thereby can affect a patient's general health, mental health and life satisfaction. Thalassemia and sickle cell such haemoglobinopathies are inherited disorders of red blood cells and are preventable [2,3]. Beta-thalassemia is the most common and severe form of thalassemia that is known as thalassemia major or Cooley's anaemia [4]. It imposes an immeasurable burden on millions of children around the world particularly in developing countries [5,6]. Worldwide, thalassemia was estimated to occur in 4.4 in 10,000 live births in (Aug. 30, 2022) [7]. It is considered life threatening blood disorder if not properly treated [8]. Children with thalassemia usually need regular blood transfusion for the rest of their life to manage chronic anaemia. Regular blood transfusion leads to iron accumulation in organs that may disrupt their functions. So, long-term transfusions should be accompanied by iron chelation therapy. Thalassemia is likely to be one of the great health problems that affects the quality of life (QoL) of children [4,9]. Quality of life is a multidimensional concept that focuses on the impact of disease and its treatment in well-being of an individual. The quality of life of children with thalassemia are influenced by many factors. As a chronic illness, thalassemia leads to difficult physical, psychological, academic as well as social problems [10,23].

Chronically ill children with disorders of blood can be susceptible to depression and anxiety owing to societal issues like family separation, facial and physical malformations, anxiety of death, and limitations in societal, play and school activities [11]. In a different manner, there are studies reporting early psychological maturation in chronically ill children as they are coping with consequences of the chronic disorder either medical or psychological [12]. Coping has been outlined as a response aimed toward decreasing the physical, psychological and emotional burden that is associated with stressful life events and daily bothers. Coping is known to be adaptive activity that involves effort [13]. It is the component of effort, which permits us to draw the distinction between coping and ready-made adaptational devices such as reflexes [14].

Material and Methods

Design and data source

This descriptive survey was conducted from 06 March 2023 to 01 April 2023, at R. G. Kar MCH & N. R. S. MCH, Kolkata, India, recruited 100 school going children with thalassemia to assess the quality of life and coping strategies.

Inclusion and exclusion criteria

School going children (age group of 8 to 12 years) who are clinically diagnosed with thalassemia for more than 3 months and are available during data collection, willing children and can understand English, Bengali or Hindi. Excluded very sick or debilitated children and mentally retarded children.

Ethical consideration

The institutional ethical committee approved the study protocol vide letter no RKC/Ethics/591 dated 30/7/2022. Written informed consent was obtained from all the parents and assent was taken from all the participants.

Tools of data collection: Data was collected by using Tool-I: Unstructured interview schedule for collection of demographic characteristics; Tool-II: Structured interview schedule, was to assess quality of life comprises four domains and 23 items [35]. Tool-III: Structured interview schedule, was to see coping strategies of the children with thalassemia comprises 10 domains and 15 items[36]. Average time taken by each respondent for completion of their response to all the questions was 25 to 30 minutes approximately.

The reliability was established by Cronhbach's Alfa formula was used for assessment of quality of life (tool-II, Peds QL) and coping strategies (tool-III, Kid COPE) and the value of 'r' was 0.89 and 0.75 respectively.

Recruitment of subjects

A non-probability convenience sampling technique was used to collect the sample. The sample size of 100 was calculated based on a previously published study [23,34] with a precision/absolute error of 5% and a type 1 error of 5%.

Statistical analysis

The collected data were coded, and analysed using Statistical Package for Social Sciences (SPSS). Descriptive statistics and inferential statistics were computed. Chi-square was calculated to identify the association of quality of life with selected demographic variables.

Results

Most of the respondents (55%) belonged to the age group 10 years or more, majority of the respondents (54%) were females and most of the respondents (61%) belonged to II to IV standard(table-1). Majority of the respondent's fathers (40%) were daily wagers(figure-1). Most of the respondents (61%) had monthly family income Rs. 5000-10000(figure-2). Majority of the respondents (93%) had duration of the disease condition more than 5 years, most of the respondents (53%) had received blood transfusion more than once per month, majority of the respondents' siblings (55%) were not suffering from thalassemia(table-1). In physical domain most of the respondents (55%) had unfavourable quality of life, majority of the respondents (55%) had favourable quality of life in emotional domain, in social domain most of the respondents (51%) had

favourable quality of life and majority of the respondents (64%) scored favourable quality of life in school domain(table-2). In this study maximum respondents (66%) adopted moderate coping strategies, highest mean percentage (79.38%) belonged to social support domain and ranked 1st among all ten (10) domains of coping strategies(table-3). In this study computed 'r' value between quality of life and adopted coping strategies was -0.15 so, there was a weak negative relationship between quality of life and adopted coping strategies which is statistically non-significant and the computed 't' value was 1.03 which was less than the table value [$t' df (98) = 1.98$] which indicates there was some significant relationship between quality of life and adopted coping strategies(table-6). The findings of the present study revealed that 50% respondents scored favourable quality of life and 50% respondents scored unfavourable quality of life(table-2). The chi square (χ^2) value showed statistically significant association between quality of life (school domain) and selected demographic variables like age, educational qualification and frequency of blood transfusion(table-8). The relation between quality of life and adopted coping strategies are non-linear.

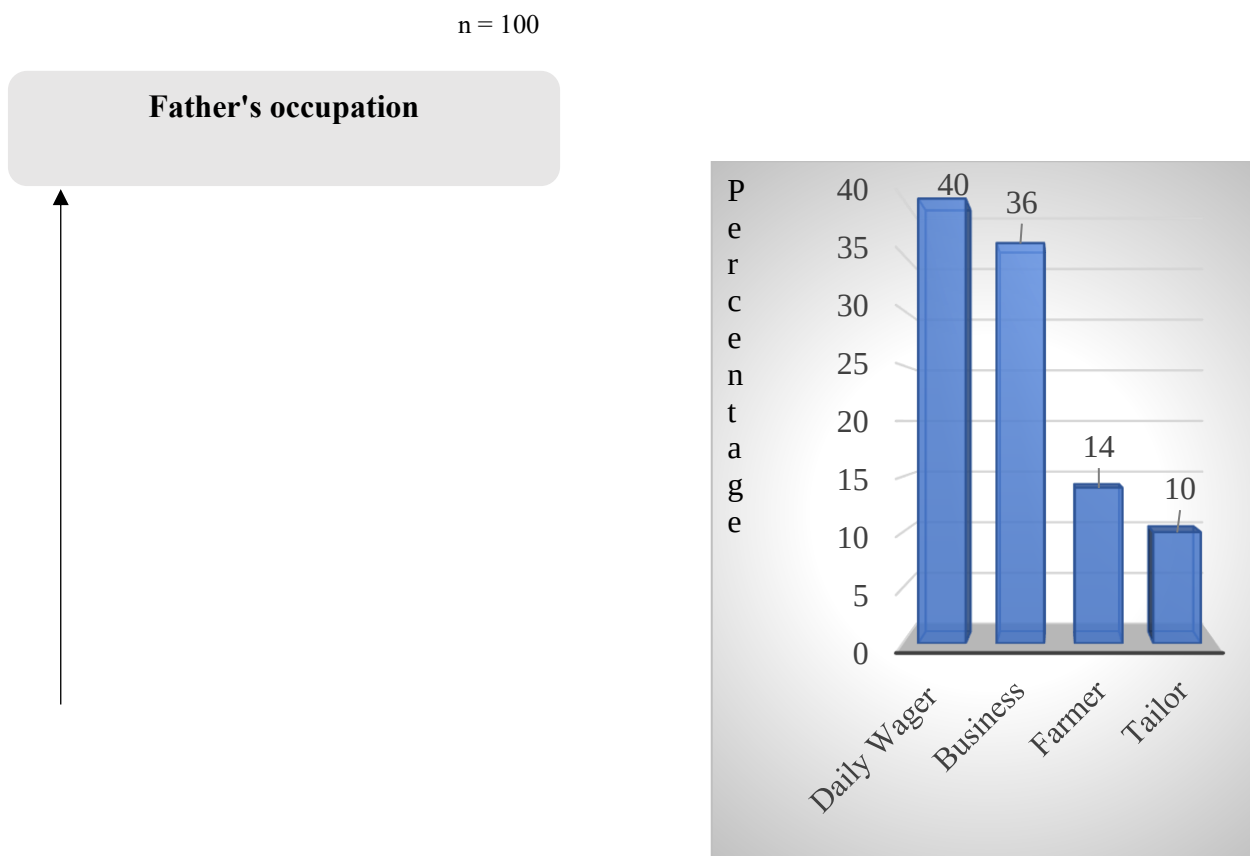


Figure-1: Bar diagram showing distribution of respondents according to their fathers' occupation.

n = 100

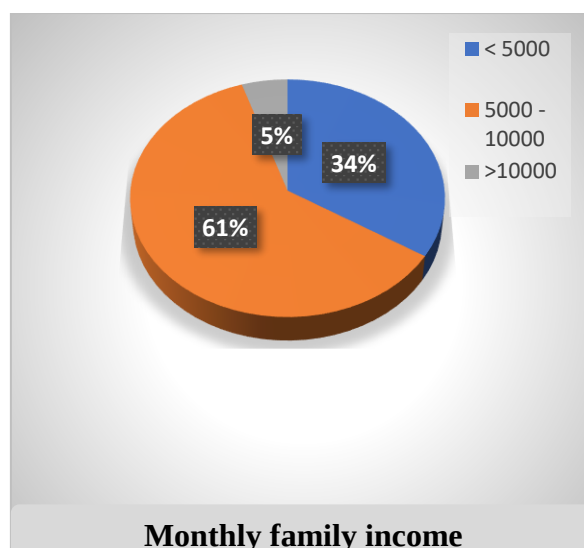


Figure-2: Pie diagram representing percentage distribution of respondents according to their monthly family income.

Table 1 Distribution of respondents in terms of duration of disease condition (in year), frequency of blood transfusion (per month) and sibling suffering from thalassemia.

n = 100

Sample characteristic (Clinical profile)	Frequency	Percentage (%)
Age (in years)		
< 10	45	45
≥ 10	55	55
Gender		
Male	46	46
Female	54	54
Educational qualification		
II-IV	61	61
V-VII	39	39
Duration of disease condition (in years)		
< 5	07	07
≥ 5	93	93
Frequency of blood transfusion (per month)		
< 1	47	47
≥ 1	53	53
Sibling suffering from thalassemia		
Yes	06	06
No	55	05
Having no sibling (NA)	39	39

Table 2 The quality-of-life score with reference to median of the thalassemic children.

n = 100

Domain	≤Median	Percentage	>Median	Percentage
Total quality of life	50	50%	50	50%

Physical	55	55%	45	45%
Emotional	45	45%	55	55%
Social	49	49%	51	51%
School	36	36%	64	64%

3 Mean, mean percentage and rank according to domains of coping strategies of the respondents

Coping strategies	Range	Score	Mean	Mean (%)	Rank
Distraction	0-200	109	1.29	32.25	8 th
Social withdrawal	0-100	78	1.14	28.47	9 th
Cognitive restructuring	0-200	109	1.20	59.89	3 rd
Self-Criticism	0-100	21	0.78	38.89	5 th
Blaming others	0-100	66	1.20	60.00	2 nd
Problem solving	0-100	97	1.12	28.03	10 th
Emotional regulation	0-200	103	1.30	32.59	7 th
Wishful thinking	0-200	117	1.34	33.43	6 th
Social support	0-200	154	1.59	79.38	1 st
Resignation	0-100	81	0.90	45.00	4 th

Table 4 Mean, mean percentage and rank according to domains of quality of life of respondents

Domains	Mean	Mean-percentage	Rank
Physical	76.97	76.97%	2 nd
Emotional	69.30	69.30%	3 rd
Social	77.95	77.95%	1 st
School	65.80	65.80%	4 th

Table 5 Frequency and percentage distribution of overall coping strategies of children with thalassemia

Overall Coping Strategies	Frequency	Percentage (%)
Low (<1.00) (< $\mu-1\sigma$)	20	20
Moderate (1.00 – 1.46) ($\mu-1\sigma$ to $\mu+1$)	66	66
High (> 1.46) (> $\mu+1\sigma$)	14	14

$\mu = 1.23, \sigma = 0.2$

Table 6 Chi-square value showing association between physical and emotional domain score of quality of life with age (in years), educational qualification, duration of disease condition (in years) and frequency of blood transfusion (per month).

Sample Characteristics	Physical Score < Median ≥ Median	χ^2
------------------------	-------------------------------------	----------

Physical Score

Age (in years)			
<10	23	22	0.86
≥10	23	32	
Educational qualification			
II – IV	30	31	1.70
V – VII	14	25	
Duration of disease condition (in years)			
< 5	03	04	0.004
≥ 5	41	52	
Frequency of blood transfusion (per month)			
<1	31	16	1.31
≥1	29	24	

Emotional Score

Age (years)			
<10	13	32	1.80
≥10	23	32	
Educational qualification			
II – IV	21	40	0.17
V – VII	15	24	
Duration of disease condition (in years)			
<5	03	04	0.38
≥ 5	51	42	
Frequency of blood transfusion (per month)			
<1	21	26	1.00
≥ 1	29	24	

 χ^2 df (1) = 3.84, P>0.05

Table 7 Correlation Coefficient and their significance existing between quality of life and adopted coping strategies of children with thalassemia.

n=100

Variable	Correlation Coefficient (r)	t value
Quality of life	-0.15	1.03
Vs		
Coping strategies		

 t df = (98) = 1.98, at p > 0.05

Table 8 Chi-square value showing association between social and school domain score of quality of life with age (in years), educational qualification, duration of disease condition (in years) and frequency of blood transfusion (per month).

n = 100

Sample Characteristics	School Score		χ^2
	< Median	≥ Median	

Social Score

Age (in years)			
<10	21	24	0.06
≥10	27	28	
Educational qualification			
II – IV	26	35	0.03
V – VII	16	23	
Duration of disease condition (in years)			

<5	02	05	1.14
≥5	46	47	
Frequency of blood transfusion (per month)			
<1	31	16	0.0001
≥1	35		

School Domain

Age (years)			
<10	15	30	8.04*
≥10	34	21	
Educational qualification			
II – IV	19	42	6.28*
V – VII	22	17	
Duration of disease condition (in years)			
<5	03	04	1.31
≥5	60	33	
Frequency of blood transfusion (per month)			
<1	18	29	7.70*
≥ 1	35	18	

χ^2 df (1) = 3.84, P>0.05

Discussion: Discussion related to other studies

This section represents the explanation of the results and findings where the researchers explain their research findings through critical analysis along with comparison with other similar research findings.

In this section, major findings of the study have been discussed with reference to the results found in other studies.

Findings related to assessment of quality of life of respondents with thalassemia

- The findings of the present study revealed that 50% respondents scored favourable quality of life and 50% respondents scored unfavourable quality of life.
- The chi square (χ^2) value showed statistically significant association between quality of life (school domain) and selected demographic variables like age, educational qualification and frequency of blood transfusion.
- The relation between quality of life and adopted coping strategies are non-linear.

The findings of this study shows that in school domain most of the respondents (64%) had favourable quality of life, followed by emotional domain (55%), social domain (51%) and physical domain (45%), supported with the study conducted by **Jajhara I, Choudhary G, Singh J, Chachan V, Kumar A (2021)**; A study on quality of life among thalassemic children aged 8 to 18 years, study shows 46% of children had fair emotional QoL and 20% had bad emotional QoL, 46% had fair school QoL. 75% of children, who had not teased by others had very good social QoL, only 11% of children, who had teased by others had severe problems with social interaction and does not support in physical domain 80% had no problem with self-care [16].

The findings of this study in school domain most of the respondents (64%) scored favourable quality of life, which is consistent with the study conducted by **Saha R, Misra R, Saha I. (2016)**; School Functioning Activity of Bengali Thalassemic Children Attending a Tertiary Care Hospital of Eastern India. majority of thalassemic children (49.3%) had fair school functioning activity [21].

The findings of this study are also inconsistent with the study conducted by **Bains M, Mandal K (2019)** Safdarjung Hospital, New Delhi, India. A study to assess the quality of life among children with thalassemia and its relationship with selected factors in selected hospitals of Delhi. The major findings of the study where majority of children were having moderate quality of life and there was a significant association between quality of life of thalassemic children and selected demographic variables [24].

The findings of this study shows that in physical domain most of the respondents (55%) had unfavourable quality of life, followed by social domain (49%), emotional domain (45%), and school domain (36%); this was in accordance with the findings of a study by **Biswas B, Naskar N.N., Basu R.** Knowledge of the caregivers of thalassemic children regarding thalassemia: A cross-sectional study in a tertiary care health facility of eastern India, shows mean QoL score maximum in social domain (62.8) followed by emotional domain (58.5), physical domain (50.1) and school domain (48.9). The

difference in findings may be due to study population variation, as the child grows older, he or she copes with the disease's burden [23].

Findings related to coping strategies adopted by the respondents with thalassemia

The findings of this study, highest mean percentage (79.38%) belonged to social support domain in coping strategies. In this study avoidance coping like distraction (mean=1.29), resignation (mean=0.90) is supported with the study conducted by **Abdelmageed R. I., Elhenawy Y. I., Zaafar D. K., Abdelaziz A. W.**; Coping strategies among children and adolescents: validity and reliability of the Arabic Version of the KidCOPE scale mean in distraction=1.28 and resignation=0.81[38].

In this study respondents were 8 to 12 years and among them majority that is 66% respondents adopted moderate coping strategies, most common age group using coping strategies, this is supported by the study conducted by **Ali M A, Bilsha M. A. E., Ahmed D M.** Coping strategies among children with thalassemia [15].

Finding related to correlation between quality of life and adopted coping strategies of children with thalassemia

Present study indicates there was some significant relationship between quality of life and adopted coping strategies ('t' value = 1.03) which is supported by a study of **Ali M A, Bilsha M. A. E., Ahmed D M.** Coping strategies among children with thalassemia [15], found a significant relationship between coping strategies and educational level of thalassemic children.

Findings related to association between quality of life of children with thalassemia and selected demographic characteristics.

In this study, frequency of blood transfusion in school domain showed statistically significant association with quality of life, supported by a study of **Biswas B, Naskar N.N., Basu R.** Knowledge of the caregivers of thalassemic children regarding thalassemia: A cross-sectional study in a tertiary care health facility of eastern India [23], and a study of **Saha R, Misra R, Saha I.** School Functioning Activity of Bengali Thalassemic Children Attending a Tertiary Care Hospital of Eastern India. *Int J Travel Med Glob Health* [21].

A study by **Ankush A, Dias A, Silveira M P, Talwadker Y, Souza J P.** Quality of life in children with thalassemia major following up at a tertiary care center in India (GOTQoL) [18] says thalassemic children scoring significantly lower in overall School functioning, which is in accordance with the present study.

Conclusion

Thalassemia is a blood disorder characterized by the reduction or absence in the synthesis of the globin chains of hemoglobin. Thalassemia had a negative impact on perceived physical, emotional, social and school functioning. There was a significant association between the total quality of life and compliance with blood transfusion in child. The major findings of the study were, majority of children were having moderate quality of life and there was a significant association between quality of life of thalassemia children and selected demographic variables. Based on the result of this study, it can be concluded that 75% of children with thalassemia belonged to moderate quality of life. Emotional function had the lowest mean of the four domains assessed, followed by school, physical, and social. Health services that could improve the quality of life of thalassemic children could be provided optimally with effective and efficient management strategies which involve all sectors, both formal and informal so that the quality of life for children with thalassemia would not be different from that of the normal children.

Adaptive coping strategies were more evident as compare to maladaptive strategies. 66% respondents were in moderate coping strategies and 14% were in high coping strategies. Like for other disease conditions there are many national or international health programme for their management so, same for thalassemia there should be health programme on prevention and management of thalassemia. There is great need to plan, implement health awareness programme regarding prevention and management of thalassemia.

The study findings provided a base line data that helps to be utilized as a guide in teaching health personnel and advocacy to caregiver of thalassemic children regarding how adopted coping strategies help to improve quality of life. Therefore, it is necessary to pay attention to improve social health and emotional health to improve their quality of life. Depending on the result of this study appropriate strategies and interventional protocol have to develop to enhance quality of life of thalassemia patient.

Implications

Nursing is a profession, with changing trends, it is imperative for the nursing personnel to keep themselves aware with the changes and it must advance to keep the pace with the advancing technology and growing demands of the people. The

result obtained from the study has helped the researcher to derive certain implications for nursing practice, education, administration and research.

Nursing practice

Nursing practice is mainly based on holistic care and evidence-based nursing practice. The study emphasizes on the importance of improving the quality of life of the children with thalassemia by economic quality care. Factors related to adopt coping strategies to improve quality of life to be taken care of. The incidence of morbidity and mortality due to thalassemia is still high in developing countries. By proper nursing practice the rate of morbidity and mortality among thalassemia children can be reduced. Clinical nurse should supervise from time to time and identify the learning need of the parents to improve quality of life of thalassemia. Nurses should give emphasis on awareness programme in the hospital as well as in the community settings about the impact of thalassemia on daily life and the way out to live a quality life.

Nursing education

Sensitising the nursing student and health care personnel in developing awareness program for improving the quality of life in thalassaemic children. In order to provide care to the thalassaemic children students need to have knowledge and skills in assessing the children affected with thalassemia; so, it need to be emphasized in existing nursing curriculum. Lack of knowledge regarding pre-marital counselling and genetic counselling is an important part of preventing thalassemia and improving quality of life by adopted coping strategies. Good communication and effective follow up may be the important intervention to improve quality of life by adopted coping strategies among children with thalassemia.

Nursing administration

Nursing administrators have a major role in planning activities at community level as well as in the health care setting by organizing public awareness programme regarding importance of marital and pre-marital counselling. The nurse administrator must have appropriate policy to acquire modern technological audio and video aids for continuing education program and symposium to be carried out for nurses in child care unit regarding various treatment modalities, blood transfusion techniques and iron chelation therapy, dose calculation, identifying complications etc. so that the knowledge can be utilized for better patient care. Proper supervision and counselling are required to enhance coping strategies and to improve quality of life by regular follow up.

Nursing research

Future research should be carried out by utilizing reliable methodologies and consistent measure of treatment. More research will be necessary to refine and further elaborate the findings. In clinical setting small researches can improve the quality care among the nurses by improving the knowledge regarding care related to thalassaemic children and also improve the skills among the working nurses. Quantitative approaches could be used with large sample size and focus group interview for further detail information.

Limitations

The present study was limited to-

- A small number of participants (100) limiting generalization of findings.
- Only selected pediatric unit of selected hospital, Kolkata which further limiting the generalization of findings.
- The subjectivity of the self - report of the respondents.

Recommendations

On the basis of findings, the following recommendations are offered for future research:

- A similar study can be conducted on larger number of samples to generalize findings.
- A longitudinal study can be conducted to assess the quality of life of children with thalassemia.
- A study could be conducted to find out the effect of good and effective communication and education strategies focused to improve the quality of life of thalassemic children.
- Future study could be conducted to find out the effect of different coping strategies on their quality of life.
- An experimental study can be conducted on effect of cognitive behavioral therapies for reduction of stress and depression among thalassemic children.
- A study can be conducted to explore different factors effecting quality of life of thalassemic children.

References

1. Weatherall DJ, Clegg JB. The thalassemia syndromes. John Wiley & Sons; 2008.
2. Dr. Vardhan H. inaugurates the Thalassemia Screening and Counselling Centre at Indian Red Cross. By Delhi <https://pib.gov.in/PressReleasePage.aspx?PRID=1646731> Posted On: 18 AUG 2020 5:58 PM

3. Verma IC, Choudhry VP, Jain PK. Prevention of thalassemia: a necessity in India. *Indian J Pediatr.* 1992;59(6):649-654. doi:10.1007/BF02859390
4. Rown S, Nelson K, Ashwill A. *Nursing Care of Children: Principles and Practices.* 4 th ed. Elsevier Inc; 2013.
5. Hockenberry M, Wilson D. *Wong's Nursing Care of Infants and Children.* 10th ed. Elsevier Inc; 2015.
6. Kamal S. *Hepatitis C in Developing Countries: Current and Future Challenges.* Elsevier Inc; 2018.
7. Elsayed A, Mahmoud S. Nursing Guidelines for Children Suffering from Beta Thalassemia. *Journal of Nursing Science* 2015; 5(4): 131-5.
8. Thavorncharoensap M, Torcharus K, Nuchprayoon I, Riewpaiboon A, Indaratna K, Ubol B. Factors affecting health-related quality of life in Thai children with thalassemia. *BMC Hematology.* 2010; 10(1).
9. Wahyuni MS, Ali M, Rosdiana N, Lubis B. Quality of life assessment of children with thalassemia. *Paediatrica Indonesiana* .2011; 51(3): 163-9.
10. Baghianimoghadam MH, Sharifirad G, Rahaei Z, Baghianimoghadam B, Heshmati H. Health related quality of life in children with thalassemia assessed on the basis of SF-20 questionnaire in Yazd, Iran: a case-control study. *Central European Journal Of Public Health.* 2011 Sep;19(3):165-9. doi: 10.21101/cejph. a3640.
11. Pradhan PV, Shah H, Rao P, Ashturkar D, Ghaisas P. Psychopathology and self-esteem in chronic illness. *Indian J Pediatr.* 2003; 70:135–138.
12. Yengil, E., Acipayam, C., Kokacya, M. H., Kurhan, F., Oktay, G., & Ozer, C. Anxiety, depression and quality of life in patients with beta thalassemia major and their caregivers. *International Journal of Clinical and Experimental Medicine.*2014; 7(8), 2165–2172.
13. Mazzone, L., Battaglia, L., Andreozzi, F., Romeo, M. A., & Mazzone, D. Emotional impact in β -thalassaemia major children following cognitive-behavioural family therapy and quality of life of caregiving mothers. *Clinical Practice and Epidemiology in Mental Health.*2009; 5(5): <http://doi.org/10.1186/1745-0179-5-5>.
14. Jain M, Bagul AS, Porwal A. Psychosocial problems in thalassemic adolescents and young adults. *Chron Young Sci* .2013; 4:3-21.
15. Ali M A, Mona Ahmed, E B, Ahmed D M. Coping strategies among children with thalassemia. *IOSR Journal of Nursing and Health Science* .2018;7920:2320–1959.
16. Jajhara I, Choudhury G, Singh J, Chachan V, Kumar. A study on quality of life among thalassemic children aged 8 to 18 years. *International Journal of Contemporary Pediatrics.*2021;8(10): 1667.DOI:10.18203/2349-3291.ijcp20213727
17. Sharma S, Sood SK, Colah R, Bhatia LH. Frequency of β -thalassemia trait and other hemoglobinopathies in northern and western India. *Indian J Hum Genet.* 2010 Jan;16(1):16-25. doi: 10.4103/0971-6866.64941.
18. Ankush A, Dias A, Silveira M P, Talwadker Y, Souza J P. Quality of life in children with thalassemia major following up at a tertiary care center in India (GOTQoL). *International Journal of Contemporary Pediatrics.* 2019; 6(1).
19. Pushpa, Rani R, Nebhinani M. Knowledge, burden and coping strategies among caregivers of thalassaemic children attending thalassemia day care center of selected hospital, Jodhpur. *International Journal of Community Medicine and Public Health* .2021;8 (6).
20. Shafie A A, Chhabra I K, Wong J H et al. Health-related quality of life among children with transfusion-dependent thalassemia: A cross-sectional study in Malaysia. *Health and Quality of Life Outcomes* volume .2020;18:141.
21. Saha R, Misra R, Saha I. School Functioning Activity of Bengali Thalassemic Children Attending a Tertiary Care Hospital of Eastern India. *Int J Travel Med Glob Health.* 2016 Sep;4(3):82-87 doi 10.20286/ijtmgh-040303.
22. Mohammed S, Hassan E, Sayed S E, Ibrahim H, Azzab E. Study of the Health Instructions Effect on Quality of Life and Psychological Problems among Children with Thalassemia. *International Journal of Studies in Nursing* .2016;1(1).
23. Biswas B , Nath Naskar N.N., Basu R. Knowledge of the caregivers of thalassemic children regarding thalassemia: A cross-sectional study in a tertiary care health facility of eastern India. *Iraqi Journal of Hematology* .2018;7(2).49-54.

24. Bains M, Mandal K. A study to assess the quality of life among children with thalassemia and its relationship with selected factors in selected hospitals of Delhi. *Indian Journal of Youth and Adolescent Health* .2019;6(9).
25. Fatkuriyah L, Hidayati. Factors related to quality of life among children with thalassemia major: a literature review. *Nurse and Health: Journal Keperawatan*.2022;11(1). DOI: <https://doi.org/10.36720/nhjk.v11i1.340>.
26. Atshan R S, Rafay S A, Matter R M, Hassan S E. Impact of Lifestyle Modification Module on Adherence to Therapeutic Regimen of Children and Adolescents with Beta Thalassemia Major. *Medico-Legal Update*.2021;21(2).
27. Ayoub M D, Radi S A, Azab A M, Abulaban A A, Balkhoyor A H, Bedair S W et al. Quality of life among children with beta thalassemia major treated in Western Saudi Arabia. *Saudi Med J*. 2013 Dec;34(12):1281-6.
28. Monem A A, Shehata S, Elsayed M, Ayad A. Descriptive clinical study of children with beta-thalassemia at Damanhour Medical National Institute.2021;34(1):67-73.
29. Chordiya K, Katewa V, Sharma P, Deopa B, Katewa S. Quality of Life (QoL) and the Factors Affecting it in Transfusion-dependent Thalassemic Children. *Indian J Pediatr*.2018;85:978–983. DOI: 10.1007/s12098-018-2697-x
30. Kavitha K, Dr. Padmaja A. Effectiveness of SCOPE Programme on Health-Related Quality of Life and Health Status of Thalassemic Children. *International Journal of Health Sciences & Research*.2019;9(8).
31. Batta A T A, Abusaad F E S, Sarhan M M. Knowledge of Thalassemic Children about Their Pain and the used Coping strategies. *International Journal of Novel Research in Healthcare and Nursing*.2018;5(3):70-80.
32. Kaheni S, Yaghobian M, Sharefzadah G H, Vahidi A, Ghorbani H, Abderahemi A . a study quality of life in children with β -thalassemia major at center for special diseases. *Iran J Ped Hematol Oncol*. 2013;3(3):108-13.
33. Adly A A M, Ebeid F S E. Cultural Preference and limited public resources Influence the Spectrum of Thalassemia in Egypt. *Journal of pediatric hematology/Oncology*.2015;37(4). DOI:10.1097/MPH.0000000000000327.
34. Saha S., Ghosh S., Basu K. & Bhattacharyya M. Prevalence of β -haemoglobinopathies in Eastern India and development of a novel formula for carrier detection, Eastern India, 8th July 2020.
35. James W. Varni; Scaling and scoring of the Pediatric Quality Life Inventory TM (PedsQLTM) Generic Core Scales for Young Children (ages 5-7), Children (ages 8-12), Teens (ages 13-18); Mapi Research Trust, 27 rue de la Villette, 69003 Lyon, France; pages 7,8.
36. Spirito A, Stark, J., & Williams, C., (1988), Development of a brief coping checklist for use with pediatric populations to measure cognitive and behavioral coping in children and adolescents; Antony_Spirito@Brown.edu KIDCOPE.
37. Behera S. K., Das S., Xavier A. S., Selvarajan S., Anandabaskar N.; Indian Council of Medical Research's National Ethical Guidelines for biomedical and health research involving human participants: The way forward from 2006 to 2017; PMC, National Library of Medicine.
38. Abdelmageed R. I., Elhenawy Y. I., Zaafar D. K., Abdelaziz A. W.; Coping strategies among children and adolescents: validity and reliability of the Arabic Version of the KidCOPE scale; *Heliyon*, 04 Jan 2022, 8(1):e08706 <https://doi.org/10.1016/j.heliyon.2021.e08706> PMID:PMC8741452