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Advancing Quality of Life through Thalassaemia Awareness with THALEA

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Abstract

Thalassaemia is a severe hereditary disease, but most carriers are unaware of their risk, increasing the chance of having children with thalassaemia major. Premarital screening is important, but awareness among youths remains low. To address this, we developed and validated the Thalassaemia Education and Awareness (THALEA) Kit, a theory-based intervention for high school students using the ADDIE framework. THALEA contains nine educational materials and shows strong validity. The S-CVI/Ave was 0.95, and the average S-FVI/Ave was 0.96, indicating excellent agreement and validity across all items. In conclusion, THALEA has the potential to improve thalassaemia knowledge and screening intentions among adolescents.

Keywords: Thalassaemia diagnosis; Premarital counselling; Health education; Thalassaemia prevention and control

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1.0 Introduction

Thalassaemia is among the most common inherited blood disorders across the globe, with a particularly high prevalence across Asian and Middle Eastern countries (Chun et al., 2023). The condition places a heavy burden on affected individuals, families, and even public health systems, as thalassaemia major patients require lifelong blood transfusions and chelation therapy. These ongoing treatments often negatively impact their mental health and financial well-being, thereby severely affecting their quality of life. (Ibraheem et al., 2022). Countries like Malaysia, which subsidise treatments for these patients, are also economically compromised, as the lifetime cost of managing a single thalassaemia major patient is estimated at approximately three million Malaysian Ringgit, equivalent to 714,000 United States Dollars (Shafie et al., 2021). Without early screening, two asymptomatic thalassaemia carriers may unknowingly marry, with each pregnancy carrying a 25% risk of producing a child with thalassaemia major (Ibrahim et al., 2020). Of particular concern is the estimate that Malaysia has over 2 million thalassaemia carriers, with hundreds of new cases identified annually, a trend that highlights the persistent public health burden. This requires an urgent need for effective preventive strategies. Premarital screening for thalassaemia in Malaysia has long been recognised as a pivotal prevention strategy; however, unlike premarital HIV testing, thalassaemia screening remains voluntary and is not mandated by law. To address this, the government launched the National Thalassaemia Prevention and Control Programme back in 2016, which introduced early screening for students in government secondary schools.

However, this initiative excluded those enrolled in private secondary schools, despite their students being equally at risk of inheriting the disorder. Moreover, recent studies further indicated that awareness of thalassaemia remains alarmingly low among young people, despite ongoing health promotion efforts (Mohd Nor et al., 2022). Hence, in response to this, we developed and validated the Thalassaemia Education and Awareness (THALEA) Kit—a theory-driven educational intervention designed to improve knowledge, shape attitudes, and strengthen intentions to pursue voluntary screening among private secondary school students. This effort can potentially enhance the quality of life among the younger generation. Specifically, our objectives include:

1) To develop the THALEA Kit for private secondary school students to be delivered by medical personnel.
2) To determine the validity of the THALEA Kit.

2.0 Literature Review

2.1 Thalassaemia on the global and local platform

There are approximately 15 million people who are currently living with thalassaemia, and it is further estimated that 56,000 infants are born each year with severe forms of the disease (Thalassaemia International Federation, 2023). The global prevalence of thalassaemia carriers is even higher, with an estimated range of 1.5% to 4.8% of the population worldwide, equivalent to approximately 270 million individuals (Kattamis et al., 2020). Despite long-standing prevention efforts, thalassaemia remains a significant public health issue in Malaysia. The Malaysian Thalassaemia Registry in 2023 recorded 8,749 patients nationwide, emphasising the ongoing need for treatment and support. While new affected births have declined over the past few years, 34 infants were still born with severe forms of thalassaemia in the same year, indicating the hereditary nature of the condition. The mortality rates remain a concern, as they have not seemed to waver since 2014, with 148 cumulative deaths reported at the end of 2023. These figures emphasise the urgent need to implement effective and widely accepted preventive measures to safeguard the future quality of life of the population and reduce the burden of this debilitating hereditary disease.

2.2 Clinical Theory of Thalassaemia

Thalassaemia, a complex and diverse group of inherited blood disorders, is characterised by the reduced or absent synthesis of haemoglobin chains, resulting in impaired red blood cell function (Kattamis et al., 2020). The severity of thalassaemia can vary widely. People who carry the thalassaemia trait, often referred to as thalassaemia minors or thalassaemia carriers, typically exhibit only mild changes in their blood and do not display obvious signs or symptoms. (Musallam et al., 2024). In contrast, thalassaemia major is characterised by severe forms of anaemic symptoms such as shortness of breath, fatigue, and growth impairment, requiring frequent blood transfusions for survival (Thalassaemia International Federation, 2021). Specific literature classifies thalassaemia into transfusion-dependent thalassaemia (TDT) and non-transfusion-dependent thalassaemia (NTDT), based on the requirement for blood transfusions. Many individuals remain unaware that the initial step of thalassaemia screening is a straightforward and rapid process. They can be completed quickly and interpreted within a short timeframe. More advanced testing is only necessary when initial screening results are inconclusive or when a definitive diagnosis is required.

2.3 Thalassaemia and the Quality of Life (QoL)

Beyond the outward signs of anaemia, thalassaemia has a significant impact on patients' health-related quality of life (HRQoL). According to studies that employ validated tools such as the SF-36, EQ-5D, and PedsQL, TDT patients consistently report worse scores across physical, emotional, and social dimensions compared to the general population (Shafie et al., 2021). The burden of chelation therapy, including the problems of iron overload and the requirement for lifelong blood transfusions, all contribute to fatigue, limited physical functioning, and long-term organ damage, which collectively lower QoL (Chun et al., 2023). Overall well-being is further jeopardised at the family level by the high financial costs of treatment, the time needed for hospital visits, and carer stress (Alwi & Syed-Hassan, 2022). When considered as a whole, research indicates that thalassaemia not only reduces life expectancy but also negatively affects daily functioning and psychological well-being, underscoring the importance of early detection and preventive measures in maintaining quality of life.

2.4 Screening for Thalassaemia

Screening typically begins with a simple blood test, such as a complete blood count (CBC) or a full blood count (FBC), which evaluates the size and concentration of red blood cells. The test is performed by collecting a small blood sample using standard venipuncture techniques. This is followed by a confirmatory haemoglobin analysis and molecular testing, as indicated, which aligns with recent international and Malaysian guidelines. Many individuals remain unaware that the initial step in thalassaemia screening is a straightforward and rapid process. They can be completed quickly and interpreted within a short timeframe. More extensive testing is only necessary when initial screening results are inconclusive or when a definitive diagnosis is required, such as in complicated or borderline cases. Another form of thalassaemia screening is prenatal testing, which is available through government health services (Ibrahim et al., 2020). However, parents may consider terminating their pregnancy if the prenatal testing diagnoses a child with thalassaemia major. That decision is considered culturally and religiously sensitive, particularly in Muslim-majority countries like Malaysia, where abortion is generally not permitted by the law (Kuek, 2022). Consequently, relying solely on prenatal diagnosis at the antenatal stage may not be the most appropriate preventive strategy in a country with a rich cultural and religious background. Instead, the implementation of early carrier detection through school-based programmes and premarital screening initiatives offers a more proactive, culturally acceptable, and ethically sensitive approach to reducing the incidence of thalassaemia major births in Malaysia (Wong et al., 2011)

2.5 Educational Gaps and Awareness among Adolescents

Studies have shown how adolescents lack awareness of the hereditary transmission of thalassaemia and the importance of screening, most often due to misconceptions about the carrier status, stigma, and limited health education exposure (Hasanshahi & Khanjani, 2021). School-based health programmes in Malaysia have demonstrated the potential to enhance adolescent knowledge, but translating this into long-term behavioural change remains a challenge. For example, the 'Eat Right, Be Positive about your Body and Live Actively' (EPaL) programme, targeting Malaysian adolescents, improved health knowledge and attitudes post-intervention, but changes in intention and sustained behaviour were limited (Sharif Ishak et al., 2020). Another example is the *Eduvariome* programme, which promoted knowledge about thalassaemia among school students. However, the evaluation is limited to assessing knowledge alone, thereby limiting its overall impact (Rashid et al., 2020). It is imperative to integrate health educational interventions with appropriate theories to guarantee effective and comprehensive outcomes for adolescents.

2.6 The Theory of Planned Behaviour (TPB)

The TPB by Fishbein & Ajzen (1977) was chosen as the framework for this intervention because it has the potential to predict and improve behavioural intentions, which is the key outcome for the THALEA Kit. According to the TPB, attitudes, subjective norms, and perceived behavioural control collectively shape behavioural intentions, making the model well-suited for designing health promotional interventions, as per Figure 1. Extensive evidence supports its use, as evidenced by a recent randomised controlled trial in Iran, which found that a TPB-based programme significantly improved preventive behaviours among mothers of thalassaemia patients (Zareban et al., 2024). Similarly, school-based interventions targeting diet and physical activities also reported positive gains in adolescent behavioural intentions (Jha et al., 2023). In the Malaysian context, the TPB is particularly relevant, as it accounts for cultural and social determinants—such as family expectations and peer norms—that strongly influence adolescent decision-making.

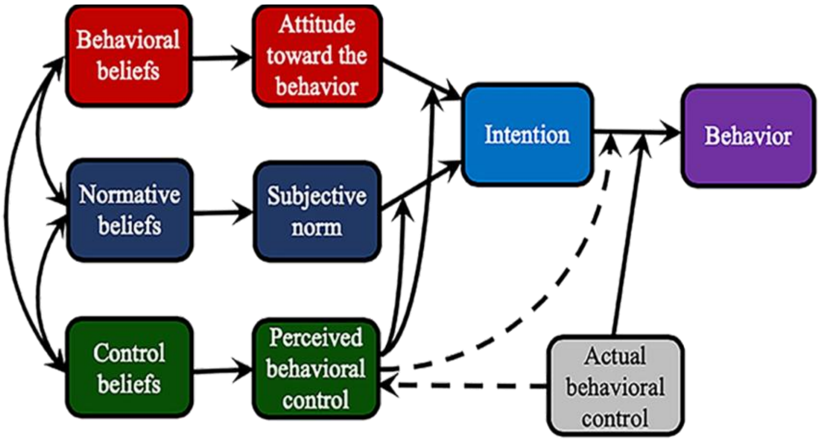

Fig. 1: The Theory of Planned Behaviour
(Fishbein & Ajzen, 1977)

2.7 Culturally Adapted Digital Edutainment Strategies

The integration of edutainment strategies, which combine education with entertaining elements, has become a powerful approach to engage adolescents in learning about health. Digital health interventions and multimedia tools, including interactive platforms, have demonstrated their effectiveness in improving retention, motivation, and health-related outcomes, particularly among younger generations (Whitehead et al., 2024). In Malaysia's multicultural setting, cultural and linguistic adaptation can be critical for the effectiveness of health educational programmes. Studies on health literacy and knowledge suggest that younger and ethnically diverse populations require accessible content, particularly in a language they can understand, to overcome barriers to comprehension (Azlan et al., 2021). Another study also demonstrated how cultural beliefs significantly influence the public perception of genetic testing in the Klang Valley, Malaysia (Chin & Tham, 2020). Therefore, apart from being digitally enhanced, health interventions should incorporate entertaining elements and be culturally adapted to the target population to maximise engagement, effectiveness, and retention.

3.0 Methodology

The development and validation of the THALEA Kit followed the ADDIE instructional design model as illustrated in Figure 2.

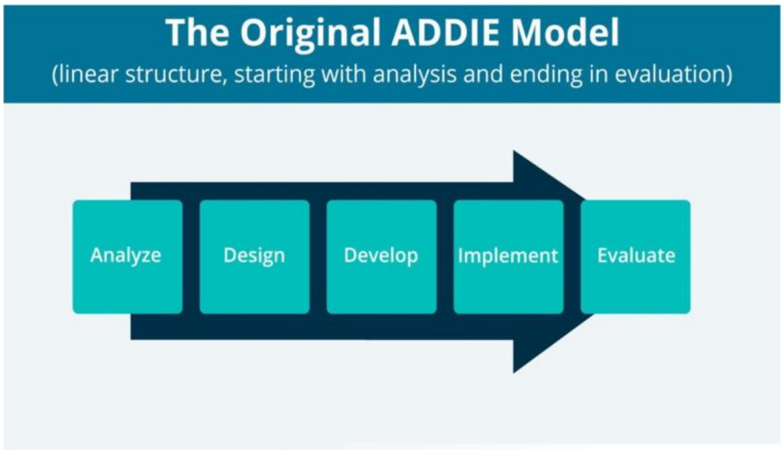

Fig. 2: The ADDIE Model
(Bouchrika, 2022)

3.1 Analysis phase
For the initial phase, two types of information were collected and utilised in a standardised manner. First, there is pre-existing information which are available online. These include national guidelines, national registries, information from governmental health campaigns, research based in Malaysia, and several international resources mainly from the World Health Organisation (WHO), the Thalassaemia International Federation (TIF), and published international studies. The second information source was new information obtained from a panel of experts via the Modified Delphi Technique. The panel comprised nine experts from both the medical and educational fields, each with more than five years of professional experience and bilingual proficiency in the Malay and English languages. Both types of information were analysed, and findings were then used in the next stage of the ADDIE model.

3.2 Designing phase
In this phase, findings from the initial analysis were systematically mapped into the constructs of the TPB. The knowledge component was designed to address behavioural beliefs, such as understanding inheritance patterns and recognising the benefits of early screening. For the normative belief components, analytical findings suggested the inclusion of peers and social acceptance. Regarding perceived behavioural control, it is suggested that students require a practical guide on accessing screening services in the country. Building on this, the attitude component was designed to foster positive perceptions toward premarital thalassaemia screening. Additional reinforcements were also added to the components of subjective norms and control beliefs. Collectively, these elements were structured to strengthen students' intention to pursue premarital thalassaemia screening, which represents the outcome targeted by the second phase of this research.

3.2 Development phase
The development phase focused on producing a kit, based on part of the Bloom's Taxonomy of Learning, that could be easily delivered to secondary school students by healthcare personnel. As most clinical resources on thalassaemia are available in English, the contents of the kit were drafted in English and subsequently translated into Malay by two independent language and teaching experts. This is to ensure linguistic accuracy and minimise bias. The majority of the materials were created by the researcher using digital design platforms such as Canva, while a professional illustrator illustrated the comic book. All content had been identified and refined during the initial analysis and design phase, enabling the development process to transform these resources into a cohesive educational kit.

3.3 Implementation phase
Following development, the implementation phase ensued, during which the THALEA Kit was integrated into validation procedures. Two methods of validation were employed: content and face validity. For content validation, nine experts independently evaluated each item using a four-point relevance scale, allowing for the calculation of the item-level content validity index (I-CVI) and the scale-level average content validity index (S-CVI/Ave). For face validation, 30 fourth-form students from a private secondary school assessed the clarity, relevance, and cultural appropriateness of the materials using a four-point Likert scale, from which item-level (I-FVI) and scale-level (S-FVI/Ave) indices were computed.

3.4 Evaluation phase
According to established standards, an I-CVI of ≥0.78 and an S-CVI/Ave of ≥0.80 are considered acceptable (Nirdnoy et al., 2023). Calculations were made based on a formula by Polit &Beck (2006), as shown below:

1) Item-level content validity index formula:

$$I-CVI = \frac{Nc}{n} \qquad (1)$$

Nc = Number of experts agreeing on each item (values 3 & 4)

n = Total number of experts

2) Scale-level content validity index formula:

$$S - CVI = \frac{\Sigma(I-CVI)}{p} \tag{2}$$

p = Total number of items

For face validation, a minimum threshold of 0.83 is recommended (Yusoff, 2019). The formula used for face validity was also taken from Polit & Beck (2006), as shown below:

1) Item-level face validity index formula:

$$I - FVI = \frac{Number\ of\ respondents\ who\ rated\ the\ item\ as\ 3\ or\ 4}{Total\ number\ of\ respondents} \tag{3}$$

2) Scale-level face validity index formula:

$$I - FVI = \frac{Total\ I{-}FVI}{Total\ number\ of\ items} \tag{4}$$

4.0 Results and Findings

4.1 Development outcomes

The THALEA Kit was finalised as a bilingual education package (English and Malay)to ensure understanding and cultural appropriateness for secondary school students in Malaysia. It was designed for delivery by healthcare personnel in school settings. The materials of the THALEA Kit are summarised in Table 1.

Table 1. Materials of the THALEA Kit

Number	Materials	Format	Purpose/Function
1.	Slide presentation	Interactive Canva slide deck	Provides structured health education with prompts to stimulate discussion and engagement based on the behavioural belief component of the TPB.
2.	Poster	Large-format print	Reinforces key messages on the normative beliefs and subjective norms components of the TPB.
3.	Comic book	Illustrated booklet	Presents complex concepts in a youth-friendly, entertaining, and relatable format based on the behavioural belief component of the TPB.
4.	Guidebook	Illustrated manual	Offers step-by-step information on inheritance, screening procedures, and service access based on the control beliefs section of the TPB
5.	Web-based quiz	Kahoot quiz	Assesses knowledge acquisition and reinforces learning through self-testing, mainly covering most of the components of the TPB
6.	Short videos (3)	Digital media clips	Complement other materials by delivering concise, visually engaging health messages

4.2 Content Validity Index (CVI)

The I-CVI value ranged from 0.89 to 1.00, reflecting strong consensus among the expert panel. Eight of the 15 items (53.3%) achieved perfect agreement (I-CVI = 1.00), while the remaining seven items scored 0.89, which still surpassed the minimum recommended threshold of 0.78 for panels of six or more experts. At the scale level, the S-CVI/Ave was 0.95, indicating excellent overall content validity.

4.3 Face Validity Index (FVI)

Face validity testing, conducted among 30 secondary school students, utilised a four-point Likert scale, where participants rated the clarity, relevance, and cultural appropriateness of the materials. The I-FVI scores ranged from 0.90 to 2.00, indicating that nearly all items were perceived as clear and understandable by students. At the scale level, the S-FVI/Ave was calculated at 0.96, with 96% of raters agreeing that the THALEA Kit was clear, relevant, and appropriate.

5.0 Discussion

The application of the ADDIE instructional design model is vital to ensure that the development process is done systematically and with rigour. Each stage—from analysis to development and implementation—was carried out, ensuring the involvement of both experts and students. Notably, the involvement of experts from diverse fields, including healthcare professionals and teachers from various educational backgrounds, significantly added value to the development. Their combined perspectives ensured that the content was not only medically accurate but also suitable for adolescents enrolled in various types of high schools. This multidisciplinary approach strengthened the overall quality and relevance of the THALEA Kit, which aligns with research recommendations that health education tools must integrate subject matter expertise with instructional design principles to maximise effectiveness (Li & Cheong, 2023).

The intervention was based on the TPB, which states that attitudes, subjective norms, and perceived behavioural control together shape behavioural intentions (Fishbein & Ajzen, 1977). By providing information on inheritance and the benefits of screening, reinforcing beliefs through family and peer support, and improving perceived control by offering practical guidance on accessing screening, the THALEA Kit was carefully designed to affect the psychological factors influencing screening intentions. This combined use of the ADDIE model and TPB ensured that the intervention was both methodically developed and theoretically sound, thereby having the potential to produce meaningful behavioural outcomes. Evidence from a randomised controlled trial in Iran shows that TPB-based programs can improve preventive behaviours among mothers of thalassaemia patients (Zareban et al., 2024). Additionally, school-based programs guided by TPB have successfully shaped adolescent health intentions in areas like diet and physical activity (Jha et al., 2023). While direct evidence linking family and peer norms to thalassaemia screening behaviour among Malaysian youth is limited, some studies indicate that peer pressure and parental bonding play important roles in predicting adolescents' risk-taking attitudes (Hanapi et al., 2023). These findings suggest that similar social influences might impact attitudes and intentions regarding health screening behaviours.

The validation findings of this study show that the THALEA Kit is a relevant, clear, and culturally appropriate educational tool for promoting thalassaemia screening among private secondary school students in Malaysia. The content validity indices (CVI) were consistently high, exceeding recommended thresholds. This reflects a strong agreement among experts on the relevance and suitability of the materials (Nirdnoy et al., 2023). Similarly, the high face validity indices (FVI) from student evaluations confirm that they found the kit clear, understandable, and relatable to their sociocultural context. These results indicate that the THALEA Kit meets essential criteria for being scientifically sound, user-friendly, and suitable for the intended target group. This establishes a solid foundation for future implementation and evaluation of outcomes.

When compared to existing literature, the THALEA Kit shows several unique contributions. Previous efforts, such as the *Eduvariome* programme, successfully enhanced genetic literacy among students but only measured knowledge outcomes, with no mention of the theoretical development behind the intervention (Rashid et al., 2020). Other pre-existing national health promotional efforts were also not targeted to specific groups, as the focus was on the public. Additionally, many genetic education programs lack cultural or language adaptation, which limits their acceptance in diverse groups (Chin & Tham, 2020).

The THALEA Kit provides a validated and theory-based resource that healthcare personnel can easily use in school health education programs. Its availability in two spoken languages in Malaysia ensures that students from different verbal backgrounds can access it. The kit incorporates a comic, videos, and an interactive quiz, which may improve engagement and retention. This aligns with recent evidence that affirms the positive effects of digital and educational entertainment strategies for promoting adolescent health (Whitehead et al., 2024). Importantly, by focusing on private secondary school students, who are currently excluded from the National Thalassaemia Prevention and Control Programme, the kit addresses a significant policy issue. This demonstrates its potential to complement existing national efforts and broaden preventive strategies to groups that have not been adequately reached.

Beyond the private school setting, this kit also shows potential for broader use. Its clear and culturally relevant design suggests that it can be applied in different educational contexts, including government schools and community youth programs. Additionally, the kit's digital flexibility allows it to be integrated into online health education platforms and national awareness campaigns, increasing its reach. In the long term, providing young people with accurate information and promoting positive attitudes and intentions toward screening may help reduce the impact of thalassaemia in Malaysia. This effort aligns with public health goals to improve population health and quality of life (Alwi & Syed-Hassan, 2022; Ibrahim et al., 2020).

6.0 Conclusion and Recommendations

This study developed and validated the THALEA Kit, showing strong content validity and high face validity among students. These findings support its use in promoting adolescent health. The limitations of the study include that face validation was only conducted among students, excluding parents and teachers whose feedback could have improved the clarity and acceptability of the materials. Usability testing with healthcare personnel who would deliver the kit was also not conducted. This step is important to ensure the kit can be implemented effectively in real settings. Future work should include usability testing with healthcare personnel to ensure the kit's practicality and feasibility in real settings. Engaging more stakeholders, such as parents, teachers, and school administrators, will provide a holistic understanding of the intervention's integration into educational and family contexts. Controlled trials should evaluate the kit's effectiveness in reducing thalassaemia burden and improving students' knowledge, attitudes, and screening intentions. Moving forward, the kit can be expanded to public schools, integrated into national prevention efforts, and explored for commercialisation and training of healthcare personnel, enabling delivery to private institutions. Ultimately, THALEA has strong potential as a culturally adapted tool to reduce thalassaemia burden and enhance the quality of life of youth in Malaysia.

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Paper Contribution to the Related Field of Study

This paper contributes to the field of public health, especially in the educational and promotional fields.

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