Brief Report

Redesigning Thalassemia Prevention Program in Northwestern Province, Sri Lanka: A Regional Experience

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Abstract

Thalassemia is an inherited blood disorder that causes significant public health challenges in Sri Lanka, contributing to a substantial burden on healthcare systems and impacting the lives of the affected individuals and their families. Kurunegala has the highest burden of thalassemia compared with other regions of the country. Despite its prevalence and impact, thalassemia has historically received limited attention in public health policy. This article aims to shed light on the reworked thalassemia prevention program in the northwestern province (NWP) of Sri Lanka, a hands-on experience with a specific focus on screening initiatives targeting school children in grade 10 and above, as well as youth populations. The prevention programs outlined in this article encompass a spectrum of interventions, including advocacy, partnership, community empowerment, health system strengthening, carrier detection by screening, and counselling. Additionally, this article explores the establishment of a comprehensive data surveillance system to track and monitor thalassemia screening programs within the province. Screening programs commenced in 15 schools in six Medical Officers of Health areas in Kurunegala District, testing 4030 students for thalassemia. Results revealed that 10.9 % (n= 438) of the sample exhibited iron deficiency anemia, while 3.8% (n=40) were identified as carriers of β-thalassemia, E, D, and H thalassaemia.

Keywords: Screening; Strategies; Thalassaemia Carriers; Prevention

Background

Thalassemia is an inherited blood disorder characterized by reduced hemoglobin synthesis. It leads to anemia and severe complications, such as β-thalassemia major, which often requires regular blood transfusions and results in high mortality and morbidity [1]. The primary cause of major thalassemia is conception between two carriers, with a 25% chance of having a child with thalassemia major if both parents carry the trait [2]. Globally, 40,000 babies are born annually with thalassemia [3]. In Sri Lanka, more than 3,000 diagnosed patients account for 5% of the national health budget [4][5]. A study in Kurunegala district revealed a β-thalassemia trait prevalence of 5.7% among students aged 14–17 years, exacerbated by cultural practices such as consanguineous marriages [6]. Despite the small number of patients, the economic burden is significant, and families face catastrophic costs [7]. Community screening and awareness are cost-effective interventions that enable early detection and informed reproductive decisions, which are critical for reducing the prevalence of this condition and preventing its transmission to future generations [8].

Thalassemia imposes a significant public health challenge in Northwestern Province, with Kurunegala shouldering the greatest burden. The district has the highest prevalence of thalassemia major in Sri Lanka, surpassing other regions of the country [9]. The National

Thalassemia Center (NTC) at the Teaching Hospital, Kurunegala (THK), showed that 1275 thalassaemia major patients were already under their care, with 861 receiving active treatment. However, there is a lack of literature or a proper database indicating the prevalence of thalassemia traits in Kurunegala, primarily due to the absence of a comprehensive surveillance system in the province.

The high prevalence of thalassemia carriers in the province [3] necessitates a proactive and comprehensive approach to address this issue, leading to the establishment of a thalassemia screening program. Since 2017, the Provincial Department of Health Services (PDHS) has conducted a screening program for premarriage youth groups in high-risk areas in the province. However, this screening program has been suspended since 2020 owing to the COVID-19 pandemic and financial constraints in the country.

Goal and objectives

The goal of the program was to prevent the birth of babies with β-thalassemia major in Northwestern Province by enabling the youth to make informed decisions on marriage based on their thalassemia carrier status. The general objective was to identify the thalassemia carrier state through screening among grade 10 and above students in government/private schools and higher education centers in Northwestern Province while enabling them to make informed decisions on marriage based on one's own thalassemia carrier status is the general objective.

Methods

The implementation of the thalassemia prevention program in the NWP was designed based on five strategic areas.

Strategic Area 1: Advocacy, Partnership, and Leadership of thalassaemia prevention program in NWP

The initiative was discussed among key officials from the PDHS-NWP and NTC-THK, the primary collaborators driving the thalassemia prevention program in the province. Ongoing advocacy and joint planning efforts are being made to ensure the program's sustained momentum and long-term impact.

Furthermore, a productive advocacy meeting was held with the Deputy Director General of Health Services (NCD)- MoH, Chief Secretary-NWP, and the Secretary of the Provincial Ministry of Health Services to foster multi-sectoral collaboration and secure the financial sustainability of thalassemia prevention programs in the province. This discussion emphasizes the need for a multi-sectoral approach to engage sectors such as health, education, higher education, and other key stakeholders. Advocacy and awareness programs were strategically continued within the education sector, targeting Zonal Directors, school principals, and teachers, recognizing their crucial role in the thalassemia prevention program.

Strategic area 2: Community awareness and empowerment of adolescents, youth, and parents of adolescents and youth in NWP

Grade 10 and above students of all government and private schools in the NWP and their parents, and youth studying in higher education centers in the NWP are taken as the target population for community awareness and empowerment.

These efforts aimed to dispel the misconceptions and stigma attached to being a carrier, promote early detection through screening, and encourage informed decision-making regarding genetic counselling and family planning. Awareness was initiated to empower each individual and family member with adequate knowledge to make informed decisions. We leveraged the invaluable support of public health workers to implement a comprehensive community awareness program for thalassemia prevention. These dedicated professionals have been instrumental in disseminating crucial information about thalassemia in various settings, including routine antenatal care, child welfare, NCD clinics, community centers, and outreach activities. Government and private school awareness programs were integrated through school health programs targeting parents and students. Several health-promoting techniques were used to raise awareness of the target population, including the dissemination of video clips, leaflets, and focus group discussions.

Strategic area 3: Health system strengthening for thalassaemia prevention and Screening program in NWP

A comprehensive training session was conducted for all MOHs in the Kurunegala district, promoting the importance of their leadership and involvement in

the thalassemia prevention program. By advocating for active participation and support, the program was strengthened at the grassroots level, facilitating more effective implementation of prevention strategies and interventions across the province. Continuous training and capacity building was launched for public health inspectors, midwives, and laboratory staff to further support the program's success.

The financial stability of the program was secured through multiple discussions with the Provincial Ministry of Health (NWP). The estimated cost for procuring reagents for school children screening programs, including clearing the three-year backlog, amounted to approximately 90 million Sri Lanka Rupees (LKR). However, the fund was released in phases, with progress being closely monitored throughout the program's implementation. In the initial stages, reagents were procured using provincial funds and subsequently by the MoH and handed over to the NTC to facilitate the program's operation.

A project proposal for fundraising was submitted to NGOs and foreign agencies to ensure the long-term sustainability of the thalassemia program.

Strategic area 4: Thalassemia carrier detection by streamlined screening program.

The screening program encompasses various activities including advocacy, carrier screening, health education, counselling services, community awareness campaigns, and access to medical treatment and support.

a. Identification of target population-

The primary target population for the screening program in the NWP consists of school children aged 15–19 years, as screening can be completed before marriage decisions are made. Approximately 130,000 schoolchildren in grades 10 and above were identified for primary screening. Following the clearance of the three-year backlog, the annual target would be 30,000 grade 10 students. Additional target groups included students attending higher education centers, nursing schools, and universities, as well as adolescents and young adults employed in factories and other workplaces.

a. Carrier detection by screening

The screening program is being conducted for grade 10 and above students in all government and private schools within the MOH area in collaboration with school authorities and public health staff from the MOH office. All blood samples were tested at state hematology laboratories, with the Full Blood Count (FBC) used as the primary screening method to determine the mean corpuscular volume (MCV) and mean corpuscular Hb concentration (MCH). Individuals with normal MCV and MCH results were issued green cards at the MOH level. Those who had low MCV and MCH results with suspected iron deficiency underwent a three-month iron treatment, after which the test was repeated. For cases that remained highly suspicious, further evaluation was conducted using high-performance liquid chromatography (HPLC) to quantitatively assess HbA2 levels, the definitive test for identifying beta thalassemia traits.

Strategic area 5: Implementation of a data surveillance system for the thalassaemia program in NWP

The program established a data surveillance system specifically tailored to achieve the following objectives. The system integrates various components, including data collection, analysis, reporting, and dissemination, to facilitate evidence-based decision making and resource allocation.

1: To develop a centralized database for collecting, storing, and managing comprehensive information on thalassemia cases, including demographic details, clinical history, treatment outcomes, and follow-up profiles.

2: To ascertain the prevalence of thalassemia traits and detect iron deficiency anemia in the target population.

3: To improve monitoring and evaluation mechanisms for assessing the effectiveness of interventions and informing planning and policy decisions.

4: To develop research for evidence-based practice in thalassemia prevention programs.

A web-based data surveillance system (THIS - Thalassemia Health Information System) was developed by the health informatics unit of the PDHS, NWP, in collaboration with the Ministry of Health, Sri Lanka, and is currently hosted by the Ministry's data center. This system is structured to capture data at both the MOH and laboratory levels, thereby decentralizing data collection and enhancing the identification of individuals with thalassemia traits. This decentralization is more

effective in the prevention of thalassemia major births through targeted interventions such as health promotion and counselling for thalassemia carriers. The system enables tracking of individuals through various stages of screening, providing a comprehensive overview of screening statuses. It analyzes the collected data across all screening levels and offers critical insights into the prevalence of thalassemia major cases, thalassemia carriers, and other relevant indicators.

Capacity-building programs for public health workers in MOH offices were initiated by providing training and technical support for robust data collection, analysis, and utilization within the surveillance system.

Through these initiatives, training sessions were conducted in clusters, ensuring the participation of key personnel including MOHs, Public Health Inspectors, Public Health Nursing Sisters, and Development Officers.

Results of the first phase of the screening programme

The first phase of the screening programs commenced in 15 schools in six MOH areas in Kurunegala district, and a total of 4030 students were tested for thalassemia from September 2023 to March 2024. Of the total sample, 82% (n=3306) were cleared by issuing green cards by MOH, 10.9% (n= 438) had iron deficiency anemia (IDA), and 3.8% (n=155) were identified as β-thalassemia carriers (Fig. 1). According to available data, the highest percentage of thalassemia carriers (8.3%, n=40) was identified in the Galgamuwa MOH division (Table 1, Fig 2). Identifying and treating individuals with IDA will improve the physical and intellectual capacity of the students [10].

Table 1: Data analysis of thalassemia screening program conducted in six MOH areas in Kurunegala District.

MOH Area	Total No screened	FBC/ HPLC normal (Green card)	%	Iron deficiency detected by FBC	%	Beta Thalassaemia D/E/H trait	%	Others (possible alpha thalassaemia trait/ iron deficiency anemia)	%
Galgamuwa	480	325	67.7%	91	18.9%	40	8.3%	24	5%
Pannala	173	132	76.3%	35	20.2%	6	3.4%		
Rideegama	2290	1921	83.9%	228	10.0%	69	3.0%	72	3.1%
Ududbaddawa	395	340	86.0%	41	10.3%	10	2.5%	4	1.0%
Panduwasnuwara West	419	361	85.9%	21	5.0%	17	4.0%	20	4.7%
MC Kurunegala	273	227	83.1%	22	8.0%	13	4.7%	11	4.0%
Total	4030	3306	82.0%	438	10.9%	155	3.8%	131	3.2%

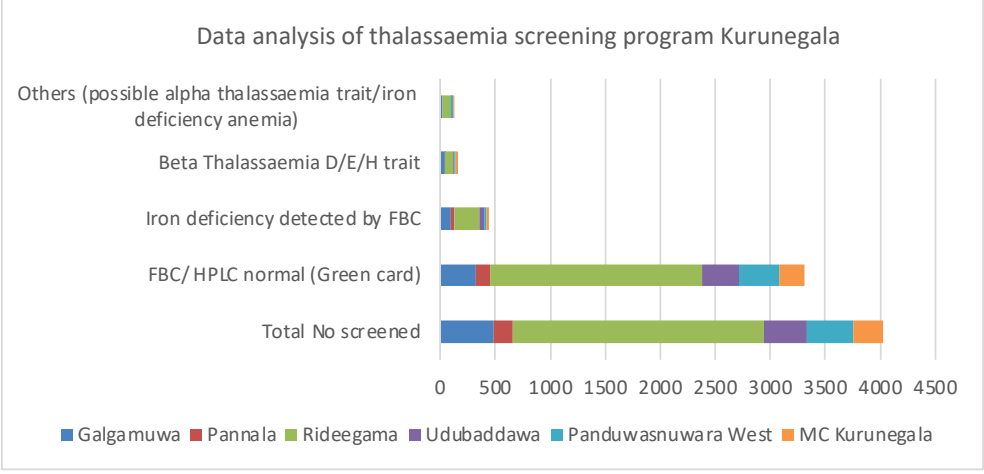

Figure 1: Overall data analysis of thalassaemia screening conducted in 6 MOH divisions (From September 2023 to March 2024)

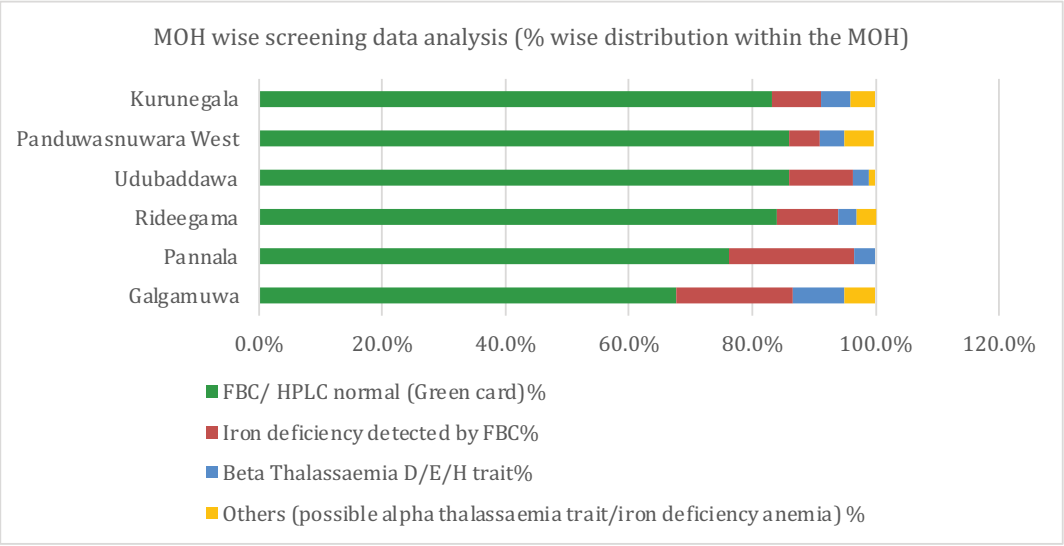

Figure 2: MOH-wise screening data analysis (This indicates % wise distribution within the MOH)

Discussion

This brief report outlines the strategies and interventions implemented in the thalassemia prevention program in Northwestern Province. The primary objective of the program is to identify individuals with thalassemia traits and enable informed decisions regarding marriage between carriers based on an individual's carrier status.

Existing data reveal a significant prevalence of iron deficiency anemia and a substantial number of thalassemia carriers in Kurunegala district, highlighting the relevance of ongoing screening sessions and prevention programs. Conducting a screening program and mapping the regional epidemiology of the disease will be crucial for identifying high-risk areas and emerging hotspots. These data-driven insights will allow for the implementation of targeted public health interventions to strengthen thalassemia prevention efforts in the province.

Conclusion and Recommendation

A multisectoral approach is essential for a comprehensive nationwide thalassemia prevention program that incorporates advocacy, resource mobilization, capacity building, and voluntary screening. Lessons learned from the Northwestern Province program should guide the development of similar action plans in other regions of the country.

Author declaration

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