Socio-economic impact of thalassemia
A case study of Kurunegala district, Sri Lanka

Omala Perera
Department of Geography, University of Colombo, Sri Lanka
omala@geo.cmb.ac.lk

Abstract

Thalassemia that appears in two types - alpha (minor) thalassemia (without symptoms) and beta (major) thalassemia (with symptoms) - is a genetically transmitted disease where an inherited blood disorder that causes the body to have less hemoglobin than normal. The thalassemia patients' resistance against malaria has caused the disease to be concentrated in the dry zone of Sri Lanka. The Kurunegala district reports the highest of its prevalence rate in Sri Lanka. This non-medical research attempts to explore the socio-economic impact of thalassemia in the Kurunegala district. A random sample of 75 thalassemia patients (15% of the 516 registered patients reside in the Kurunegala district) were engaged in a questionnaire survey supplemented by semi-structured interviews. Further, medical practitioners and health officers were interviewed separately. The secondary data was obtained from the National Thalassemia Center, Kurunegala, and the Department of Census and Statistics, Sri Lanka. It was discovered that the disease shows a possible diffusion mainly towards the adjoining districts as observed in the migration pattern. The impact of thalassemia is suffered not only by the patients but also their families and the state. Lifelong transfusion-dependent, the thalassemia patients have no normal life, including schooling. They suffer from frustration due to the social perception of their maladies. Within a single-breadwinner household, the monthly income cannot withstand the monthly medical costs. Therefore, the paper endeavors to suggest that, to prevent the agony of the disease, the inhabitants in the thalassemia-prone districts should be subjected to a medical test on their suitability to have thalassemia-free children.

Keywords: major thalassemia, minor thalassemia, socio-economic impact, migration

1. Introduction

Hemoglobin disorders including thalassemia, are the most common genetic or hereditary disorders in the world. According to the Thalassemia International Federation (TIF) (2019), it is estimated that over 60,000 thalassemia affected children are born every year globally. Thalassemia is related to the abnormal morphology of red cells in the human blood due to the unbalanced production of

hemoglobin. There are two main types of thalassemia i.e. beta (β) or major thalassemia (those who have thalassemia symptoms) and alpha (α) or minor thalassemia or thalassemia trait (asymptomatic and act as a carrier). Both types of thalassemia may have abnormalities in red blood cells, but carriers (minor thalassemia) have no symptoms other than mild anemia (hemoglobin level: 100-119 g/l for children as per the World Health Organization (WHO), (2011). Therefore, most people having minor thalassemia may be unaware that they are carriers. Major thalassemia children are normal at birth and the symptoms can be seen after the child's third month and remain for the whole life (Ishfaq et al., 2013). They have severe anemia (hemoglobin level: below 70/80 g/l) that may first require regular blood transfusion once every three or four weeks and may have morbidity from overloaded iron as a side effect. Therefore, they need regular iron chelation therapy. Some patients may have several other diseases such as liver disorders as the side effects of treatments for thalassemia. If the thalassemia child is not treated with blood transfusion, their life would be limited to one to eight years (Ishfaq et al., 2013). Therefore, they are transfusion-dependent for the whole life and should afford the cost as well. The only treatment for thalassemia major patients is bone marrow transplantation which is costly on one hand and it is difficult to find a compatible donor on the other hand.

The main cause for thalassemia is the marriage or conception between a man and a woman who (both) got minor thalassemia. If one parent has major thalassemia, there is a 50% chance of having a major thalassemia child and another 50% for having a child with minor thalassemia (Ishfaq, 2013). The probability of having a baby with thalassemia vary according to the thalassemia trait of the parents, as shown in table 01.

Father	Mother	Probability of having a child with major thalassemia	Probability of having a child with minor thalassemia	Probability of having a normal child
Normal	Normal	0%	0%	100%
Minor thalassemia	Normal	0%	50%	50%
Normal	Minor thalassemia	0%	50%	50%
Minor thalassemia	Minor thalassemia	25%	50%	25%

Table 01: Probability for thalassemia births according to thalassemia trait of the parents
Sources: Mudiyanse, 2009; Ishfaq, 2013

De Sanctis and Yassin (2017) reveal that this is an ancient disease that has been diffused from the Mediterranean basin towards Africa, Middle East, Indian subcontinent, Southeast Asia, and Pacific Islands which is known as the thalassemia belt. But the disease prevails all around the world due to the mass human migrations. It is estimated that globally there are 80 million carriers of thalassemia and 23,000 babies are born with major thalassemia each year (De Sanctis and Yassin, 2017). According to Old et al. (2013), there are 6000 known major thalassemia patients in Italy, 3264 in Turkey, 100,000 in India, 35,000 in Thailand, and 3410 in Sri Lanka. Several factors have contributed to the current situation and the distribution pattern of thalassemia. Resistant to malaria has converged this disease into malaria-prone regions worldwide (De Sanctis and Yassin, 2017; O'Donnell et al., 2009). Consanguinity or marriage between blood relatives has resulted in the diffusion of the disease in certain regions (Premawardhena et al., 2019). Improvements in universal nutrition and reduction of infections have reduced the mortality. Social and cultural challenges on premarital screening, impact on thalassemia birth rates. Mass migration of the carriers has underpinned the diffusion of the disease towards new regions such as Europe. Prevention strategies in countries such as Iran, Italy, Cyprus, and Greece have an impact in decreasing major thalassemia births substantially (De Sanctis and Yassin, 2017).

As it was identified by O'Donnell et al. (2009), thalassemia is resistant to malaria which was a common catastrophe before the launch of the Malaria Prevention Project in the 1940s in Sri Lanka. Therefore, those who survived the malaria epidemic most probably could be thalassemia carriers from generation to generation. Thus, more thalassemia carriers and patients can be expected areas in the dry zone where malaria existed in Sri Lanka. At the end of 2017, there were 1063 total major thalassemia patients registered in the National Thalassemia Centre (NTC) with an annual average of 44 new patients. The main focus of the present study is the Kurunegala district where the highest number of patients (516) are living in. Kurunegala is reported as the third largest district in terms of population (1,618,465) and contributes for 7.9% of the population in Sri Lanka (Department of Census and Statistics (DCS),2012). It is situated in the North-Western province and belongs to dry and intermediate climatic zones. Despite the prevalence of thalassemia is expected in the malaria-prone dry zone, it has spread even to the wet zone. Therefore, not only the biological or medical attributes but also social attributes including migration patterns should be considered in preventing this fatal disease.

Several studies (Ebeid and Khan, 2020; Premawardhena et al., 2019; Kularatne, 2017; Sananayake, 2011; O'Donnell et al., 2009; Mudiyanse, 2009) have been carried out mainly to investigate the causes and health effects of thalassemia in the context of Sri Lanka. Mudiyanse (2009) has predicted that there would be 160 thalassemia risk marriages between two carriers out of 150,000 marriages in Sri Lanka per year. Old et al. (2013) estimated that there are 64 births with major thalassemia syndromes per year in Sri Lanka, with 2.2% of thalassemia carries in the population (nearly 500,000 carriers according to Mudiyanse, 2009).

Thalassemia patients are transfusion-dependent and require treatments for secondary disorders throughout their average life span of 20 years (Mudiyanse, 2009). This fatal disease affects not only the patient but also their families bringing many socio-economic and psycho effects. Ishfaq et al. (2013) identified the cost of thalassemia treatment and social problems faced by the parents in the context of Pakistan. Sharma et al. (2017) have studied the quality of life of patients in India. Gharaibeh et al. (2009) reveal the psychological burden of patients in Syria. The present study attempts to explore the impact of thalassemia in the context of Sri Lankan socio-economic background within a non-medical approach on thalassemia. Social aspects were taken into consideration in suggesting preventing measures.

2. Objective

The objective of this study is to identify the socio-economic impact of major thalassemia patients and their families.

3. Methodology

Secondary data were obtained from DCS (2012) and the NTC (2018). Registered patients living in other districts were excluded. Representing a 15% sample, 75 major thalassemia patients were involved in the questionnaire survey following a simple random sampling method. The meeting point of the respondents was the thalassemia clinic in Kurunegala General Hospital. If the patient was below 15 years of age, the assistance of the parent or guardian of the patient was requested. Also, information obtained from two medical practitioners, three nursing officers, and ten parents and guardians of the patients through informal interviews was supplemented. Information about the residence, family history, income and expenses, education, and social life were included in the questionnaire while the interviews covered the issues related to the disease, treatments, and prevention strategies. The study employs a descriptive approach.

There were several limitations in this study. The main limitation is that all the thalassemia patients might not have been registered in the NTC or have been registered in other regional thalassemia centers. Some patients may not be registered anywhere at all. Due to the ethical concern of the research, sensitive questions regarding the illness (e.g., death, mental situation, and life expectancy) were avoided. The patients were involved in the research voluntarily and no one was forced to participate.

4. Results

The number of all patients registered annually at NTC from 2003 to 2017 was fluctuating with the highest number of patients (77) in 2011. The trend line, however, shows a gradual decline of registered patients. The highest number of patients (516, 62.5%) was reported from the Kurunegala district. Other patients were reported from 17 districts including Anuradhapura (100), Matale (63), Puttalam (53), Kegalle (31), Kandy (18), and Gampaha (18) (NTC,2018). The highest concentration of major thalassemia patients was reported from Ibbagamuwa (45) and Polpithigama (45) Divisional Secretariat divisions (DSDs) followed by Kurunegala (30) and Nikaweratiya DSDs (30). The average number of patients per DSD was 17.2.

The sample consisted of 31 males (41%) and 44 females (59%). They were from 2 years to 32 years of age. The median age for female patients was 12.5 years and 17.5 for male patients. The patients were living in their father's native village (55%) or mother's native village (12%) and sometimes both parents were descendants from the same village (33%). All the respondent patients were unmarried. The percentage of the parents who had passed the Ordinary Level examination was 73. Twenty-five percent of the parents have done Advanced Level and 2% have obtained a degree. None of the parents had an education level below grade six. It could be revealed that 59% of the families earn less than Rs. 35000 per month. The majority (47%) of the patients spend 20% to 29% of the monthly family (father's) income for the medical expenses. Another 34% of them spend 10% to 19%. Fifty-four percent of the patients were having treatments for secondary illnesses.

The number of patients who were of school age was 32. Only 10 % of the patients of school age were able to manage their studies while only 5% of them had a normal life with normal care in school. Others have either felt intolerable due to over-care of the teachers (68%) or kept their illness as a secret (27%) expecting a normal life at school. Most of the patients (88%) attend social and cultural gatherings while 38% of them feel uncomfortable at such gatherings. The patient is the only child in 42%

of the families. The total number of family members of the patients was 297 out of which 57.6% (171) including the parents, were positive for thalassemia minor. Another 6.4% of the family members were not aware (or not been tested) whether they are thalassemia carriers or not.

Population in Kurunegala, including thalassemia patients and carriers, migrate to other districts, mainly to Gampaha (23.9% of total out-migration), Puttalam (15.5%), and Anuradhapura (12.9%). Marriage was the main reason (42%) for migration (DCS, 2012).

5. Discussion and Conclusion

Present distribution pattern of thalassemia patients

If the number of cases reported to the regional thalassemia centers is added, thalassemia major patients would be higher than the given numbers. However, a slight decrease in annual patients can be expected according to the trend line shown in figure 01.

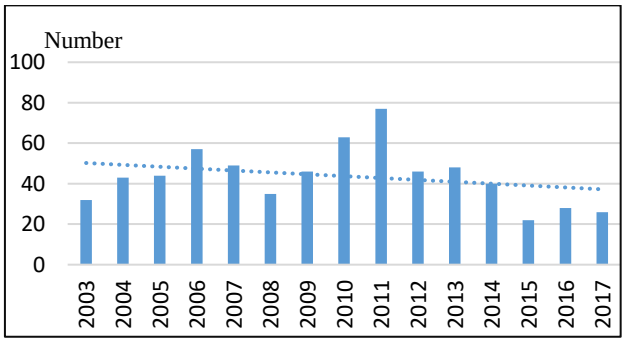

Figure 01: Major thalassemia patients registered at NTC, Kurunegala (2003-2017)
[Data Source: NTC, Kurunegala (2018)]

The diffusion of the disease is more significant in Puttalam, Anuradhapura, Matale, Kandy, Kegalle, and Gampaha districts which are adjacent to Kurunegala. Also, patients were reported from Trincomalee, Polonnaruwa, Colombo, Ampara. Mannar, Rathnapura, Kalutara, Vavunia, Nuwaraeliya, Moneragala and Hambantota districts (NTC, 2018). It is noteworthy that thalassemia has become a widely spread disease in many districts including malaria-free districts in the wet zone. Therefore, prevention of the disease would not be successful unless the prevention measures are expanded to other districts as well.

5.2 Socio-economic background of the patients and their families

The oldest patient in the sample was 32 years old showing higher mortality among the patients. Figure 02 shows the gender and age distribution of the patients in the sample.

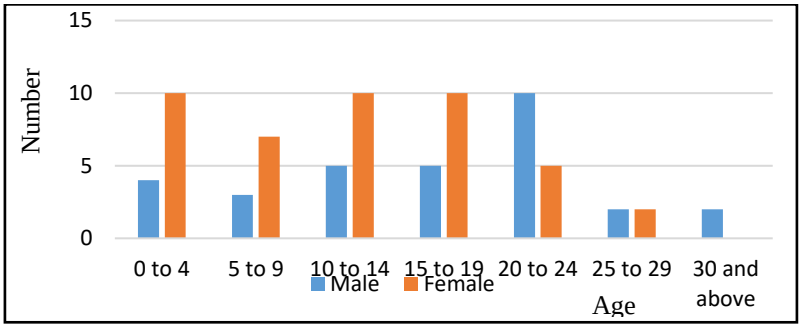

Figure 02: Gender and age of the patients in the sample

Thus, the life span of the thalassemia patients is much lower than an average person in Sri Lanka (median age in Sri Lanka is 31.1 years and life expectancy is 76 years: DCS, 2012).

There was no significant link between parents' education level and the thalassemia children since the distribution is similar to the average level of education in the country. Thirty-three percent of the parents were from the same village and there will be a possibility for them to be blood relatives. Premawardhena et al., (2019) have revealed that 14.5% of major thalassemia patients were born to consanguineous (married with blood relatives) parents in Sri Lanka. The rate of consanguineous marriages in the Kurunegala district was reported as 4.8% of the total annual marriages. Therefore, a family unit consisting of two thalassemia carriers is mostly predictable in such marriages.

Father is the breadwinner of the family of all 75 patients since the mother is obliged to spend her time to take care of the sick child or children. The patients over 18 years are also unemployed and receive no income. Table 02 shows the income distribution of the families.

Income (LKR)	Number	Percentage
Below 25,000	8	11
25,000- 35,000	36	48
35,000- 45,000	15	20
45,000 -55,000	12	16
Above 55,000	4	5

Table 02: Monthly income of the family of the patient

5.3 Economic burden of major thalassemia patients

Although the parents spend an additional amount for the treatments and other necessities of the sick children there is no opportunity for the mother to engage in earning. Mother is compelled to be unemployed spending the whole time of the day taking care of the sick child or children. Table 03 shows the share of monthly health care expenses as a percentage of the father's income.

Monthly health cost as a share of income	No. of patients	Percentage
Below 10%	2	3
10-19 %	26	34
20-29%	35	47
Above 30%	12	16

Table 03: Share of health care expenses as a percentage of father's monthly income.

Sixty-three percent of the parents spend more than 20% of the income on the sick child/children's needs. The family expenses are directly linked with the sickness including traveling to Kurunegala hospital once or twice a month, buying iron chelation machines, and having bone marrow surgeries. On average, a parent spends Rs. 1500-2000 for one visit to the hospital for blood transfusion. Iron chelation machine (to remove overloaded iron from the patient's body that was deposited because of the frequent blood transfusion) costs around Rs. 16000 (local product) or around Rs. 55000 (imported product). Particularly if the patient is required to do a bone marrow transplant, they need to spend around six million to eight million rupees although the result is uncertain. The father of a patient said that he spent additional three million rupees due to a post-surgery infection. Although the medicines are supplied at the cost of the government, the parents are required to buy some prescribed medicines at their cost as well. Also, they spend on treatments for secondary illnesses. Break of bones, abnormal appearance, abnormalities of hands and legs, neural disorders, abnormalities in the shape of the head, allergies, diabetes, cirrhosis, abnormal heartbeat, and infections including hepatitis are the common health problems of the patients. Patients need more suitable modes of transportation and other facilities than normal people need to spend a normal life. If the needs cannot be fulfilled through monthly income, they might have to borrow money from someone else. It was revealed that 47% of the parents are always under debt due to the inability to afford the expenses of sick children. Thus, major thalassemia has become a burden to families with sick children. The government expenditure on

major thalassemia patients is also substantial. According to Mudiyanse (2009), the state spends between LKR 100,000 and LKR 300,000 per year per patient (recent data are not available) and therefore, a burden to the country.

5.4 Social burden of thalassemia patients and families

Thalassemia patients and their family members face various societal difficulties in their day-to-day life including schooling, marriage and having children. The patients always live with the uncertainty of life and therefore their social interactions are very complex. Fifty-seven percent of the patients in the school-age were not attending school while the other 43% attending school amidst their sickness. One of the hurting feelings experienced by 68% of these sick school children was, overly caring by school teachers and friends. Another 27% of the patients in the school-age had kept their sickness as a secret and never let the others know about it. This reveals that showing over sympathy towards the patients makes the patients uncomfortable. On the other hand, 70% of these students drop the opportunity to obtain school education regularly due to frequent treatments including blood transfusion.

Attending social gatherings such as weddings and other get-togethers has also become a burden to these patients. While 88% of the patients attend such events, 12% of them avoid the gatherings since they prefer not to meet relatives and friends in such gatherings. Although they like to attend social gatherings, 38% of them revealed that they feel uncomfortable when others question how they are doing. For instance, they feel miserable when the others (relatives) ask '*are you doing well now*?' knowing this is not a curable disease. Those who keep their sickness as a secret (21%) responded that they face no problem in such gatherings. Fear of death, disappointments, the uncertainty of life, and disgust had thrown down their dignity. However, it was observed that the patients pretend that they are doing well.

If the first child is affected, the parents tend to avoid the birth of a second child. As a result, 42% of the patients are the only child in the family. Another 41% have two children and 17% have three. There were six cases that all the children are thalassemia infected. Misunderstanding regarding the genetic inheritance of the disease creates social disrupts within this patriarchal society. The mother of the family is often accused by the other relatives, especially by the in-laws, of giving birth to a thalassemia infected child, although the father is also definitely responsible for being a carrier. Similarly, this disease is also regarded as a disease coming through the circle of rebirths (*sansara*). Siblings of the patients (normal or carriers) were also victimized by social perceptions regarding the disease. Although they are neither major thalassemia patients nor thalassemia carriers, they are often refused by

the common society in marriages. Eventually, siblings of the patients who are completely free from the disease are reported to be unmarried. This can also be considered as a social burden of thalassemia.

As revealed by a medical practitioner at NTC, the couples, both positive for minor thalassemia agree either to separate themselves or not to reproduce children during the premarital counseling sessions. But after some time, they appear in the NTC clinic with a thalassemia baby. Since the public does not take this matter seriously even if they are well aware, they reproduce a burden not only to the government and the society but also to themselves.

5.5 Circulation of thalassemia patients and carriers

Prevention and awareness programs for thalassemia in Sri Lanka have been mostly focused on the Kurunegala district due to the highest prevalence. But the disease is not limited to Kurunegala or dry zone. The situation would be worsened unless the migration pattern of thalassemia patients and carriers (10:1 of the population) from Kurunegala is not considered. Similarly, migration from other districts (especially from the dry zone) to Kurunegala should also be considered. The out-migration pattern from the Kurunegala district to other districts, therefore, is very crucial in this regard. The largest out-migration flow from Kurunegala was reported to Gampaha, Puttalam, and Anuradhapura districts (Table 04). Kurunegala contributes to the largest migration flow to Puttalam and Anuradhapura and the second-largest migration flow to Gampaha, Matale, and Kegalle.

District	Share of out-migration from Kurunegala district (%)
Gampaha	23.9
Puttalam	15.5
Anuradhapura	12.9
Other districts	47.7

Table 04: Out-migration from Kurunegala district in percentages (2012)
[Source: Department of Census and Statistics, 2012]

Table 05 shows the share of in-migration from Kurunegala to the adjoining districts.

District	Share of in-migration from Kurunegala (%)
Puttalam	27.7
Anuradhapura	18.6
Gampaha	9.9
Matale	12.7
Kegalle	14.3

Table 05: Share of in-migration from Kurunegala district to adjoining districts (2012)
[Source: Department of Census and Statistics, 2012]

There may be thalassemia patients and carriers in this volume of migrants. It would increase the vulnerability since thalassemia patients and carriers are already living in these five districts, especially in Kegalle. Marriage was the main reason (45.6%) for migration to the Kurunegala district similar to the pattern in the other districts as well. But the exchange of people between Kurunegala and other districts, mainly because of marriage, cannot be ignored in the attempt of preventing thalassemia in Sri Lanka.

5.6 Suggestions

Public awareness: Thalassemia prevention strategies including awareness programs for young couples have been already implemented through NTC and other regional health institutions. But awareness of thalassemia among the young couples in Sri Lanka was found as 31% in Premawardhena et al. (2019). One of the patients burst her feelings into words saying, "*if the government needs to prevent thalassemia, someone should bring all the patients to one spot and shoot and kill them*". But prevention is possible by avoiding a conception between two carriers. Proper awareness regarding the disease would eradicate not only the transmission of the disease from generation to generation but also the myths regarding the disease. Those who have minor thalassemia may prefer to hide the truth since it would be a problem for their lives. It is essential to implement awareness programs at the school level since premarital counseling is insufficient.

Avoiding thalassemia births: There is less opportunity for a major thalassemia patient to have a child since they do not enter a marriage life within their short life span. The main cause of the disease is the conception of a new life by a couple who are inherited minor thalassemia. A simple prenatal blood test to diagnose minor thalassemia is the main and most effective action to prevent major thalassemia. If a couple can ensure that at least one of them is not a thalassemia carrier, thalassemia would be prevented forever or at least can reduce the birth rate of such children to a considerable level. Lessons from countries like Iran can be applied. Producing a medical assurance for a thalassemia-free marriage should be legitimized. Further, marriages between blood relatives which exist as a tradition in some countries like Sri Lanka should also be limited.

There will be some other measures to prevent thalassemia births, but the implementation is questionable. One is to allow an abortion if the risk of having a major thalassemia baby is diagnosed in prenatal testing, as followed in some countries. Other medical technologies such as artificial insemination and gene

therapy can be practiced to avoid new thalassemia births. But the cost and technology would be an obstacle for people in developing countries.

5.7 Conclusion

Thalassemia is a genetically transmitted disease that causes many socio-economic issues to the patients themselves, their families, and the community. As a tip of an iceberg, major thalassemia patients are exposed to the community but the hidden majority with minor thalassemia is the cause of the diffusion of the disease. It is a widely spread disease in the entire country. The highest number of patients was reported from the Kurunegala district with a diffusion mainly in the adjacent districts. There is a slight decrease of reported major thalassemia patients during 2003 and 2017. They have a shorter life span than the average. Major thalassemia patients, who are blood transfusion-dependent, come across with economic burdens due to the high cost of treatments. A considerable share of the father's income is allocated for health care expenses. Continuing school education is also a problem. They spend life with disappointment and no self-dignity. There are some myths regarding the inheritance of the disease. Approximately 10% of the population in the Kurunegala district can be thalassemia carriers and the migration factor should be considered in the preventing measures. Island-wide school-level awareness programs, pre-marital or prenatal testing, and legitimizing pre-marital tests would be effective in reducing the new births of major thalassemia.

References

De Sanctis, V., & Yassin, M.A. (2017). β-thalassemia distribution in the old world: a historical standpoint of an ancient disease. DOI: 10.4084/mjhid.2017.018

Ebeid, F.S.D., & Khan, N.I.H (2020). The adverse impact of thalassemia major on adolescents' oral health-related quality of life. DOI**:** https://doi.org/10.1097/MPH.0000000000001729

Gharaibeh, H., Amarneh, B.H., & Zamzam, S.Z. (2009). The psychological burden of patients with beta thalassemia major in Syria. https://doi.org/10.1111/j.1442-200X.2009.02833.x

Ishfaq, K., Naeem, S.B., & Ali, J. (2013). Socio-economic factors of thalassemia major on patients' families: a case study of the children's hospital and the institute of child health Multan, Pakistan. https://www.researchgate.net/publication/289355323_Socio-Economic_Factors_of_Thalassemia_Major_on_Patients'_Families_A_case_study_of_the_Children's_Hospital_the_Institute_of_Child_Health_Multan

Kularatne, W.N., Jayasinghe, R.M., Diyunugala, M.C., Bandara, D., Abeysundara, S., & Perera, I. (2017). Sociodemographic profile and oral health status of thalassemic patients

attending the National Thalassemia Centre, Kurunegala, Sri Lanka. DOI: 10.1111/jicd.12293

Mudiyanse, R. M. (2009). Thalassemia rogaya ha eya valakva genima. Thalassemia Prevention Project, North Western Province Health Director office, Kurunegala

O'Donnell, A., Premawardhena, A., Arambepola, M., Samaranayake, R., Allen, S.J., Peto, T.E., Fisher, C.A., Cook, J., Corran, P.H., Olivieri, N.F., & Weatherall, D.J. (2009). Interaction of Malaria with a common form of severe thalassemia in an Asian population. Proceedings of the National Academy of Sciences of the United States of America. Volume 106. https://www.ncbi.nlm.nih.gov/pubmed/19841268

Old, J., Angastiniotis, M., Eleftheriou, A., Galanello, R., Cornelis L., Harteveld, C.L., Petrou, M., & Traeger-Synodinos, J. (2013). Prevention of thalassaemias and other haemoglobin disorders volume 1: Principles. TFI. https://thalassaemia.org.cy/wp-content/uploads/2019/08/PreventionVol1_English.pdf

Premawardhena, A.P., De Silva, S.T., Goonatilleke, M.D.D.C., Ediriweera, D.S., Mettananda, S., Rodrigo, B.K.R.P., Allen, A., & Weatherall, D.J. (2019). Marriage patterns in Sri Lanka and the prevalence of parental consanguinity in patients with β-thalassaemia: a cross-sectional descriptive analysis. Journal of Biosocial Science. https://doi.org/10.1017/S0021932019000658

Riaz, H., Riaz, T., Khan, M.U., Aziz, S., Ullah, F., Rehman, A., Zafar, Q., & Kazi, A.N. (2011). Serum ferritin levels, socio-demographic factors and desferrioxamine therapy in multi-transfused thalassemia major patients at a government tertiary care hospital of Karachi, Pakistan. https://doi.org/10.1186/1756-0500-4-287

Senanayake, Manori. (2011). Thalassemiawa gena danuwathwemu. Borella: Wijesuriya Grantha Kendraya.

Sharma, S., Seth, B., Jawade, P., Ingale, M., & Setia, M.S. (2017). Quality of life in children with thalassemia and their caregivers in India.
https://link.springer.com/article/10.1007%2Fs12098-016-2267-z

Thalassaemia Federation International (TFI) Booklet. (2019).
https://thalassaemia.org.cy/wp-content/uploads/2019/11/Preventiondiagnosis-of-Hbpathies_BOOKLETNEW-1.pdf

World Health Organization. (2006). Resolution on Thalassaemia and other haemoglobinopathies.
http://www.emro.who.int/images/stories/ncd/documents/b118_r1-en1.pdf

World Health Organization. (2011). Haemoglobin concentrations for the diagnosis of anaemia and assessment of severity. Vitamin and Mineral Nutrition Information System. Geneva, World Health Organization. http://www.who.int/vmnis/indicators/haemoglobin.pdf