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Examining the Socioeconomic Dynamics of Beta-Thalassaemia Screening Carriers and Dropouts among Secondary School Adolescents: A Comparative Study in Sabah and Sarawak

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This study provides a novel analysis of the socioeconomic factors influencing screening dropout rates among beta-thalassemia carriers in Sabah and Sarawak, Malaysia, using 2018 data from the National Thalassemia Screening Programme. Our retrospective design focused on form four students, examining the interplay of ethnicity, locality, and gender with dropout rates. Notably, male carrier rates were higher in Sabah (49.90%) compared to females (50.10%), while Sarawak showed 51.56% for males and 48.44% for females. Gender disparities in dropout rates were particularly pronounced in Sabah, where females had double the dropout rates of males (70.62% vs. 29.38%). Extreme dropout rates were found in certain localities, namely Pitas, Sabah (47%) and Belaga, Sarawak (55%). The study highlights the substantial prevalence of thalassemia carriers among natives, with 93.9% in Sabah and 59.7% in Sarawak, underscoring the critical need for targeted, gender-sensitive screening interventions. This research contributes significantly by demonstrating the importance of precision in thalassemia screening programs to mitigate dropout rates and reduce the incidence of thalassemia births. These findings strongly advocate for early carrier identification as a strategic measure to improve educational outcomes and public health in high-risk regions.

Keywords: *Thalassaemia Screening Programme, socioeconomic profile, carrier rates, dropout rates, Sabah, Sarawak*

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Introduction

Thalassemia, a hereditary blood disorder, affects about 7% of the global population, with beta-thalassemia being particularly prevalent in the "thalassemia belt" regions, including Sub-Saharan Africa, the Mediterranean, the Middle East, and Southeast Asia (Lorey et al. 1996, Taher et al. 2021). These regions account for 95% of thalassemia births (Haque et al. 2015), making them a focal point for research and intervention. However, with increasing transmigration and interethnic marriages, thalassemia is now affecting a broader range of populations, including those in Southeast Asia and those of Asian Indian ancestry (Lorey et al. 1996).

In Southeast Asia, the prevalence of thalassemia remains alarmingly high, with approximately 55 million carriers (Shafie et al. 2021). In Malaysia, it is estimated that around 4.5% of Malaysians are beta-thalassemia carriers (Miri et al. 2013). The rate has not seen a rapid decline. Despite these concerning figures, there is a notable research gap in understanding the socioeconomic factors influencing dropout rates among beta-thalassemia carriers, particularly in regions like Sabah and Sarawak. Existing studies have not adequately explored how ethnicity, locality, and gender intersect and impact educational outcomes for these adolescents. This study aims to fill this gap by examining these dynamics to inform more effective thalassemia screening and prevention programs. The findings have the potential to improve educational outcomes and reduce the incidence of thalassemia births in high-risk regions, contributing to more targeted public health strategies.

Literature Review

Thalassemia is recognised as the most common genetic disorder in Malaysia, yet there remains limited information about its prevalence among Indigenous populations, particularly in Sabah and Sarawak (Tan et al. 2010). The Indigenous peoples, or "bumiputra," of these regions represent the majority of the population (Foo et al. 2004), comprising approximately 89% in Sabah and 76.1% in Sarawak (Aaron 2022). Despite this high representation, research specific to these groups, especially concerning the prevalence of thalassemia, is sparse. According to the Malaysian Thalassemia Registry, Sabah has the highest prevalence rate at 22.72%, with the most affected age group being 5.0-24.9 years (Ibrahim et al. 2019). Among the Kadazandusun community, where consanguineous marriages are common, there is a significant risk of producing children with beta-thalassemia major, with 12.8% of the community carrying the Filipino β-thalassemia deletion (Tan et al. 2010).

Beta-thalassemia carrier screening has been widely implemented in several countries as a preventive measure. In Malaysia, the Ministry of Health launched the Thalassemia Prevention and Control Programme in 2004 to reduce the morbidity and mortality of thalassemia patients and to lower the prevalence of transfusion-dependent thalassemia cases (Ministry of Health 2016). However, this program initially targeted only high-risk families and antenatal mothers. Since 2016, Malaysia has made a significant shift in its approach to thalassemia prevention. The introduction

of nationwide screening for Form 4 students has broadened the demographic included in the screening process. This shift towards early screening in adolescents, aligning with global practices, has identified 31,716 carriers out of 689,460 students screened, demonstrating Malaysia's commitment to early detection and prevention (Division of Family Health Development 2009). The programmes are designed to identify asymptomatic carriers and provide them with critical information about their reproductive risks, thereby empowering them to make informed decisions about their health and family planning.

This study uses the Social Determinants of Health (SDH) as the theoretical foundation. It hypothesizes that socioeconomic factors such as ethnicity, income, education, and geographic location influence health outcomes, including the prevalence of genetic disorders like beta thalassemia (Sargolzaie et al. 2018). Using this framework, we could explore how these factors contribute to higher rates of beta-thalassemia carriers and the dropout rates among adolescents in Sabah and Sarawak. Previous studies have highlighted certain demographic factors, such as the prevalence of thalassemia among Indigenous people. However, little, if not none, has fully explored the socioeconomic dimensions that might influence dropout rates among carriers.

A study by Guan Chin et al. (2019) found that only 13.9% of parents were aware of thalassemia before the birth of their first affected child. Almost all parents (91.7%) were not aware of their thalassemia carrier status before marriage, and the majority (94.4%) did not undergo pre-marital thalassemia screening before marriage among thalassemia major patients in Sabah. The study also concluded that the lack of awareness, low education levels, and poor socioeconomic status have been highlighted as significant. The profile of Beta-thalassemia major patients was mostly from the indigenous Kadazan, Dusun, Murut, Rungus, and Sungai ethnic groups, and parents mostly had low education levels and socioeconomic status.

While these studies provide valuable insights, they often fail to offer a comprehensive understanding of how socioeconomic factors influence the prevalence of beta-thalassemia and screening dropout rates among adolescents. The screening dropout rates refer to the proportion of individuals who did not attend, discontinued, or did not complete the screening process at any stage, from initial testing to confirmatory analysis, before completion. This gap in the literature underscores the need for more targeted research that examines the interplay of ethnicity, gender, and locality in these high-risk regions. By addressing these limitations, the current study aims to provide a more nuanced analysis that can inform the development of more effective and targeted thalassemia screening and prevention programs.

Methodology

This study is a retrospective descriptive analysis utilizing secondary data from the National Thalassemia Screening Program conducted by the Ministry of Health, Malaysia. The study focused on 16-year-old school adolescents during the 2018 screening period from January to December 2018. The screening included students from secondary schools in East Malaysia, with a high participation rate of 91.4% in

Sabah and 99.8% in Sarawak. Ethical approval was obtained from the Malaysian Research Ethics Committee and registered under the National Medical Research Register Malaysia (NMRR ID-22-00985-D1X (IIR)) and the Family Health Development Division, Ministry of Health Malaysia provided the anonymized line listing of the study sample of Form 4 students. The data collection process for this study involved several key steps. First, the screening program employed universal sampling, targeting all Form 4 students across Sabah and Sarawak secondary schools. This approach ensured a comprehensive sample that would closely reflect the prevalence of beta-thalassemia carriers among the adolescent population in these regions. Informed consent was obtained from all participants or guardians to maintain ethical standards. The collected data was anonymised to protect the students' privacy, removing any personally identifiable information.

Blood samples were collected from the participants during the screening procedures and tested for beta-thalassemia traits. The results of these tests were then compiled into a comprehensive dataset, which was carefully checked to ensure accuracy and completeness. This anonymised dataset was later retrieved from the Malaysian Ministry of Health and used for the analysis in this study. The data analysis was conducted using SPSS-18 software. It included descriptive statistics to summarize the participants' sociodemographic characteristics and the prevalence of beta-thalassemia carriers.

A chi-square significance test was also employed to examine the relationships between sociodemographic variables—such as ethnicity, locality, and gender— and dropout rates. A p-value of less than 0.05 was considered statistically significant, indicating that the observed associations were unlikely to have occurred by chance. Despite the comprehensive nature of the data collection and analysis, several potential limitations should be considered.

Adopting a retrospective design for this study may limit the ability to establish causal relationships between thalassemia carrier status and dropout rates. Additionally, the reliance on secondary data means that the researchers had limited control over the quality and completeness of the data, which could affect the study's findings if there were any inconsistencies or errors in the original data collection.

The anonymisation of data, while crucial for protecting participant privacy, may also restrict the ability to link certain variables or follow up on individual cases for further insights. Furthermore, the study's focus on Sabah and Sarawak may limit the generalisability of the findings to other regions in Malaysia or other countries with similar demographics. Finally, although the participation rates in the screening program were high, a small percentage of non-consenting students could introduce a selection bias, potentially affecting the sample's representativeness.

By acknowledging and addressing these limitations, this study aims to comprehensively analyse the socioeconomic dynamics that influence beta-thalassemia carriers and dropout rates in East Malaysia. The detailed data collection process and careful consideration of potential confounding factors contribute to the study's validity and relevance.

Results

This study found significant differences in three key sociodemographic profiles among beta-thalassemia carriers and dropouts, namely ethnicity, gender, and location. The total number of samples studied was 36,860 for Sabah and 35,161 for Sarawak. However, the analysis focused on the 65,990 consented students, with 33,142 from Sabah and 32,848 from Sarawak.

Table 1. *Gender and Ethnic Distribution between Consented Population, Prevalence by Carrier and Dropout, Gender and Ethnicity of Thalassaemia Carriers and Dropouts*

Sociodemographic profile		**Sabah**		**Sarawak**		**X^2**	**p value**
		n	**(%)**	**n**	**(%)**		
Gender	Male	15, 037	45.4	15, 579	47.3	28.04	<0.001
	Female	18,105	54.6	17, 269	52.4		
Ethnic Group	Sabah natives	29776	89.8	164	0.5	55528.61	<0.001
	Sarawak natives	181	0.5	11828.6	71.8		
	Chinese	1944	5.9	7165	21.8		
	Malay	1130	3.4	1878	5.7		
	Indians	104	0.3	51	0.2		
	Others	7	0	8	0		
Carrier vs Dropout		**Sabah**		**Sarawak**		**X^2**	**p value**
		n	**(%)**	**n**	**(%)**		
Category	Carrier	2036	77.9	576	22.1	352.377	< 0.001
	Dropout	5678	57.9	4129	42.1		
	Total	7714		4705			
Profiles		**Sabah**		**Sarawak**		**X^2**	**p value**
		n	**(%)**	**n**	**(%)**		
Carrier (Gender)	Male	1016	49.90	297	51.56	0.495	0.48
	Female	1020	50.10	279	48.44		
	Total	2036		576			
Dropout (Gender)	Male	1668	29.38	1494	36.18	50.7	<0.05
	Female	4010	70.62	2635	63.82		
	Total	5678		4129			
Carrier (Ethnics)	Sabah natives	1912	93.9	5	0.9	2174	<0.001
	Sarawak natives	5	0.3	344	59.7		
	Chinese	58	2.9	195	33.9		
	Malay	59	2.9	32	5.6		
	Indians	2	0	0	0		
	Others	0	0	0	0		
	Total	2036	100	576	100		
Dropout (Ethnics)	Sabah natives	5237	92.2	27	0.7	8467	<0.001
	Sarawak natives	18	0.3	3043	73.7		
	Chinese	219	3.9	810	19.6		
	Malay	183	3.2	237	5.7		
	Indians	21	0.4	9	0.2		
	Others	0	0	3	0.1		
	Total	5678	100	4129	100		

Table 1 shows the gender distribution among the consented students in both states, revealing proportionate comparability. In Sabah, 45.4% of the samples were male, while 54.6% were female. Similarly, in Sarawak, 47.3% of the samples were male, and 52.4% were female. A chi-square test of interdependency was performed to examine the relationship between gender distribution across the two states. The

results indicated that the proportion of females is significantly higher than males in both states ($\chi^2 = 28.04$, $p < 0.001$). In Sabah, the Sabah natives account for the largest ethnic population with 89.8%, and similarly, in Sarawak, the Sarawak natives were the highest with 71.8%. Both these distributions were significant ($\chi^2 = 55528.61$, $p<0.05$). In both states, the Chinese population represents the second-largest ethnic group, followed by the Malays.

There is also a prominent disparity between carriers and dropouts in Sabah and Sarawak, with carriers in Sabah account for 77.9% of the total carrier population (2036 out of 2612) showing a threefold per cent higher compared to Sarawak represent 57.9% of the total dropout population (5678 out of 9807). The study revealed a balanced distribution of beta-thalassemia carriers across genders in both Sabah and Sarawak. In Sabah, the carriers were nearly evenly split between males and females, with a slight predominance of females (50.10%). Similarly, Sarawak showed a comparable distribution, with males constituting 51.56% of carriers ($\chi^2 = 352.377$, $p < 0.001$. A more detailed examination by gender reveals that in both states, there is a relatively equal distribution of males and females among the carriers, as indicated by the non-significant Chi-Square test. Conversely, when focusing on thalassemia program dropouts, gender differences become apparent. In this case, females (Sabah: 70.62%; Sarawak: 63.82%) outnumber males (Sabah = 29.38%; Sarawak = 36.18%) in both states, but the percentage of dropouts in Sabah surpasses that in Sarawak. ($\chi^2 = 50.696$, $p < 0.05$).

The same table showed the relationship of thalassemia carriers amongst the ethnic groups. Sabah natives were the predominant group, comprising 93.9% of the carrier population, while in Sarawak, the Sarawak natives constituted 59.7%, and these relationships are statistically significant ($\chi^2 = 2172.14$, p-value <0.001). Likewise, the study showed statistically significant differences between thalassemia programs dropouts by ethnic groups. The dropout rates were calculated based on the total district population. Dropout rates were highest among the Sabah natives (92.2%), followed by Chinese and Malays. Whilst in Sarawak, most dropouts were observed among Sarawak natives (73.7%), followed by Chinese and Malays.

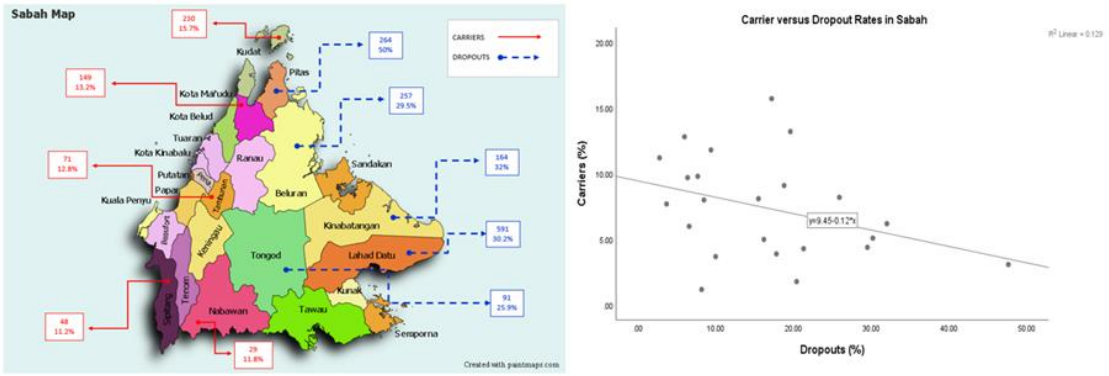
The carriers and dropouts in Sabah were not uniformly distributed. Table 2 shows the distribution of carriers and dropouts by district in Sabah. The table presents these figures both as a percentage of total numbers and in relation to districts' sample enrolment (representing the consented population). The districts with the highest prevalence of thalassemia carriers were Kudat (15.7%), followed by Kota Marudu (13.2%), Tambunan (12.8%), Nabawan (11.8%), and Sipitang (11.2%). The same table also shows the dropouts by locality. More than half of the districts in Sabah were with double-digit dropout rates. Pitas had the highest dropout rate of almost 50%, followed by Kinabatangan (32.0%) and Lahad Datu (30.2%). Additionally, there was a significant relationship between locality by carrier and dropout screened per district ($\chi^2 = 908.455$; $p < 0.001$).

Table 2. *The Proportion of Carriers and Dropouts by Districts and the Prevalence Rate by Districts in Sabah*

Districts of Sabah	Carriers				Dropouts			
	Frequency	Percentage of carriers per state carriers	Number of students screened in Sabah	Percentage of carriers per district population	Frequency	Percentage of dropouts	Number of students screened in Sabah	Percentage of dropouts per population screened in Sabah
	n	(%)	n	(%)	n	(%)	n	(%)
Pitas	17	0.80	555	3.10	264	4.60	555	47.60
Kinabatangan	32	1.60	513	6.20	164	2.90	513	32.00
Lahad Datu	100	4.90	1960	5.10	591	10.40	1960	30.20
Beluran	38	1.90	871	4.40	257	4.50	871	29.50
Tongod	29	1.40	352	8.20	91	1.60	352	25.90
Sandakan	202	9.90	3220	6.30	793	14.00	3220	24.60
Penampang	59	2.90	1380	4.30	294	5.20	1380	21.30
Semporna	31	1.50	1718	1.80	350	6.20	1718	20.40
Kota Marudu	149	7.30	1129	13.20	221	3.90	1129	19.60
Keningau	212	10.40	2320	9.10	435	7.70	2320	18.80
Tuaran	66	3.20	1672	3.90	297	5.20	1672	17.80
Kudat	230	11.30	1467	15.70	253	4.50	1467	17.20
Kota Kinabalu	203	10.00	4023	5.00	650	11.40	4023	16.20
Ranau	100	4.90	1237	8.10	192	3.40	1237	15.50
Papar	66	3.20	1771	3.70	177	3.10	1771	10.00
Nabawan	29	1.40	245	11.80	23	0.40	245	9.40
Kota Belud	95	4.70	1191	8.00	101	1.80	1191	8.50
Tawau	46	2.30	3804	1.20	313	5.50	3804	8.20
Kuala Penyu	28	1.40	285	9.80	22	0.40	285	7.70
Beaufort	67	3.30	1125	6.00	74	1	1125	6.60
Tenom	79	3.90	812	9.70	52	0.90	812	6.40
Tambunan	71	3.50	554	12.80	33	0.60	554	6.00
Kunak	39	1.90	509	7.70	19	0.30	509	3.70
Sipitang	48	2.40	429	11.20	12	0.20	429	2.80
Total	2036	100	33142	100	5678	100.00	33142	100
$\chi^2 = 908.455$	$p < 0.001$							

Figure 1 illustrates the spatial distribution of both the carriers and drop-out prevalence on the Sabah map. Carriers are higher on the eastern coast, while dropouts are higher on the western coast. The scatter plot in Figure 1, was performed to show if the strength of the relations distribution between carrier rates and dropout rates in different districts of Sabah. The plot reveals an R-squared value of 0.129, indicating that only 12.9% of the variance between carrier rates and dropout rates can be explained by the relationship depicted in the scatter plot.

Figure 1. *The Spatial Distribution of Both the Carriers and Drop-out Prevalence in Sabah*



In Sarawak, the distribution of carriers and dropouts also varies across the state, as shown in Table 3, and the chi-square test showed a significant difference with X^2 862.915, $p < 0.001$. The districts in Sarawak with higher prevalence rates of carriers include Limbang (5%), Lawas (4.3%), and Betong (3.7%); all of them were at least 3 times lower than Sabah. However, like in Sabah, half of all the districts record double-digit dropout rates, with the highest in Belaga at 55%. This was followed by Daro (21.7%), Lundu (20.7%) and Kuching (19.6%). Figure 2 shows the spatial distribution of both carriers and drop-outs in Sarawak. District with high dropout rates were predominantly observed in the southwest districts of Sarawak.

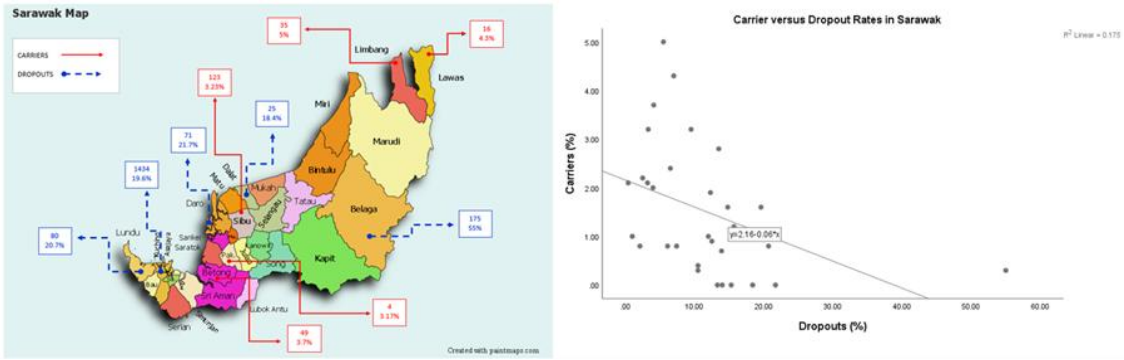
Table 3. *The Proportion of Carriers and Dropouts by Districts and the Prevalence Rate by Districts in Sarawak*

	Carriers				Dropouts			
Districts of Sarawak	**Frequency**	**Percentage of carriers**	**Districts population**	**Percentage of carriers per district population**	**Frequency**	**Percentage of dropouts**	**Districts population**	**Percentage of dropouts per district population**
	n	**(%)**	**n**	**(%)**	**n**	**(%)**	**n**	**(%)**
Belaga	1	0.20	318	0.30	175	4.20	318	55.00
Daro		0.00	327	0.00	71	1.70	327	21.70
Lundu	3	0.50	387	0.80	80	1.90	387	20.70
Kuching	114	19.80	7309	1.60	1434	34.70	7309	19.60
Dalat		0.00	136	0.00	25	0.60	136	18.40
Serian	29	5.00	2411	1.20	379	9.20	2411	15.70
Mukah		0.00	619	0.00	95	2.30	619	15.30
Miri	69	12.00	4449	1.60	657	15.90	4449	14.80
Kapit		0.00	694	0.00	97	2.30	694	14.00
Simunjan	4	0.70	547	0.70	76	1.80	547	13.90
Samarahan	18	3.10	652	2.80	88	2.10	652	13.50
Matu		0.00	180	0.00	24	0.60	180	13.30
Bintulu	21	3.60	2409	0.90	302	7.30	2409	12.50
Kanowit	7	1.20	375	1.90	46	1.10	375	12.30

Asajaya	7	1.20	699	1.00	84	2.00	699	12.00
Julau	1	0.20	275	0.40	29	0.70	275	10.50
Tatau	1	0.20	306	0.30	32	0.80	306	10.50
Pakan	4	0.70	126	3.17	12	0.30	126	9.50
Meradong	4	0.70	498	0.80	37	0.90	498	7.40
Lawas	16	2.80	373	4.30	26	0.60	373	7.00
Sri Aman	18	3.10	749	2.40	49	1.20	749	6.50
Bau	7	1.20	838	0.80	51	1.20	838	6.10
Limbang	35	6.10	707	5.00	39	0.90	707	5.50
Betong	49	8.50	1315	3.70	54	1.30	1315	4.10
Selangau	2	0.30	101	2.00	4	0.10	101	4.00
Sibu	123	21.40	3807	3.23	124	3.00	3807	3.30
Lubok Antu	6	1.00	280	2.10	9	0.20	280	3.20
Sarikei	18	3.10	810	2.20	20	0.50	810	2.50
Marudi	2	0.30	241	0.80	5	0.10	241	2.10
Song	2	0.30	196	1.00	2	0.00	196	1.00
Saratok	15	2.60	714	2.10	3	0.10	714	0.40
Total	576	100.00	32848	100	4129	100.00	32848	100

The scatter plot depicted in Figure 2 illustrates the regression line that represents the relationship between carrier rates and dropout rates in various districts of Sarawak. The R-squared value of 0.175 indicates that approximately 17.5% of the variance between carrier rates and dropout rates can be explained by the depicted relationship in the scatter plot. This suggests that only a limited portion, specifically 17.5%, of the variation in carrier rates can be clarified by changes in dropout rates. Consequently, there may be additional factors influencing carrier rates that are not captured in the dropout rates. The negative estimated coefficient from the regression implies that as dropout rates decrease, carrier rates may increase. However, without the provision of a t-statistic in Supplementary Figures 1 and 2, it remains unclear whether this coefficient is statistically significant.

Figure 2. *The Spatial Distribution of both the Carriers and Drop-out Prevalence in Sarawak*



Similar to the findings in Sabah, the scatter plot in Sarawak indicates that districts with high carrier rates do not consistently demonstrate high dropout rates. The scattered data points imply a weak correlation or the absence of a consistent pattern between carrier rates and dropout rates across the districts of Sarawak.

The results of this study reveal significant variations in beta-thalassemia carrier rates and school dropout rates among different ethnic groups in Sabah and Sarawak. These variations suggest that ethnicity plays a crucial role in the prevalence and impact of thalassemia, likely due to a combination of genetic factors, cultural practices, and socioeconomic conditions that differ across ethnic groups. Understanding these ethnic disparities is essential for developing effective, culturally sensitive interventions.

The study also identified a significant gender disparity, with a higher proportion of female students in the sample. This gender difference indicates potential gender-specific factors that may influence school retention and health outcomes. For example, the higher dropout rates among females in Sabah could be attributed to cultural or economic pressures that disproportionately affect girls. These pressures may include expectations around family responsibilities or economic constraints that limit girls' access to education and healthcare services.

Geographic differences between Sabah and Sarawak were also evident, with varying rates of beta-thalassemia carriers and dropouts across different regions. This geographic variability may be influenced by factors such as access to healthcare services, educational opportunities, and the broader socioeconomic conditions of each region. The high dropout rates observed in specific areas, such as Pitas in Sabah (47%) and Belaga in Sarawak (55%), highlight the need for targeted interventions in these high-risk locations. These findings underscore the importance of tailoring public health and educational strategies to the unique needs of different communities to effectively address the challenges posed by beta-thalassemia and improve educational outcomes.

Discussion

In Malaysia, thalassaemia affects various states and ethnic groups. Sabah, Malaysia's third most populous state, has the highest number of documented thalassaemia cases, with a prevalence of 0.39 per 1,000 people based on the Malaysian Thalassaemia Registry in 2019. This study found that Sabah has a higher prevalence of thalassaemia carriers among 16-year-old students, with a rate of 6.8 per 100 students, and most carriers are Sabah natives. The study samples in Sabah and Sarawak both have a significant proportion of indigenous populations, accounting for 89.8% and 71.8% of their respective populations. Chinese ethnicity is the second most prominent in Sabah (5.9%) and Sarawak (21.8%), followed by Malays, Indians, and others.

Research conducted by Sena et al. (2019) reported that the Kadazan-Dusun indigenous ethnicity had the highest prevalence of thalassaemia carriers in Sabah, with a rate of 16.2 per 1,000 students. They also identified the β-Filipino deletion (β°) as the main genetic mutation responsible for beta-thalassaemia in 90% of Kadazan-Dusun individuals (Elizabeth & Ann 2010). Sabah's primary Indigenous ethnic groups, including Kadazan-Dusun, Bajau, Malays, Muruts, and others, were

identified based on the most recent national census (Pauzy et al. 2018). Further molecular characterization studies have revealed that each ethnic group in Sabah possesses a unique set of mutations contributing to thalassaemia (Mary Anne Tan et al. 2006). Consequently, the Kadazan-Dusun ethnic group has the highest prevalence of thalassaemia disorders in Sabah, which aligns with findings from the Malaysian Thalassaemia Registry.

Although the study showed no significant difference between male and female carriers in both states, it is worth noting that Laghari has noted a higher prevalence of thalassaemia among males than females (Laghari et al. 2018). The study noted that it may be related to factors such as transfusion-related infections, which are more common among males. On the other hand, iron deficiency anaemia (IDA) is more prevalent among females due to menstruation (Roslie et al. 2019). These gender and ethnic distributions provide valuable insights into the demographic composition of Sabah and Sarawak. They can be useful for understanding the prevalence and impact of various health conditions, including thalassaemia, in different population groups.

While specific studies on gender differences in thalassaemia prevalence are limited, research on sociodemographic determinants related to thalassaemia knowledge has found that males, higher education, and higher income are associated with better understanding of thalassaemia disease and screening services (Manzoor & Zakar 2019). This may align with the observation of higher dropout rates among female students in the present study.

The elevated occurrence of malaria in Malaysia, particularly in Sabah, has posed a significant public health challenge. Nevertheless, initiatives aimed at malaria control, such as the implementation of the Nationwide Anti-Malaria Program in the 1980s, have played a role in diminishing its prevalence. Interestingly, there is a belief that the thalassaemia trait offers a certain level of protection against malaria (Abouelmagd & Ageely 2013). This protective advantage might have contributed to the selective survival and persistence of the thalassaemia mutation in regions with a high malaria prevalence, such as Sabah. Referred to as a heterozygous advantage, this benefit for carriers of the thalassaemia trait could be a contributing factor to the continued existence of the thalassaemia mutation in Sabah, leading to its persistent high incidence over the years.

The distribution of thalassaemia carriers can vary based on ethnic groups and geographical location. Bumiputera Sabah accounted for the vast majority of carriers in Sabah, while Bumiputera Sarawak predominated in Sarawak, reflecting the genetic predisposition of these indigenous populations. Previous studies have identified the Dusun ethnicity, primarily in Kota Kinabalu, as having a significant proportion of thalassaemia patients in Sabah (Chin et al. 2019). Other studies have found high prevalence rates of alpha and beta thalassaemia carriers in Kota Marudu and Hb E carriers in Kudat (Sena et al. 2019). Notably, this study found that thalassaemia carriers are more concentrated in coastal districts than inland districts in both Sabah and Sarawak. High concentrations of carriers, such as Kudat and Keningau in Sabah and Sibu and Kuching in Sarawak, highlighting the importance of prioritising resource allocation and outreach programs in these areas Understanding the distribution of carriers is essential for planning effective prevention activities.

The study showed that dropout rates were pervasive throughout the districts, with some districts registering higher rates than others. Although the study showed weak associations between the dropouts and locality and that high carrier rates in a district do not necessarily correspond to high dropout rates, the study revealed localities or districts that need serious attention. Half of the states, both in Sabah and Sarawak, have high dropout rates. Notably, Sabah is on the eastern, more rural coast and is far from the capital cities. In Sarawak, the district of Belaga has the highest dropouts, involving 50% of the sample. The result of this study can be a pointer to access issues for some of the less developed support systems in the respective locality.

The aim of countries embarking on thalassemia prevention and control programs is to decrease the incidence of new thalassemia-affected births swiftly. Hence, implementing strategies should focus on easily attainable goals with special emphasis on states with high prevalence and higher risk profiles such as gender, ethnicity, and locality or, namely, the" low-lying fruits". The reasons behind dropouts need to be thoroughly investigated while identifying them to encourage and ensure they undergo thalassemia testing. Mandatory testing can be an option and has been successful for pre-marital screening (Jaffar et al. 2021). However, there are not yet successful reports for adolescents. The key challenges may be fear of negative effects or demands for close follow-up actions for non-compliance.

Thalassemia screening and testing strategies are subjected to long-term outcomes. It requires regular monitoring of the relationships of targeted profiles with choices and the outcomes, would require a simple but robust electronic register across each carrier cohort (Aydınok et al. 2018). With a strong system in place, aiming for zero thalassemia births within the next 10 years is a genuine possibility (Voskaridou et al. 2012). The triumphant achievements in the prevalence of Sardinia, Cyprus, and Greece have prompted many countries to emulate their successful reduction of cases.

The study identifies several potential confounding factors that could influence the observed prevalence of thalassemia and the associated dropout rates. One such factor is transfusion-related infections, which are more common among males. This could contribute to the higher prevalence of thalassemia observed in male students, as the increased risk of infections might exacerbate the condition or lead to more frequent diagnoses in males than females.

Another significant factor is iron deficiency anaemia (IDA), which is more prevalent among females due to menstruation. This condition could be linked to the higher dropout rates observed among female students, as anaemia can affect cognitive function, physical energy, and overall school performance, leading to increased absenteeism and, eventually, higher dropout rates.

Socioeconomic status strongly influences thalassemia prevalence and educational outcomes. Variations in income, education levels, and access to resources between different ethnic groups and regions may lead to disparities in health outcomes and thalassemia prevalence. Additionally, socioeconomic status can influence dropout rates, as students from lower-income families may face greater economic pressures to leave school early to contribute financially to their households.

Access to healthcare services is another important confounding factor. Differences between urban and rural areas regarding healthcare availability and quality can significantly impact the detection and management of thalassemia. In less accessible

areas, especially in rural areas, thalassemia may go undiagnosed or inadequately managed, leading to worse health outcomes and higher dropout rates among affected students.

Looking forward, there are several areas where further research could provide valuable insights and guide more effective interventions. A detailed analysis of the genetic and environmental factors contributing to the high prevalence of thalassemia among specific ethnic groups, such as the Kadazan-Dusun in Sabah, would be particularly useful. Understanding these factors could help tailor public health strategies to address the unique needs of these populations.

Finally, analysing the impact of healthcare accessibility on thalassemia detection, management, and educational retention in different regions could provide essential information for guiding resource allocation and policy decisions. It is imperative that ensuring the availability of healthcare services in all areas, particularly in underserved rural regions, may improve both health and educational outcomes for students with thalassemia.

Conclusions

The study's findings highlight the crucial need to consider ethnic, locality, and gender differences when analyzing the prevalence of thalassemia carriers among Form-four students in Sabah and Sarawak. The significant disparities observed underscore the importance of a targeted approach in addressing these differences. Investigating the underlying factors contributing to gender disparities and the higher dropout rates in specific and similar localities is essential for developing tailored strategies to combat the high prevalence of thalassemia in these regions.

The data indicates that native groups, male carriers, female dropouts, and regions with higher dropout rates are particularly affected, necessitating focused efforts to address these vulnerabilities. The geographic variation in thalassemia prevalence, with Sabah exhibiting a notably high prevalence of beta-thalassemia carriers, provides a critical context for prioritizing specific similar high prevalence regions in public health initiatives.

The effectiveness of the National Thalassemia Control and Prevention Program, which successfully identifies carriers in early adulthood, is a positive foundation. However, the dropout rates highlighted in this study suggest areas for improvement. Early identification of thalassemia carriers is vital in preventing the birth of affected individuals, emphasizing the need for precise and effective screening programs.

This research contributes to the understanding of how socioeconomic factors influence dropout rates in screening programs. The study offers valuable insights into the impact of these factors on participation and the overall effectiveness of the program. The study proposes practical interventions through targeted screening based on ethnicity, gender, and locality, providing actionable strategies to reduce thalassemia prevalence among specific demographic groups.

It is recommended that comparative analysis be further conducted with other screening programs that could enhance understanding by highlighting unique challenges and successes in thalassemia screening. Such comparisons can inform

improvements in other genetic screening initiatives, offering a broader perspective on effective public health strategies.

For policymakers and public health practitioners, the study provides several key recommendations:

- Develop tailored screening programs considering ethnic, gender, and locality differences to ensure more effective identification and intervention.
- Implement strategies to mitigate socioeconomic barriers that affect participation in screening programs, ensuring broader access and equity.
- Increase awareness about thalassemia, particularly in high-risk regions and among vulnerable demographic groups, to foster early detection and prevention.
- Strengthen efforts to identify carriers early to prevent the birth of affected individuals and ensure better long-term health outcomes.
- Regularly monitor and evaluate the effectiveness of screening and intervention programs, making necessary adjustments to enhance their impact.
- Conducting longitudinal studies to track beta-thalassemia carriers over time.
- Exploring region-specific dropout determinants through qualitative methods.
- Analyzing the impact of healthcare accessibility on carrier outcomes and educational retention.

By addressing these critical areas, it is possible to make significant strides in reducing the prevalence of thalassemia and improving public health outcomes in Sabah, Sarawak, and beyond.

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