GIS Based Thalassemia Disease Database System for Prevention

By

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M.Sc. **2014**

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5998MD2012042

MSC/GR/2012044

Thesis submitted to the University of Sri Jayewardenepura for the Award of the Degree of Master of Science in Geographic Information Systems and Remote Sensing

15th June 2014

DECLARATION

The work described in this thesis was carried out by me under the supervision of Dr. Dilantha Dharmagunawardene and Mr. H. M. Prabath Jayantha and a report on this has not been submitted in whole or in part to any university or any other institution for another degree/Diploma.

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DECLARATION

We certify that the above statement made by the candidate is true and that this thesis is suitable for submission to the university for the purpose of evaluation.

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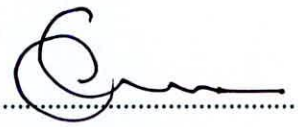

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Abbreviation

USD	-	United State Dollar
GIS	-	Geographical Information System
CBC	-	Completed Blood Count
MCV	-	Mean Corpuscular Volume
MCH	-	Mean Corpuscular Hemoglobin
HPLC	-	High Pressure Liquid Chromatography
GN	-	Grama Niladhari
DSD	-	District Secretariat Division

ACKNOWLEDGEMENT

I wish to place on record my acknowledgement to all those individuals who extended their support and guidance in compiling this report successfully.

First and foremost my sincere appreciation goes out to Dr. Milan who is the in-charge of National Thalassemia Center of Kurunegala teaching Hospital for sharing their wealth of knowledge with me. Who in turn, enhanced my knowledge regarding in this research area. As well as, all GaramaNiladhari Officers in Nikaweratiya Division, volunteers in Sri Lanka Red Cross Society and community Police officers are very much appreciated in connection with gathering data for this research.

I also owe to my academic supervisor, Dr. Dilantha Dharmagunawardene and Mr. Prabhath Malavige who gave the guidelines to prepare this report and as well to the course coordinator. Last but not least I owe a special word of thanks to my family for the support given to me to spare my time to complete this tour of study.

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ABSTRACT

Thalassemia is a gene based inherited disease. Main objective of this research was to develop a web page which shows geographical distribution of thalassemia patients in the Nikaweratiya Division and to present information about how to prevent from thalassemia. From each 30 Grama Niladhari division, data was gathered for analysis by volunteers. Data analyzing was done by using GIS technology, bar charts and pie charts. Afterwards, mapping was done to identify the mostly populated areas of thalassemia patients.

According to the results of the study, Nikaweratiya DSD can be identified as the mostly affected area for thalassemia. So, it indicates to provide solutions and awareness programs in that area to control the thalassemia distribution.

The webpage helps to get help from the worldwide donors / funding agencies to support them. Locally it will help to organize blood donation campaigns to provide required blood groups and to provide required assistance for them.

CHAPTER ONE

INTRODUCTION

1.1 Introduction

Thalassemia is a gene-based hereditary disease which causes anemia or red blood cell shortage that has originated in the Mediterranean region. People with thalassemia make less hemoglobin and have fewer circulating red blood cells than normal, which results in mild or severe anemia. Thalassemia will be present as microcytic anemia where red cells become smaller than normal in addition to the shortage. Since Thalassemia is the name of a group of genetic blood disorders, to understand how thalassemia affects the human body, one must first understand how blood is made.

Hemoglobin is the oxygen-carrying component of the red blood cells. It consists of two different proteins, an alpha and a beta. If the body doesn't produce enough (reduced or absent production) of either of these two proteins, efficient and adequate production of quality red blood cells will not be done. Ordinary healthy red blood cells have a life of 120 days. But the red blood cells of a thalassemia patient have a shorter life. It is caused by the untimely breakdown of red blood cells due to this hereditary abnormality.

The result is anemia that begins in early childhood and lasts throughout the life. Since thalassemia is not a single disorder but a group of related disorders that affect the human body in similar ways, it is important to understand the differences between the various types of thalassemia. They are,

- Alpha (α) thalassemias
- Beta (β) thalassemia
- Delta (δ) thalassemia
- Combination with other hemoglobinopathies

The thalassemias, including alpha and beta thalassemia, are the most common monogenic diseases in humans. Thalassemia was first recognized as a disorder by

researchers in the United States and Italy, in 1925 (Weatherall, 2004). The name of the disease was coined by George Whipple and is derived from the Greek words meaning "sea" and "blood" due to the mistaken notion that the disease was restricted to individuals of Mediterranean origin (Weatherall, 2004). Over the years, however, it became apparent that the disease was equally, if not more prevalent, in many parts of the world.

The thalassemia is a group of inherited disorders of hemoglobin, first reported independently from the United States and Italy in 1925. The word 'thalassemia', derived from Greek roots for 'the sea' and 'blood', was invented under the mistaken belief that these disorders were confined to the Mediterranean region. It was only later that it was discovered that they are the commonest genetic disorders and have a widespread distribution in many countries of the world. Thalassemia affects men and women equally and occurs in approximately 4.4 of every 10,000 live births. About 5% of the world's population has a globin variant, but only 1.7% has α- or β-thalassemia trait. Thalassemia trait affects 5-30% of people in these ethnic groups. Globally, an estimated 15 million people have How Thalassemia is expanded at world level is demonstrated by below Figure 1.1.

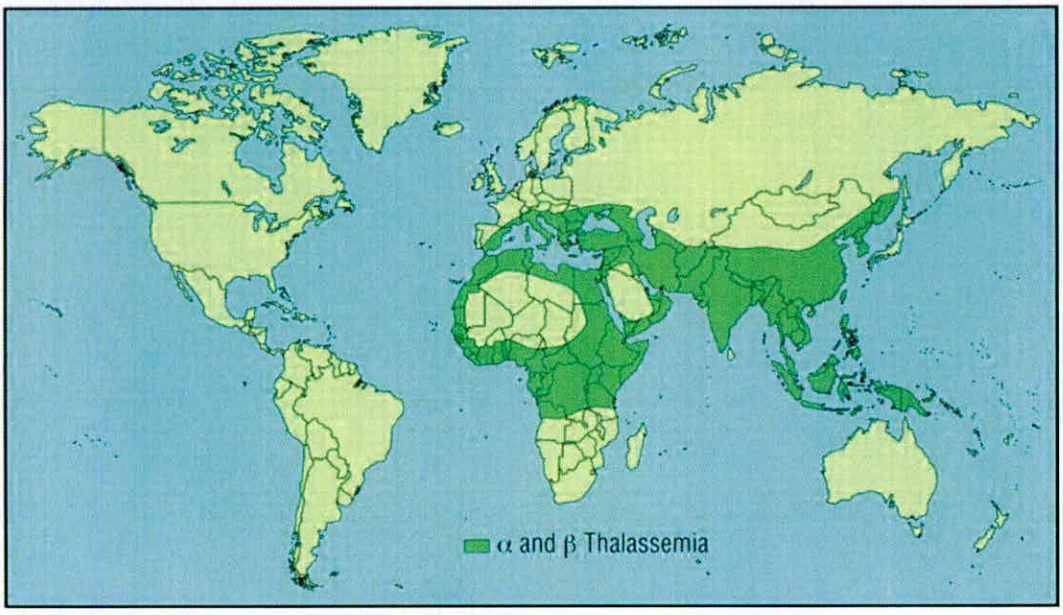

Figure 1.1: Distribution of Thalassemia in the world.

The thalassemia was among the first diseases to be characterized at the molecular level, work that provided some indications of the repertoire of mutations that underlie human genetic disease. This led to a better understanding of their clinical features and now much can be done to prevent and treat these conditions. This is important because, with improving socioeconomic conditions in many of the developing countries in which they are common, these diseases will pose a major public health problem in the new millennium

The β-thalassemia, including the hemoglobin E disorders, are not only common in the Mediterranean region, South-East Asia, the Indian subcontinent and the Middle East but have now become a global problem, spreading to much of Europe, the Americas and Australia owing to migration of people from these regions. Approximately 1.5% of the global population is heterozygote or carriers of the β-thalassemia.

While the overall frequencies of carriers of these disorders are known in most countries, there have been few attempts at micro-mapping and wherever this has been done, significant variations are seen even within small geographic regions. Thus, the figures for the estimated numbers of births each year of homozygous β-thalassemia and the severe compound states involving other hemoglobin disorders may be an underestimate. Screening strategies have varied from premarital to antenatal in different countries depending on socio-cultural and religious customs in different populations. Prenatal diagnosis programs are ongoing in many countries and the knowledge of the distribution of mutations has facilitated the establishment of successful control programs. Many of these were through North-South partnerships and networking. Yet, there are many countries in Asia where they are lacking, and South-South partnerships are now being developed in South-East Asia and the Indian subcontinent to link centers with expertise to centers where expertise needs to be developed. Although the carrier frequencies will remain unaltered, this will eventually help to bring down the burden of the birth of affected children with β-thalassemia and hemoglobin E disorders in Asia.

1.2. Research Problem

According to explanation in the background of the study, prominent issues are expanding of thalassemia patients mainly in the Kurunegala district. This will shorter the lifetime of thalassemia patients. So, it is important to identify the distribution and help them to live long period of time. In order to overcome the effects of thalassemia in Sri Lankan Society two perspectives should be considered. One is to ensure the long life time for existing thalassemia patients by giving friendly and effective medical treatment. It is the main reason to have shorter life span for Sri Lankan thalassemia patients than patients in other countries.

Even though thalassemia cannot be cured it will not make a much of interruption to lead a normal life for patients. In first, this impression should be inculcated in patients and their family members' minds. In Cyprus, The lives of Cypriots with beta thalassemia have changed over the years. Improved health care during the last several decades has increased life expectancy for those with beta thalassemia from three or four years to almost thirty. These extended life expectations, however, have come with a hefty cost to this Mediterranean nation. They have placed enormous demands on care-giving institutions, for example, resulting in crisis proportions in terms of shortage of blood for transfusions. They have contributed to rise in medical costs, threatening the very existence of the entire health care system of Cyprus.

It is important to consider how the other countries including Cyprus in establishing proper effective system to deal with thalassemia patients. Few institutions in Sri Lanka are engaged in comprehensive thalassemia management activities. They are Sri Lanka's National Thalassemia Center – Kurunegala and Thalassemia unit of Medical Faculty, University of Kelaniya. From national thalassemia centre perspective, they have two burning issues in treating to thalassemia patients. To do regular blood transfusion, it is required to have more than 650 pints of blood & 70,000 USD worth of Desferrioxamine monthly. Iron chelating is done with a machine, which costs 470 USD per each patient.Management of thalassemia patients in Sri Lanka is a major health care burden due to the high financial cost of treatment. Cost of care for thalassemia is 5% of the national health care budget. The World Health Organization has estimated that an

annual average consumption of 27 units of blood and Sri Lankan Rupees 400,000 worth of the drug are needed to manage each patient according to recommended standards. However, despite high expenditure, high morbidity and limited life expectancy of thalassemia patients in Sri Lanka are a concern. It can be argued that since the cost associated with establishing and maintaining this much of complex health system will not be affordable for a country like us.

Therefore, the most appropriate strategy is to eradicate the possibility of occurrence of thalassemia. Thalassemia can be afflicted only by the child born out of the sexual union of two male and female parents both of whom are carriers of thalassemia. Therefore it is essential to educate the general public about the nature of this disease to prevent such risky marriages. Education is offered in countries in which premarital thalassemia carrier screening is mandatory, such as Iran. Even though people are unable to make their own decision about whether to undergo testing, it is believed that they should still be informed about the test that they must undergo.

In Iran, classes on thalassemia are conducted in high schools and are also conducted for young men in the military. Public education has also been carried out in Iran through mass media, annual public education programmes and information booklets written by the Youth Thalassemia Group. The main factors that can lead to a reduction in disease incidence is an increase in the uptake of prenatal diagnosis and use of reproductive technologies to prevent the births of affected children, as well as a decrease in marriages between carriers. A premarital screening programme began in Cyprus in 1973 and the number of affected births decreased from 51 in 1974 to 8 in 1979.The incidence continued to decrease after the screening programme further developed into a mandatory screening programme in the early 1980s, with only five affected births occurring between 1991 and 2001 and no affected births occurring between 2002 and 2007.Before carrier screening began in Cyprus, difficulties were experienced in obtaining enough blood supply for the treatment of all affected individuals and this would have become a larger problem if the incidence continued to rise. This decrease in incidence has benefitted those affected with thalassemia, as the demand for blood has decreased; therefore improving the supply of treatment in Cyprus.