Knowledge on thalassaemia among students aged 14-17 years in Kurunegala district, Sri Lanka

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Abstract

Introduction: Prevention and control of thalassaemia in a country needs public education to prevent marriages between carriers. Correct message has to be delivered to the community so that the public will understand the importance of prevention. Kurunegala is one of the districts in Sri Lanka where thalassaemia is highly prevalent.

Objectives: The aim of this study was to assess the knowledge on thalassaemia of school children aged 14-17 years in Kurunegala district, Sri Lanka.

Method: Descriptive cross-sectional study. Using probability proportional to size sampling technique, 55 clusters of 30 students in age range 14-17 years each, were selected from all schools in Kurunegala district. Within each selected school, the required number of children was selected randomly.

Results: Out of the 1821 participants 92.6% had heard of thalassaemia before. Majority (83.4%) of participants showed high knowledge score regarding thalassaemia. Age, gender, ethnicity and the type of school correlated with knowledge score.

Conclusions: Based on the study findings, students of Kurunegala district showed satisfactory level of knowledge regarding thalassaemia.

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Introduction

Thalassaemia is considered the most common single gene disorder worldwide occurring with high frequency from the Mediterranean basin through the Middle East, Indian subcontinent, Burma and South East Asia, and Islands of Pacific[1]. Thalassaemia and other haemoglobinopathies are a significant public health problem in 71% of 229 countries worldwide. Over 330,000 affected infants are born annually (83% sickle cell disorders, 17% thalassaemias). Haemoglobin disorders account for about 3.4% of deaths in children less than 5 years of age[2]. Globally, there are 269 million carriers of thalassaemia and 150 million β thalassaemia alone, out of which 40 million are in South East Asia[3]. About 7% of pregnant women carry β or α zero thalassaemia, or clinically significant haemoglobin, and over 1% of couples are at risk of having a thalassaemic baby[2].

In Sri Lanka, prevalence of thalassaemia is higher in Kurunegala, Anuradhapura, Trincomalee and Hambantota districts[4]. In a recent nationwide survey on hospital based thalassaemia patients, 1774 patients with thalassaemia were identified in 23 different centres in Sri Lanka. Out of them, 68.7% had β thalassaemia major and 20.3% had Hb E/β thalassaemia[5]. The management of these disorders require about 5% of the total health budget[6]. Prevention and control of thalassaemia in a country needs public education, population screening, genetic counseling and antenatal diagnosis. The incidence of severe thalassaemia has been reduced by 96% in Cyprus, 62% in Italy, and 52% in Greece with these simple measures[3,7].

In Sri Lanka, antenatal diagnostic facilities are not freely available and abortion of thalassaemic fetuses is not legalized. Therefore, the only measure to eradicate this genetic disorder is by public education and population screening. Screening individuals before marriage and advising the thalassaemia carriers to choose a non-carrier partner is the current way of prevention practised in Sri Lanka. National thalassaemia screening programme for school children and young adults (premarital screening) has been in place since 2005. School children are the future adults. It is

important to educate them on thalassaemia, to prevent marriages between carriers, and to reduce future births of thalassaemia major children in Sri Lanka.

Objectives

This study was done to assess the awareness of thalassaemia and to describe the knowledge on thalassaemia among school children aged 14-17 years in Kurunegala district, Sri Lanka.

Method

Year of study*:* 2017-2018.

Study design: Descriptive cross sectional study.

Study setting: Kurunegala district, the capital city of North Western Province, Sri Lanka.

Study population: Children within 14-17 year age group studying in schools of Kurunegala district. There are 732 schools in Kurunegala district. The total number of school children within 14-17 year age group is 69,665 (statistics of Provincial Education office, Kurunegala-2015). Total population of Kurunegala district is 1.7 million (Census 2012).

Sample size determination: Since the expected proportion is not known, in order to arrive at the maximum sample size, it was taken as 50%. When alpha error = 5%, precision of the estimate = 5%, cluster size = 30, intra-cluster correlation coefficient = 0.1, the design effect = 3.9, and the non-response rate = 10%, the required minimum sample size amounts to 1648.

Sampling technique: Using probability proportional to size sampling technique, 55 clusters of 30 students in the age range 14-17 years each, were selected from all the schools in Kurunegala district. 54 schools were sampled (Two clusters from one school and one cluster from 53 schools). Within each school, the required number of children was selected randomly. If there were less than 30 students in the age range, 14-17 years in a particular school, all the children in the required age group were included in the study.

Inclusion and exclusion criteria: School children within the age group 14-17years studying and residing in Kurunegala district were included into the study. School children within the selected age group, studying in Kurunegala district but not residing there were excluded.

Study instruments: Self-administered questionnaire.

Data collection method: Participation in this study was voluntary. The self-administered questionnaire was administered to the participants to obtain demographic data.

Ethical Issues*:* The protocol was approved by the Ethical Review Committee of Teaching Hospital, Kurunegala (ERC/2015/16-ROI). Permission for the study was taken from the Provincial Director of Education, North Western Province and all the principals of selected schools. Written informed consent was taken from parents of the students and the students as well after reading out the information sheet and answering participants' questions by the researcher. A witness (a teacher/Principal) confirmed that the individual has given the consent freely.

Statistical analysis: Sample characteristics were analysed using descriptive statistical methods, and presented as percentages or proportions depending on their scales of measurements.

Results

A total of 1821 students aged between 14-17 years was selected for the present study. Fifty five clusters were selected from 54 schools (Two clusters x one school and one cluster x 54 schools). The study group was predominantly female (59.9%). Of the participants, 57.7% were 14-15 years old. Majority (93.6%) were Sinhalese, 5.8% were Muslim, 0.4% were Tamil and 0.2% were other ethnicities. A self-administered questionnaire was administered to the participants to obtain data. The questionnaire included two parts, demographic data and questions to assess knowledge on thalassaemia (Table 1).

Table 1: Distribution of frequencies of responses for the questionnaire

Variable	Response	frequency	%
1. Have you ever heard of thalassaemia?	Yes	1687	92.6
	No	134	7.4
2. Thalassaemia is highly prevalent in Kurunegala. **(Yes)**	Yes	1295	71.1
	No	39	2.1
	Don't know	487	26.7
3. Thalassaemia is inherited from parents. **(Yes)**	Yes	1608	88.3
	No	43	2.4
	Don't know	170	9.3
4. Thalassaemia is a blood related disease. **(Yes)**	Yes	1662	91.3
	No	24	1.3
	Don't know	135	7.4
5. Severe anaemia is the clinical presentation of Thalassaemia major. **(Yes)**	Yes	559	30.7
	No	139	7.6
	Don't know	1123	61.7
6. Thalassaemia carriers are symptom free. **(Yes)**	Yes	899	49.4
	No	318	17.5
	Don't know	604	33.2
7. Thalassaemia major children need blood transfusion.**(Yes)**	Yes	1002	55.0
	No	113	6.2
	Don't know	706	38.8
8. Thalassaemia carriers need blood transfusion. **(No)**	Yes	410	22.5
	No	601	33.0
	Don't know	810	44.5
9. Thalassaemia carrier status can be diagnosed by a blood test. **(Yes)**	Yes	1758	96.5
	No	9	0.5
	Don't know	54	3.0
10. A marriage between two thalassaemia carriers has a chance of producing a thalassaemia major baby. **(Yes)**	Yes	1637	89.9
	No	37	2.0
	Don't know	147	8.1
11. A marriage between a thalassaemia carrier and a normal individual has a chance of producing a thalassaemia major baby. **(No)**	Yes	281	15.4
	No	1166	64.0
	Don't know	374	20.5
12. If one blood relative is diagnosed with thalassaemia, other family members should also be screened. **(Yes)**	Yes	1552	85.2
	No	28	1.5
	Don't know	241	13.2

The correct answer is shown within brackets.

Great majority (92.6%) of participants had heard of thalassaemia before. Majority (71.1%) correctly stated that thalassaemia is highly prevalent in Kurunegala. Majority (88.3%) knew that thalassaemia is inherited from parents. Great majority (91.3%) correctly stated that thalassaemia is a blood related disease. Only 30.7% correctly stated that severe anaemia is the clinical presentation of thalassaemia major. 49.4% knew thalassaemia carriers are symptom free. Thalassaemia major children need blood transfusion was correctly stated by 55.0%. Only 33.0% stated that thalassaemia carriers do not need blood transfusions. Great majority (96.5%) correctly stated that thalassaemia can be diagnosed by a blood test. Majority (89.9%) knew that a marriage between two thalassaemia carriers has a chance of producing a thalassaemia major baby. Majority (64.0%) stated a marriage between a thalassaemia carrier and a normal individual has no chance of producing a thalassaemia major baby. Great majority (85.2%) knew that if one blood relative is diagnosed with thalassaemia, other family members should also be screened.

Knowledge on thalassaemia was calculated into scores by adding the number of correct answers given to question 2-12. The study group was divided into two, according to the knowledge score; students with a score of less than 50% (low score) and a score of more than 50% (high score). Majority (83.4%) had a score of >50%. When these two groups were compared among the demographic data, age, gender, ethnicity and school type had significant difference ($p < 0.05$) as shown in Table 2.

Table 2: ***Distribution of sample on knowledge score by demographic data***

Variable		Knowledge score				Total	p-value
		>50%		<50%			
Age	14-15y	833	79.6%	213	20.4%	1046	p< 0.05
	16-17y	686	88.5%	89	11.5%	775	
Gender	Female	956	87.6%	135	12.4%	1091	p< 0.05
	Male	563	77.1%	167	22.9%	730	
Ethnicity	Sinhala	1439	84.4%	266	15.6%	1705	p< 0.05
	Muslim	70	66.0%	36	34.0%	106	
	Tamil	08	100%	0	0	08	
	Other	02	100%	0	0	02	
School type	Type 1	771	85.8%	128	14.1%	899	p< 0.05
	Type 2	748	81.1%	174	18.9%	922	

Schools with all 4 subject streams in grade 12 and 13 (GCE Advanced Level) were classified as "School type 1" and schools without all four subject streams in advanced level classes were classified as "School type 2".

Discussion

In the present study, the great majority of participants (92.6%) had heard of thalassaemia. This was higher than the findings of Mudiyanse *et al* (2015)[8] who did a study in Kurunegala to assess the outcome of the project of "safe marriage" and found that 80% of partners of couples that came for registration of their marriages were aware of thalassaemia. In contrast, similar studies done in neighboring countries have shown lower results. Kukreja *et al* (2009)[9] in a Malaysian study to determine awareness of thalassaemia among parents and or married couples of a rural community found that only 46.4% participants had heard of thalassaemia. In another study done among College students in Saudi Arabia, Olwi *et al* (2018)[10] found that only 48% of students had ever heard of thalassaemia. This could be due to the fact that our study was done in a district with high prevalence of thalassaemia in Sri Lanka and awareness programmes have been done in schools in Kurunegala since 2005.

In the present study the majority (83.4%) of students had high (>50%) knowledge score and 16.6% had low (<50%) knowledge scores. High level of knowledge reflects good understanding of thalassaemia among the study participants. This may show the success of awareness programmes been done in the district especially in schools and higher education institutes since 2005. Interestingly, knowledge scores between boys and girls varied significantly; in females good knowledge (score >50%) towards thalassaemia was 87.6% and in males it was 77.1% (p <0.05). This is in accordance with the findings of Basu M (2015)[11] who found that gender was one of the significant contributing factors of knowledge regarding thalassaemia.

Some other parameters also correlated with knowledge. When Sinhalese participants were compared with other ethnicities, there was a statistically significant difference with regards to knowledge (p<0.05). Age (age group 14-15 years was compared with age group 16-17 years) and school type (type 1 and type 2) also showed statistically significant differences with knowledge (p<0.05). In contrast, Pujani M *et al* (2017)[7] found that there was no effect of age, gender, region or socio-economic class on the knowledge of thalassaemia among medical students.

The findings of this study will be helpful in improving the quality of thalassaemia awareness and screening programmes done in the island. In Sri Lanka, commonly used languages in the country are Sinhala, Tamil and English. Therefore the programmes should be done in Sinhala, Tamil and English where appropriate to educate the young generation about prevention of thalassaemia. Language should not be a barrier in getting knowledge. Also, Awareness programmes should be done to cover up all the schools in the district with special attention to schools with less facilities.

Conclusions

Based on study findings, students aged 14-17 years of Kurunegala district, showed satisfactory level of knowledge regarding thalassaemia.

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References

1. Wetherall DJ, Clegg JB. The thalassaemia syndromes, 4th ed. Oxford: Blackwell Science. 2001. https://doi.org/10.1002/9780470696705

2. Rakholia R, Chaturvedi P. Prevalence of β thalassemia carrier state in Sindhi community of Wardha and evaluation of risk factors for β thalassemia trait. *Nigerian Journal of Clinical Practice* 2013; **16**: 375-80. https://doi.org/10.4103/1119-3077.113468 PMid: 23771465

3. Premawardhena A, Allen A, Piel F, Fisher C, Perera L, Rodrigo R, *et al.* The evolutionary and clinical implications of the uneven distribution of the frequency of the inherited haemoglobin variants over short geographical distances. *British Journal of Haematology* 2016; **176**(3), 475-84. https://doi.org/10.1111/bjh.14437 PMid: 27897311

4. Premawardhana AP, Mudiyanse RA, De Silva ST, Jiffry N, Nelumdeniya U, de Silva U, *et al,* Nationwide survey of hospital-based thalassemia patients and standards of care and a preliminary assessment of the national prevention program in Sri Lanka. *PLOS One* 2019; **14**(8): e0220852. https://doi.org/10.1371/journal.pone.0220852 PMid: 31419232 PMCid: PMC6697367

5. De Silva S, Fisher CA, Premawardhene A, Lamabadusuriya SP, Peto TE, Perera G, et al. Thalassaemia in Sri Lanka: implications for the future health burden of Asian populations; Sri Lanka Thalassaemia Study Group. *Lancet* 2000; **355**(9206):786-91. https://doi.org/10.1016/S0140-6736(99)08246-X

6. Dimitris L. Haemoglobinopathies in Greece: prevention programme over the past 35years. *Indian Journal of Medical Research* 2011; **134**(4): 572–6.

7. SPujani M, Chauhan V, Agarwal C, Rana D, Singh K, Dixit S. Knowledge and attitude among Indian medical students towards thalassaemia: a study in Delhi NCR. *International Journal of Research in Medical Sciences* 2017; **5**(10): 4470. https://doi.org/10.18203/23206012.ijrms20174579

8. Mudiyanse RM. Senanayake MP, Rathnayake RMS. Safe marriages for thalassaemia prevention; A KAP survey in Sri Lanka. *Translational Biomedicine* 2015: **6**(3): https://doi.org/10.21767/2172-0479.100026

9. Kukreja A, Khan A, Xian L, Razley A, Rahim Z. Awareness of thalassaemia among rural folks in Penang, Malaysia. *The Internet Journal of Health* 2009; **12**(1):

10. Olwi DI, Merdad LA, Ramadan EK. Thalassaemia: A prevalent disease yet unknown term among college students in Saudi Arabia. *Journal of Community Genetics* 2018; **9**:277–82. https://doi.org/10.1007/s12687-017-0351-3 PMid: 29238908 PMCid: PMC6002305

11. Basu M. A study on knowledge, attitude and practice about thalassaemia among general population in outpatient department at a tertiary care hospital, Kolkata. *Journal of Preventive Medicine and Holistic Health* 2015; **1**(1): 5-1