Original Research Article

Quality of life among caregivers of thalassaemic children, attending at Thalassaemia control unit of a rural tertiary care hospital, in a sub-Himalayan district of West Bengal

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ABSTRACT

Background of Study: Thalassaemia is a disease of abnormal development of red blood cells which manifests as anaemia. This chronic disease may cause mental, social, financial burdens on the families, care givers and also on health care system.

Objectives: To assess the quality of life (QOL) of the caregivers of thalassaemic children and to identify the predictors of quality of their physical and mental health.

Materials and Methods: Institution based descriptive cross-sectional study conducted in the Thalassaemia Control Unit (TCU) of North Bengal Medical College (NBMC) from December 2018 to April 2019. Total 136 caregivers of children (≤12 years) with thalassaemia were included by complete enumeration method. Physical and mental health of the caregivers were reported in Short Form-36 (SF-36) Health Survey. Collected data were entered into MS-Excel, analysed with the help of SPSS (Version 22).

Results: Mean age of caregivers was 34.3 (SD ± 1.4 years). Most of caregivers were female (89%) and had educational qualification up to Primary school (45.6%). Majority (70.6%) of the caregivers were the mothers of the children. Most of the study participants (60.3%) had favourable Physical health Component Summary (PCS) but 64.7% of the caregivers had unfavourable Mental health component Summary (MCS). Educational status was found to be the predictor for PCS but age and relationship with the child were the predictors for MCS.

Conclusions: Counselling, psychotherapy, social support for family members or caregivers of the thalassaemic children and community involvement with their full participation should be emphasized to reduce stigma related to thalassaemia.

1. Introduction

Thalassaemia is a genetic disease causing an abnormal development of red blood cells and leads to anaemia.[1] Thalassaemia is a very common disorder worldwide with more prevalent in Mediterranean countries and Southeast Asian countries.[2] Children living with thalassaemia may need a life-long follow-up and regular treatment, which may cause major social and financial burdens on the families, care givers and also on our health care system.[3]

Globally, the prevalence of thalassaemia ranges between 2 and 25%.[4] For every 100,000 live births, approximately 4.4 children are affected by thalassaemia throughout the world.[5] Burden may also increase because of repeated visits to the hospital, repeated laboratory tests and frequent

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monitoring of symptoms in detecting complications.[6]

In India, the carrier rate for β -thalassaemia varies from 1% to 17% with 10,000 children (one-tenth of the world) with β -thalassaemia major is born every year.[7,8] In West Bengal, every 10th person is a thalassaemia carrier with more prevalent among scheduled caste, scheduled tribe and Muslim populations.[9]

Thalassaemia is also a major public health problem in the region of Northern part of West Bengal among the ethnic group (Rajbanshi families). Statistically significant association (P < 0.05) was found between HbE syndrome and the Rajbanshi families. In this region of West Bengal among those with abnormal haemoglobin, 66% belonged to the Rajbanshis.[10]

Therefore, understanding the Quality of life (QOL) of the caregivers of thalassaemic children is necessary which will help us to get more information about their experiences, difficulties, needs, concern and prevention of physical and mental health morbidities in this sub-Himalayan region of West Bengal.

2. Materials and Methods

2.1. Study design and setting

The present study was a descriptive, observational, cross-sectional study conducted in the Thalassaemia Control Unit (TCU) of North Bengal Medical College (NBMC) from December 2018 to April 2019.

2.2. Study population

All the caregivers of the children (≤ 12 years) suffering from Thalassaemia who were attended on the specific days of Thalassaemia Clinic in the Thalassaemia Control Unit (TCU) of North Bengal Medical College (NBMC), were included as study participants. Participants those who were unwilling to participate, repeat visit and the children who were more than 12 years were excluded from this study.

2.3. Sample size and sampling technique

Complete enumeration technique after applying exclusion and inclusion criteria, a total of 136 participants (n= 136) were included in this study.

2.4. Data collection tools

Data were collected using Short Form-36 (SF-36) Health Survey. The SF-36 is a self-administered QOL scoring system. The SF-36 includes a multi-item scale with 8 subscales: physical functioning, role limitations due to physical problems, bodily pain, general health perceptions, energy and fatigue, social functioning, role-limitations due to emotional problems, and emotional wellbeing. A Physical health Component Summary (PCS) and a Mental health Component Summary (MCS) were included in the test scoring. The PCS scale included physical functioning, role physical, bodily pain and general health subscales. The MCS scale included energy and fatigue, social functioning, role emotional and emotional wellbeing subscales.

In this study, the study participants rated the items using as 5 point Likert type scale (1 = none of the time; … 5 = all of the time). Several items were reversed scored. Scoring follows a series of formulas and calibration in which scores range from 0 – 100 with a mean of 50 and standard deviation of 10 [50 (SD± 10)]. Higher scores represent better functioning.

The SF-36 questionnaire was translated into Bengali from English and retranslated into English. The translated versions of the questionnaire were validated by different experts. Pretesting of the questionnaire was done for necessary modifications. The Bengali version of SF-36 Questionnaire was used for collection of data.

2.5. Data collection procedure

With the prior intimation to the In-charge of Thalassaemia Control Unit (TCU) of North Bengal Medical College (NBMC), the caregivers of the diagnosed thalassaemic children attending to Thalassaemia Clinic, were approached and informed about the purpose of this study. The willing study participants were included. Participants with repeat visit and children of age > 12 years were excluded. They were assured that information will be kept confidential and will be used only for research purpose. Participants were requested to respond to each item of scale. Those who were illiterate or faced any problems during filling were assisted to filled out the questionnaire. In this study we used both self-administration and interview technique for collection of information. Demographic information was also collected. At the end all the participants were thanked for their kind cooperation and wilful participation.

2.6. Statistical analyses

Collected data entered into Microsoft-Excel software, double checked and analysed using IBM SPSS (Version 22). Frequencies, proportions, mean and SD were used for descriptive statistics.

For inferential statistics, independent t-test for two groups, ANOVA for more than two groups were performed. Binary logistic regression was done to identify the predictors for favourable PCS and MCS.

In Socio-economic status (SES) class, as the percentage of SES class I and V were negligible, SES class I and II were clubbed into a single SES class (Upper class) and SES class IV and V were clubbed into a single class (Lower class). SES class III was considered as Middle class for better interpretation of study results.

For both PCS and MCS lowest possible score was 0 and the highest possible score was 100. In this present study,

score <50 were considered as unfavourable functioning and score ≥50 as the favourable functioning for both Component Summaries.

2.7. Ethical consideration

Approval was taken from the Institutional Ethics Committee of North Bengal Medical College, Darjeeling.

3. Results & Discussion

Present study Mean age of caregivers was 34.3 (SD ± 1.4 years), Range 23-65 years. Table 1 showed that majority (58.8%) of the study participants were in the age group of ≤ 34 years. Overall most of caregivers were female (89%). Educational qualification of the most of them were up to Primary school (45.6%), followed by Middle school (31.6%). Majority (70.6%) of the caregivers were mothers of the children. Most of the caregivers were homemakers (70.6%) by occupation. Majority of the study participants belonged to lower middle class (50%) followed by middle class (32.4%). Present results regarding socio-demographic characteristics may differ from other similar studies due to the difference in study setting. Present study was conducted in a rural tertiary care hospital which covers a large rural areas of Darjeeling and Jalpaiguri district. Naturally, study participants were mostly from rural areas and their educational level were mostly up to primary level and most of them were home maker and belonged to lower middle and middle SES Class. Present study results were almost similar to the study conducted by Biswas et al.[11]

Diagram 1 showed that, 60.3% of the study participants had favourable PCS of health. But in case of MCS of health we had found that, majority (64.7%) of the caregivers were having unfavourable MCS. This study results were slightly less than the study results by Inamdar et al and Shaligram et al. (73%-76%).[12,13]

Table 2 showed association of PCS and MCS with the socio-demographic characteristics of the study participants. Normal distribution of PCS and MCS were tested with Kolmogorov-Smirnov test (p= 0.073) and Shapiro-wilk W test (p= 0.142). Independent t-test for two groups and ANOVA for more than two groups were performed. Age group ≤34 years had better mean PCS and MCS than age group >34 years. Males had better PCS than females, but for MCS both are similar. Study participants those were Illiterate had poorest PCS and MCS than the other categories. Grandmother of the children had the poorest PCS as well as the fathers had the poorest MCS than the other categories of caregivers. Regarding occupation of the caregivers both categories had similar PCS and MCS. Lower SES Class had better PCS and MCS than the rest. Though none of these associations were statistically significant (p<0.05) in this bivariate analysis. A different result shown by Mashayekhi et al.[14] They had shown a significant positive association of maternal age and caregiver burden, with inverse relationship with their income. The variations may be attributed to the differences in socio-demographic profile of the study participants.

In Table 3 binary logistic regression analyse identified one predictor (Educational status) for favourable PCS and two predictors (age and relationship with the child) for favourable MCS were identified.
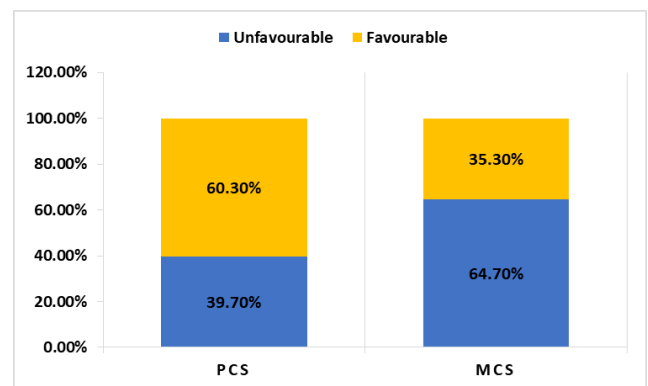

Diagram 1: Study participants according to their Physical Component Summary (PCS) score, Mental Component Summary (MCS) score (n=136)

After controlling for the predictors, the model for PCS explained between 9.5% (Cox & Snell R square) and 12.8% (Negelkerke R square) of the variance of PCS and correctly classified 64% of caregivers. There was a good fit of the model as evident from Hosmer and Lemeshow statistics (p= 0.823).

After controlling for the predictors, the model for MCS explained between 13.9% (Cox & Snell R square) and 19.1% (Negelkerke R square) of the variance of MCS and correctly classified 64.7% of caregivers. There was a good fit of the model as evident from Hosmer and Lemeshow statistics (p= 0.937) and from Omnibus test (p= 0.041).

The illiterate caregivers had statistically significant (p= 0.029) lesser Odds [AOR: 0.09 (0.01-0.78)] of having favourable PCS with reference to those having educational qualification of Higher school & above. Caregivers of age group of ≤34 years had statistically significant (p= 0.021) higher Odds [AOR: 3.11 (1.18-8.14) of having favourable MCS. Fathers had statistically significant (p= 0.030) lesser Odds [AOR: 0.05 (0.01-0.73) of having favourable MCS. These findings were similar to a study done by Ismail et al.[15] They had found, caregivers with lower educational level may be associated with poorer understanding of nature of the disease which in turn may affect the psychosocial aspects and may had poorer QOL.

Table 1: Sociodemographic characteristics of the care givers (n=136)

Variables	Number (%)
Age (in years)	
≤34	80 (58.8)
>34	56 (41.2)
Sex	
Male	15 (11)
Female	121 (89)
Educational qualification	
Illiterate	12 (8.8)
Primary school	62 (45.6)
Middle school	43 (31.6)
High school and above	19 (14)
Relationship with the child	
Mother	96 (70.6)
Father	24 (17.6)
Grandmother	11 (8.1)
Grandfather	5 (3.7)
Occupation	
Home makers	96 (70.6)
Others	40 (29.4)
Socio-economic class*	23 (16.9)
Class I & II (Upper class)	44 (32.4)
Class III (Middle class)	44 (32.4)
Class IV & V (Lower class)	69 (50.7)

*According to modified B.G. Prasad Scale (April 2019)

Table 2: Association of physical component score (PCS), Mental component score (MCS) with socio-demographic characteristics (n= 136)

Socio-demographic characteristics	PCS		MCS	
	Mean± SD	P value	Mean± SD	P value
Age				
≤34 years	54.3± 11.6	0.05	47.3± 12.3	0.05
>34 years	50.4± 11.8	t= 1.948	43.2±10.8	t= 1.980
Sex				
Male	56.3± 12.4	0.21	45.5± 13.0	0.97
Female	52.3± 11.7	t= 1.252	45.6± 11.7	t= −0.028
Educational status				
Illiterate	47.8± 11.9		43.6± 14.2	
Primary school	53.5± 12.2	0.47	46.2± 11.7	0.91
Middle school	53.4± 11.3	F= 0.841	45.3± 12.0	F= 0.174
High school & above	51.9± 11.7		45.6± 11.8	
Relationship with child				
Mother	53.5± 11.7		46.5± 12.2	
Father	50.5± 11.0	0.57	41.3± 9.8	0.17
Grandmother	49.8± 15.3	F= 0.671	44.4± 12.0	F= 1.699
Grandfather	54.2± 9.2		51.3± 9.5	
Occupation				
Home maker	53.0± 11.6	0.71	45.4± 11.0	0.72
Others	52.2± 12.6	t= 0.361	46.1± 13.7	t= −0.369
SES Class*				
Upper Class	51.5± 11.6		44.3± 11.9	
Middle Class	51.5± 12.5	0.50	44.0± 12.1	0.35
Lower Class	53.9± 11.5	F= 0.695	47.0± 11.6	F= 1.045

*SES Class- By clubbing of SES Classes according to modified B.G. Prasad Scale (April 2019), mentioned in methodology section

Table 3: Predictors of favourable Physical Component Score (PCS), Mental Component Score (MCS): Binary logistic regression(n= 136)

Variables	PCS		MCS	
	AOR (95% CI)	p value	AOR (95% CI)	p value
Age				
≤34 years	2.21 (0.97-5.03)	0.057	3.11 (1.18-8.14)	0.021*
>34 years	1	-	1	-
Sex				
Male	4.82 (0.87-26.47)	0.070	1. 92 (0.46-7.97)	0.367
Female	1	-	1	-
Educational status				
Illiterate	0.09 (0.01-0.78)	0.029*	0.20 (0.02-1.63)	0.134
Primary school	0.37 (0.07-2.05)	0.260	0.45 (0.08-2.34)	0.343
Middle school	0.48 (0.10-2.29)	0.363	0.37 (0.08-1.6)	0.200
High school & above	1	-	1	-
Relationship with child				
Mother	0.42 (0.02-6.53)	0.536	0.24 (0.02-2.7)	0.253
Father	0.38 (0.02-6.13)	0.500	0.05 (0.01-0.73)	0.030*
Grandmother	0.43 (0.02-7.43)	0.568	0.36 (0.03-4.78)	0.443
Grandfather	1	-	1	-
Occupation				
Home maker	0.98 (0.42-2.26)	0.955	0.91 (0.37-2.20)	0.826
Others	1	-	1	-
SES Class				
Upper Class	0.29 (0.06-1.39)	0.122	0.42 (0.08-2.02)	0.281
Middle Class	0.75 (0.31-1.82)	0.525	0.54 (0.20-1.42)	0.214
Lower Class	1	-	1	-

*Statistically significant p values (p< 0.05)
1=Referent
AOR: Adjusted odds ratio. CI: Confidence interval

4. Conclusion

Most of caregivers were female with educational qualification of the most of them were up to Primary school. Most of the caregivers were homemakers by occupation and most of them belonged to lower middle class. Majority of the caregivers were having unfavourable MCS. Males had better PCS than females, but for MCS both are similar. Bivariate analyses showed no statistically significant associations between QOL and socio-demographic characteristics. One predictor (Educational status) for favourable PCS and two predictors (age and relationship with the child) for favourable MCS have been identified by logistic regression.

Counselling and psychotherapy for family members of the patients with thalassaemia can be provided by health care personnel. The need of social support and community involvement should be emphasized to reduce stigma.

5. Source of Funding

None.

6. Conflict of Interest

The authors declare no conflict of interest.

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