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KNOWLEDGE AND ATTITUDE REGARDING THALASSEMIA AMONG THE COMMUNITY IN ALOR SETAR

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ABSTRACT

Thalassemia, which is an autosomal recessive disease, is a significant public health issue in Malaysia as it is one of the most common genetic diseases in our country. Between 4.5 and 5.0% of the Malaysian population were reported to be the carriers of this disease and 3.0 - 40.0% were HbE (c.79G>A) carriers. Although thalassemia is incurable, it is controllable with effective prevention strategies that could decrease the percentage of affected births by approximately 95%. Thus, this study aimed to determine the knowledge and attitude of a selected community which is Alor Setar, regarding Thalassemia. Respondents living in Alor Setar with a variety of demographic backgrounds were evaluated in terms of knowledge and attitude regarding Thalassemia. The determination of the sample size was derived from a formula that utilised the current population number of 133,000 in Alor Setar and the prevalence of Thalassemia at 5.0 percent. The results were analysed using IBM Statistical package for Social Studies (SPSS) version 29 software. Descriptive statistics were employed to illustrate the socio-demographic features of the subjects. Using the One-Way ANOVA test, the degree of knowledge and attitude were analysed, and the Chi-Square test was employed to examine the relationship between the factors. The significance level was set at 0.05. The results indicated that 98.6% of the population of Alor Setar has a good knowledge of thalassemia, while the remaining percentage has a mediocre understanding. A significant proportion of the population of Alor Setar (86.1%) holds a good attitude towards thalassemia, and the remainder individuals hold a moderate stance on the matter. In conclusion, the research undertaken in Alor Setar unveiled a commendable degree of community awareness and perspectives regarding thalassemia. Significantly, the research demonstrated a correlation between residential location and attitudes towards thalassemia, underscoring the influence of geographical location on attitudes towards the illness. These results support the alternative hypothesis that there is a substantial association between factors associated with thalassemia and that knowledge and attitude regarding thalassemia are both favourable.

INTRODUCTION

Thalassemia is one of the most common genetic blood disorders in the world. It is a genetic disorder that involves the absence of or errors in genes that affect the body's ability to produce a protein (haemoglobin) in the red blood cells. It is autosomal recessive, which means both the parents must be affected with or carriers for the disease to transfer it to the next generation. The two main types of thalassemia are alpha and beta which are further classified based on the severity: trait, minor, intermedia, and major.

Approximately 200,000 individuals are born with β-Thalassemia, with an estimated 240 million heterozygotes globally [1]. Generally, these groups of single gene disorders have an estimated 5 percent prevalence as carriers. Alpha thalassemia is prevalent in Asian and African populations while beta-thalassemia is more prevalent in the Mediterranean population, although it is relatively common in Southeast Asia and Africa too. In Malaysia, as in many other nations, thalassemia is a significant public health issue. About 4.5 percent of Malaysians are carriers of ß-Thalassemia, and the country is thought to have 5,600 patients with transfusion-dependent ß-Thalassemia each year, or 2.1 afflicted births out of every 1,000 [2]. Thalassemia has also affected individuals, and marriages, including their future babies physically, emotionally, and financially. Due to the disorder's inheritance, the Ministry of Health Malaysia (MOH) started the school thalassemia screening programme in 2016 which involves fourth-form students and premarital screenings [3].

The level of knowledge on thalassemia varies

among Malaysians. In a study among the community of Besut [3], the mean thalassemia knowledge scores among parents are still unsatisfactory with a score among the subjects was 11.8 out of a maximum score of 21. This result is similar to that of another study, which used the same questionnaire and was conducted nearly 10 years ago [4]. Among the findings was a quarter of them wrongly thought that carriers would develop thalassemia major.

The treatment options for thalassemia patients include bone marrow transplants and blood transfusion therapy. Other than that, medication to improve iron overload from blood transfusions is a chelation agent, subcutaneous deferoxamine. Less than half (48.7%) were aware that thalassemia major patients require lifelong blood transfusions and that a bone marrow transplant is a treatment option for the disease (34.4%) [3]. In Malaysia, the treatment options for thalassemia patients include bone marrow transplants and blood transfusion therapy, which put a huge economic burden on the Malaysian health system. The Malaysian government funds the cost of the therapy, including the provision of the chelation agent, and subcutaneous deferoxamine [5]. In order to reduce the burdens on patients and the government, the screening programme must be strengthened. Redistributing funds to treat current thalassemia patients with the best care possible and lessen their lifetime socioeconomic burden would be made possible by preventing the birth of newborns with thalassemia major. Therefore, it is crucial to assess the community's knowledge of thalassemia.

The prognosis for thalassemia minor is generally good and it is asymptomatic. Usually, neither morbidity nor mortality are increased by it. The long-term prognosis for thalassemia major, a serious illness, is dependent on treatment compliance with iron chelation and transfusion regimens. Repetitive blood transfusions of 2 units per month result in 400–500 mg of iron per transfusion or about 20 g in 4 years, which is 10-fold more than the normal iron content of the body for adults. Continuous accumulation of iron in the body promotes liver and heart damage due to iron toxicity [6].

In terms of knowledge regarding thalassemia major, the majority (71.4%) knew that these individuals could lead normal and healthy lives with appropriate treatment and have longer life expectancies (61.2%). One-fifth of the parents wrongly believed that the life expectancy of thalassemia carriers is short [3]. There were statistically significant differences ($p<0.005$) between the groups of medical and non-medical students on the awareness and knowledge of whether thalassaemic individuals lead normal lives with appropriate treatment [7].

A person with thalassemia especially beta thalassemia major type usually unable to lead a normal life like other healthy individuals as they are always anaemic and require mandatory blood transfusion thus a study states that half of the respondents state that diagnosis of thalassemia renders the person's daily life, but some patient may live a normal life if they only have thalassemia minors [8]. A person with thalassemia has presentations along a spectrum which ranges from asymptomatic to severe anaemia which requires lifelong blood transfusions. Besides, they may also develop complications from the disease, or it can also develop complications from its treatment which include stunted growth, bone changes, heart failure, delayed puberty and iron overload.

Thalassemia patients will have hyperbilirubinemia secondary to ongoing haemolysis and ineffective erythropoiesis. Bone changes here refer to osteoporosis which is common in thalassemia individuals and is potentially secondary to hypogonadism and other endocrine abnormalities which cause the stunted growth and expansion of marrow cavities [9]. Regular transfusions for these patients with thalassemia major to prevent complications from anaemia will cause iron overload as the iron from the transfusion will accumulate and deposit in the myocardium which will cause cardiac problems which may include arrhythmias and congestive heart failure. They also will have increased susceptibility to infection as this is characteristic of the severe forms of beta thalassemia. Thalassemia patients with severe forms of beta thalassemia both intermedia and major type will have increased tissue deposition of iron which includes due to mandatory blood transfusion that causes this iron deposition [9].

Thalassemia is a group of inherited genetic diseases which are characterized by the decrease in or in the absence of the synthesis of alpha or beta polypeptide chains that are in the normal haemoglobin molecule [10]. Thus, it is an inherited disease which has to do with family history. If a parent has a thalassemia trait and the other is normal, for each child there should be a 50% chance of inheriting the thalassemia gene which makes them a carrier while both parents with thalassemia traits mean they have a 25% chance in each pregnancy of having a child with thalassemia major and a 50% chance of the child becoming a thalassemia carrier. According to the research, most parents did have the general knowledge regarding thalassemia as an inherited disease and multiple studies have already been conducted regarding knowledge of thalassemia however there is still not much improvement in knowledge in thalassemia according to the studies conducted by Wong LP [4].

Thalassemia screening programmes have been implemented in multiple countries including Malaysia. However, the screening differs in terms of mandatory or voluntary screening, and the timing also differs in each country. The screenings are available for 15 to 16 years old school students, pre-marital screenings and screenings for the relatives of known carriers which can help to efficiently identify the beta thalassemia trait and to control the disease from increasing in the future [4]. In Malaysia, there is a school thalassemia screening programme that started in 2016 which involves form 4 students they also were being educated on

thalassemia disease and how it spreads which aims for the reduction of the prevalence of thalassemia in the future.

The World Health Organization has advised countries with a high prevalence of thalassemia to make national guidelines to manage and control the disease and WHO also advocated that focus be placed on public education to educate the public regarding this condition, detection of genetic risks in the community and premarital genetic counselling as thalassemia is an inherited genetic disease [11]. Thus, Malaysia established a programme called the National Thalassemia Prevention and Control Programme in 2004 which has outlined that one of the main activities is health education and promotion. A guideline on the programme was published in 2009 and the government currently has voluntary screening for all citizens who want to be screened and has developed prenatal diagnostic services and protocol to thoroughly investigate the family of an index case. According to Wong L.P [4], it has been reported that community health education and several outreach programmes have helped in controlling the prevalence of the disease and can reduce its health consequences.

Premarital screening can prevent the birth of beta thalassemia major. For now, several studies conducted in Malaysia among premarital couples are positive regarding screening promotions [4]. Premarital screening is the most advantageous, cost-effective, and ethically acceptable in several countries that make premarital screening a standard practice like Greece, Cyprus, and Iran. however, in Malaysia, there is no premarital screening for thalassemia but there is HIV despite the high prevalence of thalassemia compared to HIV [11].

A study was conducted to assess the level of knowledge and attitude regarding Thalassemia among the community in Alor Setar, Kedah, Malaysia.

METHODOLOGY

This study gathered data from 280 participants, consisting of 193 girls and 87 males ranging in age from 18 to 80 years. A cross-sectional study was undertaken in the community of Alor Setar using a convenience sampling method. The questionnaire is distributed via social media platforms and through in-person interviews. In conjunction with this sampling technique, participants are selected for the study based on their attendance at convenient times and places, which enables rapid, effective, and efficient data gathering from a significant number of individuals. The questionnaire is categorized into three sections; Section A pertains to social demographics; Section B concerns the level of knowledge regarding Thalassemia within the community of Alor Setar; and Section C investigates the attitude of the population of Alor Setar towards Thalassemia. In order to maintain anonymity, personal respondent information like complete name, identifying data number, and actual address is not documented. Respondents are obliged to provide a single response and are reliant on the Google form via their Google account. The research was carried out between November 8th and November 30th, 2023. The Google form questionnaire was disseminated electronically through social media platforms, specifically Facebook and WhatsApp groups associated with the Alor Setar community. We distribute the QR code and link to the questionnaire to multiple WhatsApp groups within the Alor Setar community, as each group is limited to a maximum of 1024 members. Physical copies of the questionnaire were distributed to members of the community in Hospital Sultanah Bahiyyah, Klinik Bandar Alor Setar, Pusat Kesihatan Daerah Alor Setar, Aman Central, Souq TF Mart, and Pekan Rabu, in addition to conducting in-person interviews.

The gathered data were refined and subjected to analysis utilising IBM Statistical package for Social Studies (SPSS) version 29 software. The difference between the degree of knowledge and attitude toward thalassemia in the community of Alor Setar was determined using the One-Way ANOVA test, whereas the association between two factors was examined using the Chi-Square test. The assessment of knowledge and attitude towards thalassemia is determined through the multiplication of the total number of questions and the maximum score obtained for each response, as illustrated in Table 1.

RESULTS

Demographic data were tabulated in Table 2. As shown in Table 3, 79 (28.2%) of respondents possess a moderate level of understanding of thalassemia. In contrast, 201(71.8%) are with good knowledge, consisting of 52 respondents from the B40, 50 from the M40, 28 from the T20, and 71 from the non-working respondents. One-way ANOVA test revealed a statistically significant difference ($p<0.05$) in the level of knowledge pertaining to thalassemia across the various groups of respondents based on their financial status. The post hoc analysis reveals that the distinction

Table 1: The scoring for the level of knowledge and attitude regarding Thalassemia among the community in Kota Setar District

Score	Poor	Moderate	Good
Knowledge (15 questions x 5 marks)	1 – 25	25 – 50	51 – 75
Attitude (13 questions x 5 marks)	1 – 22	23 – 44	45 – 65

Table 2: Demographic characteristics of study population regarding Thalassemia among the community in Alor Setar

	Qualitative Variables	Frequency (%)
1.	Age	
	18 - 25	124 (44.3)
	26 - 35	24 (8.6)
	36 - 45	45 (16.1)
	46 - 55	74 (26.4)
	56 - 65	9 (3.2)
	>65	4 (1.4)
2.	Gender	
	Male	87 (31.1)
	Female	193 (68.9)
3.	Ethnicity	
	Malay	261 (93.2)
	Chinese	8 (2.9)
	Indian	8 (2.9)
	Others	3 (1.1)
4.	Religion	
	Islam	265 (94.6)
	Christian	4 (1.4)
	Hindu	6 (2.1)
	Buddha	5 (1.8)
5.	Level of Education	
	Primary school	3 (1.1)
	SPM	28 (8.6)
	Foundation / Matriculation	22 (7.9)
	Diploma	97 (34.6)
	Bachelor's degree	112 (40.0)
	Master	16 (5.7)
	PhD	2 (7.0)
6.	Marital Status	
	Single	139 (49.6)
	Married	135 (48.2)
	Divorced / separated / widowed	6 (2.1)
7.	Financial status	
	B40	85 (30.4)
	M40	60 (21.4)
	T20	36 (12.9)
	Not working	99 (35.4)
8.	Place of Residence	
	Rural	62 (22.1)
	Urban	218 (77.9)
9.	Thalassemia Status in Family	
	Yes	31 (11.1)
	No	249 (88.9)

Table 3: The level of knowledge regarding Thalassemia among the community in Alor Setar according to respondents' financial status (n=280)

		Poor	Moderate	Good	Total
Financial Status	B40	0	33	52	85
	M40	0	10	50	60
	T20	0	8	28	36
	Not working	0	28	71	99
	Total	0	79 (28.2%)	201(71.8%)	280

between the B40 and T20 groups is statistically significant ($p < 0.05$).

Table 4 demonstrates that among respondents with thalassemia-afflicted family members, just three possess a moderate level of knowledge of the disease, whereas 28 respondents have good knowledge. Among the participants who do not have any family members affected by thalassemia, 76 possess a moderate degree of knowledge pertaining to the disease, whereas 173 demonstrate a high level of knowledge regarding thalassemia. A statistically significant difference in knowledge of thalassemia was found between respondents with and without thalassemia-afflicted family members as determined by a one-way ANOVA test ($p < 0.05$).

Table 5 demonstrates that among respondents residing in rural areas, 21 possess a moderate level of knowledge concerning Thalassemia, whereas 41 exhibit good knowledge in this regard. A total of 160 respondents in rural areas possess good knowledge, whereas 79 respondents have a moderate level of knowledge. A significant association was seen between the residential location of the respondents and their knowledge of thalassemia in Alor Setar, as indicated by a Chi-square test ($p<0.05$). There is no significant difference in knowledge regarding thalassemia between the age group, gender, ethnicity, religion, level of education, marital status, and place of living of the respondents. In addition, there is no significant relationship between knowledge regarding thalassemia with the age group, gender, ethnicity, religion, level of education, marital status, financial status, and family history of thalassemia ($p>0.05$).

According to the data shown in Table 6, 65 male respondents hold a positive attitude towards thalassemia, while the remaining 22 hold a moderate attitude. A total of 176 female participants possessed a positive attitude, whereas an additional 17 expressed a moderate attitude. The results of the one-way ANOVA test indicate that there is a statistically significant difference in gender-specific attitudes toward thalassemia ($p < 0.05$).

According to Table 7, individuals holding bachelor's degrees exhibit the most favourable attitude towards thalassemia (35.4 %) with certificate holders following suit (30.7 %). A mere 5.7 % of responders holding a master's degree have a positive attitude towards thalassemia, whereas only two PhD candidates do. The results of the one-way ANOVA test indicate that there is a statistically significant difference in the attitudes of the respondents about thalassemia based on their degree of education ($p < 0.05$). The results of the

Table 4: The level of knowledge regarding Thalassemia among respondents with or without family members of Thalassemia in Alor Setar (n=280)

		Poor	Moderate	Good	Total
Family Members of Thalassemia	Yes	0	3	28	31
	No	0	76	173	249
	Total	0	79	201	280

Table 5: The level of knowledge regarding Thalassemia among the community in Alor Setar according to place of living (n=280)

		Poor	Moderate	Good	Total
Place of Living	Rural	0	21	41	62
	Urban	0	58	160	218
	Total	0	79	201	280

Table 6: The attitude regarding Thalassemia according to gender among the respondents in Alor Setar

		Poor	Moderate	Good	Total
Gender	Male	0	22	65	87
	Female	0	17	176	193
	Total	0	39	241	280

Table 7: The attitude regarding thalassemia according to the level of education among the respondents in Alor Setar (n=280)

Level of education		Poor	Moderate	Good	Total
	Primary school	0	0	3	3
	SPM	0	12	16	28
	Foundation/ Matriculation	0	3	19	22
	Diploma	0	11	86 (30.7%)	97
	Bachelor's Degree	0	13	99 (35.4%)	112
	Master	0	0	16 (5.7%)	16
	PhD	0	0	2	2
	Total	0	39	241	280

Table 8: The level of attitude among respondents with or without family members of Thalassemia in Alor Setar (n=280)

		Poor	Moderate	Good	Total
Family History of Thalassemia	Yes	0	1	30 (10.7%)	31
	No	0	38	211 (75.3%)	249
	Total	0	39	241	280

post hoc analysis indicate that there is a statistically significant difference in attitude between the foundation level and the SPM level ($p<0.05$).

Table 8 reveals that only 10.7% of those with a family history of thalassemia have a positive attitude about the disease as compared with those without a family history of thalassemia (75.3%). The results of the one-way ANOVA test indicate that there is a statistically significant difference in attitudes between respondents with and without a family history of thalassemia towards the disease ($p < 0.05$). There is no significant difference in attitude regarding thalassemia between the age group, ethnicity, religion, marital status, financial status and place of living of the respondents. In addition, there is no significant relationship between attitude regarding thalassemia with the age group, gender, ethnicity, religion, level of education, marital status, financial status, place of living and family history of thalassemia ($p>0.05$).

DISCUSSIONS

Thalassemia is a common preventable haemolytic disease that is a common public health problem in Malaysia, and this places a great burden on the patient and the healthcare system in Malaysia. It is important to assess the level of knowledge and attitude towards thalassemia in order to know if the health education and promotion efforts by the Ministry of Health reach the public effectively.

In this study, a total of 280 participants responded to the questionnaires. Most of the participants who responded are Malay (93%) which is then followed by other ethnicities thus, the study is unable to analyse if there are any disparities across the ethnic groups in the aspect of knowledge and attitude. The majority of the respondents know that thalassemia is a hereditary disease (86%) and a person (85%). Most of them also know there are two types of thalassemia which are thalassemia alpha and beta (61%). Almost all of the respondents (96%) know that a blood test is a screening for thalassemia, however, there are some of the respondents who thought that imaging tests and urine tests can also determine if a person has thalassemia. 63% of the respondents were aware that thalassemia cannot be treated with antibiotics. There are mixed reactions toward the question of whether thalassemia can be treated and fully cured as 38% of the respondents disagree with the statement, 35% of them agree with the statement, and 27% of them were unsure of this. This shows that the public knows about the general knowledge about thalassemia but is unaware about the prognosis of the thalassemia and this knowledge is important for

the public to know as this could create unnecessary anxiety among the public about the disease.

In this study, people are aware about the symptoms of thalassemia as 60% of the respondents aware of the symptoms of thalassemia carrier however, when asked about the lifespan of the thalassemia carrier is shortened 30% of the respondents were unsure while 33% of the respondents agreed with the statements. They also wrongly believed or were unsure that children born to couples where either parent is a thalassemia carrier are at risk of having thalassemia major (74%). Understanding the difference between thalassemia major and thalassemia carrier state may be difficult for the public particularly for individuals with lower economic status as they have significant differences between the knowledge and the financial status of the respondent. Most of the respondents were aware of thalassemia major and how these individuals require regular blood transfusions throughout life (61%) however, half of the respondents (52%) falsely believed or were unsure that thalassemia major individuals are mentally handicapped hence this shows that the knowledge of thalassemia regarding the management of the disease satisfactory but there is some misconception that may be going around the public.

The result of this study showed that the knowledge of thalassemia among the community in Alor Setar is associated with financial status and family members with thalassemia. There is a significant difference between the B40 group and the T20 group which may suggest that awareness of thalassemia was higher in high-income categories which can be due to T20 groups who may have professional occupations as it corresponds to having higher education levels and having better access to sources of knowledge. However, more than half of the B40 respondents have a good knowledge regarding thalassemia. It is proven in this study that respondents who have family members with thalassemia have more knowledge regarding thalassemia.

In relation to the level of knowledge on thalassemia varies among Malaysians, C.R. Vasudeva et al. (2015) study among the community of Shah Alam, comparatively, 72.8 percent of non-medical students were unaware that thalassemia was linked to a decrease in red blood cells, whereas 65.7% of medical students were aware of this connection. While 82.7 percent of non-medical students were unaware that thalassemia is linked to low iron levels, 78.5 percent of medical students were aware of this connection. The prevalence of thalassemia among Malaysians was unknown to about 35 percent of medical students and 64.1% of non-medical students. According to the study, medical students are more knowledgeable**.**

Respondents were asked about their attitude towards thalassemia and 86.1% of the respondents showed a good attitude towards thalassemia while 13.9% of the respondents showed a moderate level of attitude regarding thalassemia Majority of the respondents agreed that the thalassemia screening program for form 4 student is required (73%) and for premarital thalassemia screening (82%). This reflects the positive attitude of the community in Alor Setar towards thalassemia screening In this study, 60% of the respondents agreed that individuals who are carriers of thalassemia should avoid marrying other carriers whereas the studies conducted in Kelantan, 31.7% of the respondents agreed that thalassemia carriers should not married each other. The majority of the respondents did not agree with the termination of pregnancy with thalassemia regardless of type (56%) while only a few (9%) agreed whereas others were unsure. These findings may imply that most of our respondents are practicing Islam hence they were not accepting pregnancy termination even though Islamic regulations allow termination of pregnancy for thalassemia major cases before 120 days of gestation based on National Malaysian Fatwa.

STUDY LIMITATION AND RECOMMENDATIONS

In the course of conducting this research study, several limitations emerged, impacting the accuracy of the investigation. One significant limitation was the time constraint. This study took place within a brief 6 weeks which allowed only 2 weeks for data collection. This constraint impacted the depth of our findings. Participants may not have had enough time to respond thoroughly and at the same time, we were not able to collect an adequate amount of sample size. As a result, it impacts the quality and accuracy of our study.

Moreover, we encountered issues related to limited sample representativeness. Despite targeting 300 respondents, certain groups within the Alor Setar were underrepresented or excluded, leading to potential biases in the findings. Notably, ethnic disparities were observed, with Malay ethnicity significantly dominating other ethnic groups. Additionally, there was an age bias as older individuals with limited technological access might have been excluded. These discrepancies compromised the diversity of perspectives and potentially skewed the outcomes.

Lastly, a social bias was evident in the study regarding the exposure to Thalassemia based on educational levels. Those with higher education are more likely exposed and familiar with the topic, whereas individuals with lower levels of education showed minimal to no exposure. This imbalance created an inherent bias in assessing knowledge and attitudes towards Thalassemia, as one group lacked adequate information, impacting the fairness of the assessment.

In response to these limitations, several recommendations could improve future research endeavours. One recommendation is extending the data collection period. Allowing participants more time to consider and respond thoughtfully would likely enhance the quality of responses. Additionally, widening the pool of respondents by extending the data collection duration would yield a more

comprehensive dataset. Furthermore, using diverse sampling techniques becomes crucial. Techniques like systematic sampling, stratified sampling, or snowball sampling could help reach underrepresented groups within Kota Setar, ensuring a more inclusive and diverse representation in future studies. Additionally, educational programmes aimed at increasing awareness about Thalassemia among less-informed demographics within Kota Setar allow equal exposure to information regarding Thalassemia and would contribute to a more accurate research result.

Implementing these recommendations would address the identified limitations, enhancing the depth, representativeness, and accuracy of future research studies on Thalassemia within the Kota Setar community.

CONCLUSION

The study showed positive results regarding Thalassemia knowledge and attitude. With 280 respondents in Kota Setar, the findings revealed that 98.6% of individuals have high knowledge and 86.1% have positive attitudes towards Thalassemia. There is also a significant relationship between attitude towards Thalassemia and the place of living, highlighting the impact of locality on attitudes towards the condition.

Improvement can be made for future research studies by extending the data collection period, employing diverse sampling techniques, enhancing inclusivity and reaching underrepresented groups within Kota Setar. Furthermore, implementing educational programs targeted at less-informed demographics would ensure equal exposure to Thalassemia information.

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