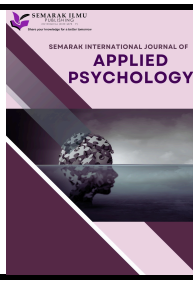
Semarak International Journal of Applied Psychology

Journal homepage:
https://semarakilmu.digital/index.php/sijap/index
ISSN: 3030-525X



Thalassemia Awareness and Screening Practices: A Study on Knowledge, Perceptions, and Attitudes among Nursing Undergraduates at International Islamic University Malaysia (IIUM)

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ARTICLE INFO

Article history:
Received 5 December 2024
Received in revised form 25 December 2024
Accepted 31 December 2024
Available online 20 January 2025

Keywords:
Thalassemia; knowledge; awareness; attitudes; nursing students

ABSTRACT

Background: Thalassemia is a significant public health concern in Malaysia, particularly among certain ethnic groups. Healthcare providers play a crucial role in managing and preventing the disorder, making it essential to assess their knowledge, awareness, and attitudes (KAA). Problem Statement: Despite thalassemia's prevalence, there is limited research on the preparedness of nursing students to address the condition, potentially indicating gaps in education and readiness for professional roles. Objective: This study evaluates the KAA of thalassemia among undergraduate nursing students at the International Islamic University Malaysia (IIUM).Method: A cross-sectional survey of 191 nursing students used a structured questionnaire to assess demographic factors, knowledge, awareness, and attitudes towards thalassemia screening. Statistical analyses, including Chi-square tests and logistic regression, were conducted to identify key factors influencing KAA. Results: Of the participants, 73.3% demonstrated good knowledge, and 99.0% exhibited high awareness of thalassemia. Positive attitudes towards screening were seen in 86.9% of students, with attitudes significantly linked to academic progression ($p = 0.03$). Conclusion: The findings highlight the need for improved educational programs on thalassemia in nursing curricula, with a focus on genetic counselling and early screening, to enhance the management and prevention of thalassemia in Malaysia.

1. Introduction

Thalassaemia remains a pressing public health concern in Malaysia, particularly among specific ethnic groups, where its prevalence is notably high [1]. As a genetic disorder, thalassaemia requires targeted public health strategies to manage its impact effectively. Central to these strategies is the role of healthcare providers, whose knowledge, awareness, and attitudes (KAA) significantly influence patient outcomes and public health initiatives. However, despite the widespread

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https://doi.org/10.37934/sijap.5.1.5464a

prevalence of thalassaemia, research suggests that awareness and understanding of the condition remain inadequate. For instance, a study conducted among university students in Bangladesh reported that only 36.42% had a fair understanding of thalassaemia [2]. This finding highlights a broader regional challenge that may reflect similar trends in Malaysia, particularly among healthcare trainees.

In the context of nursing education, particularly at the International Islamic University Malaysia (IIUM) Kuantan, equipping future healthcare professionals with comprehensive knowledge and positive attitudes towards thalassaemia is imperative. Nursing students, as future front-liners, play a pivotal role in patient education, genetic counselling, and the implementation of screening programmes. Evaluating their current perspectives and understanding of thalassaemia is therefore crucial to ensuring their readiness to assume these responsibilities effectively.

This study aims to assess the KAA of thalassaemia and its screening among undergraduate nursing students at IIUM. Such an assessment is vital for identifying gaps in knowledge and preparedness, which can then inform educational interventions. These interventions are expected to enhance the students' ability to provide informed and compassionate care, ultimately improving patient outcomes and supporting public health goals.

The significance of this research lies in its potential to bridge the knowledge gap within the nursing curriculum. By fostering a well-informed nursing workforce, the study seeks to enhance the efficacy of thalassaemia screening programmes and genetic counselling services. Nurses' attitudes towards screening are particularly critical, as they directly influence the success of these programmes. This study aims to ensure that future nurses are not only well-prepared academically but also equipped to advocate for and participate in public health initiatives aimed at managing thalassaemia.

In the context of nursing education at the International Islamic University Malaysia (IIUM) Kuantan, there is a distinct need to evaluate the current perspectives of undergraduate nursing students towards thalassaemia and its associated screening programmes. Nurses, as frontline healthcare providers, are integral to ensuring the early detection of thalassaemia, offering genetic counselling, and promoting awareness about preventive measures. However, without adequate knowledge and the right attitudes, their ability to fulfil these responsibilities may be compromised, potentially impacting the effectiveness of public health strategies and patient care.

The significance of this study lies in its potential to bridge this crucial knowledge gap. By assessing the KAA of thalassaemia among nursing students at IIUM, this research aims to provide valuable insights into the current state of education and awareness within the nursing curriculum. Identifying these gaps will enable the development of targeted interventions that can improve the preparation of nursing students, equipping them with the necessary knowledge and positive attitudes to support thalassaemia management. In doing so, this study can contribute to improving patient outcomes and enhancing the effectiveness of public health initiatives related to thalassaemia screening and genetic counselling.

In summary, this study addresses an important gap in nursing education by focusing on the KAA of thalassaemia among nursing students at IIUM Kuantan. By improving their educational foundation, this research contributes to strengthening the overall healthcare response to thalassaemia, promoting better patient outcomes, and enhancing public health strategies in Malaysia.

2. Methodology

2.1 Study Design

This study employed a quantitative cross-sectional design conducted among undergraduate nursing students at the International Islamic University Malaysia (IIUM), Kuantan campus. Participants were selected based on inclusion criteria, which comprised Year 2 to Year 4 undergraduate Malaysian nursing students, while those on study leave or unwilling to participate were excluded. Stratified random sampling was used to ensure proportional representation of students across academic years. From a total population of 376 eligible students, a sample size of 191 was calculated using the Raosoft Sample Size Calculator, applying a 5% margin of error, a 95% confidence interval, and a 50% response distribution.

2.2 Measurements

Data were collected using a structured questionnaire adapted from Wahidiyat *et al.,*[3]. The instrument comprised four sections:

- **Part A:** Demographic information, including age and year of study.
- **Part B:** Knowledge of thalassemia, assessed through 12 questions.
- **Part C:** Awareness of thalassemia, assessed through 8 questions.
- **Part D:** Attitudes towards thalassemia screening, evaluated through 4 questions.

Each section's scoring guidelines determined the range of possible scores, allowing for a comprehensive assessment of participants' knowledge, awareness, and attitudes.

2.3 Variables

The independent variables were the participants' year of study and age, while the dependent variables included the levels of knowledge, awareness of thalassemia, and attitudes towards thalassemia screening.

2.4 Ethical Considerations

Ethical approval for this study was obtained from the Kulliyyah of Nursing Postgraduate Research Committee (KNPGRC) and subsequently from the IIUM Research Ethics Committee (IREC). Upon receiving clearance, the questionnaire was distributed to participants via Google Forms. The questionnaire included a detailed explanation of the study's purpose and an informed consent form, ensuring voluntary participation. All collected data were strictly for academic use and treated with utmost confidentiality. Data were securely stored in a password-protected computer file accessible only to the researcher. Permission to use and modify the original questionnaire was obtained from its author, with necessary amendments made under the supervision of the principal investigator. Participation was entirely voluntary, with no coercion, and participants were free to withdraw at any stage without consequence.

2.5 Participant Recruitment and Data Collection

Participants were selected based on pre-defined inclusion and exclusion criteria. Undergraduate nursing students from the Kulliyyah of Nursing, IIUM, were invited to participate through an online questionnaire distributed via Google Forms. The first page of the form included an informed consent

statement, requiring participants to acknowledge their voluntary agreement to partake in the study. Only those meeting the inclusion criteria and providing consent proceeded to complete the questionnaire. Students who declined participation were excluded without coercion.

2.6 Data Analysis

Data were analysed using the Statistical Package for the Social Sciences (SPSS) version 27. Responses collected via Google Forms were exported and organised into standardised tables for analysis. Descriptive statistics were used to summarise categorical variables as proportions. The normality of the data was assessed using the Kolmogorov-Smirnov and Shapiro-Wilk tests. A p-value of less than 0.05 indicated non-normal distribution. Consequently, the relationship between the year of study and levels of knowledge, awareness of thalassemia, and attitudes towards thalassemia screening was evaluated using the Chi-square test.

3. Results

3.1 Sociodemographic Data

All 191 participants completed the questionnaire, yielding a 100% response rate. Table 1 presents the sociodemographic characteristics of the respondents, including age and year of study. Participants' ages ranged from 19 to 26 years, with the majority (93.7%) falling within the 21–24 age group.

Regarding the year of study, the distribution was well-represented across all cohorts. Fourth-year students comprised the largest proportion, accounting for 40.8% of the sample. Second-year students made up 30.9%, while third-year students constituted 28.3%. This balanced distribution ensures a comprehensive understanding of knowledge, awareness, and attitudes across different academic levels.

Table 1
Sociodemographic data (n=191)

Variables	Frequency (n)	Percentage (%)
Age (years)		
19-20	8	4.2
21-22	89	46.6
23-24	90	47.1
25-26	4	2.1
≥ 27	0	0
Year of study		
Year 2	59	30.9
Year 3	54	28.3
Year 4	78	40.8

3.2 The Level of Knowledge and Awareness of Thalassemia and Attitude towards Thalassemia Screening

Table 2 presents the levels of knowledge, awareness of thalassemia, and attitudes towards thalassemia screening among undergraduate nursing students at the International Islamic University Malaysia (IIUM).

For knowledge assessment, respondents could achieve a maximum score of 12 and a minimum score of 0. Scores were categorised into two levels: poor knowledge (0–8) and good knowledge (9–12). The data revealed that 140 respondents (73.3%) demonstrated good knowledge, while 51 (26.7%) exhibited poor knowledge.

Awareness of thalassemia was measured across eight questions, with a maximum possible score of 32 and a minimum of 8. Poor awareness was defined by scores ranging from 1 to 22, while good awareness ranged from 23 to 32. The vast majority of respondents are 189 (99.0%), demonstrated good awareness, with only 2 respondents (1.0%) scoring in the poor awareness range.

Attitudes towards thalassemia screening were evaluated through four questions, with scores ranging from 4 to 16. A score of 1 to 12 indicated a negative attitude, while scores of 13 to 16 indicated a positive attitude. The findings showed that 166 respondents (86.9%) held positive attitudes towards screening, whereas 25 respondents (13.1%) exhibited negative attitudes.

These results highlight that most nursing students possess a high level of knowledge and awareness about thalassemia, alongside overwhelmingly positive attitudes towards its screening, indicating a promising foundation for effective future healthcare practice.

Table 2
The level of knowledge and awareness of thalassemia and attitude towards thalassemia screening (n= 191)

Variables	Frequency (n)	Percentage (%)
Knowledge of thalassemia		
Poor	51	26.7
Good	140	73.3
Awareness of thalassemia		
Poor	2	1.0
Good	189	99.0
Attitudes towards thalassemia screening		
Negative	25	13.1
Positive	166	86.9

3.3 Association between Years of Study with Level of Knowledge of Thalassemia

Table 3 presents the relationship between the year of study and the level of knowledge regarding thalassemia among undergraduate nursing students at IIUM. The distribution of students with poor and good knowledge across Year 2, Year 3, and Year 4 is detailed, alongside the p-value assessing the statistical significance of the association.

The findings reveal that among Year 2 students, 21 respondents (35.6%) demonstrated poor knowledge, while 38 respondents (64.4%) exhibited good knowledge. In Year 3, only 11 respondents (20.4%) had poor knowledge, with the majority, 43 respondents (79.6%), showing good knowledge. Similarly, among Year 4 students, 19 respondents (24.4%) were classified as having poor knowledge, whereas 59 respondents (75.6%) demonstrated good knowledge of thalassemia.

In total, 51 respondents (26.7%) exhibited poor knowledge, while 140 respondents (73.3%) displayed good knowledge across all years of study. The Chi-square test yielded a p-value of 0.157,

indicating that the association between the year of study and the level of knowledge was not statistically significant. This suggests that the progression through academic years did not have a significant impact on the students' knowledge levels regarding thalassemia.

Table 3
Association between years of study with level of knowledge of thalassemia (n=191)

Year of study	Poor (%)	Good (%)	Total (%)	p-value
Year 2	21 (35.6%)	38 (64.4%)	59 (100.0%)	0.157
Year 3	11 (20.4%)	43 (79.6%)	54 (100.0%)	
Year 4	19 (24.4%)	59 (75.6%)	78 (100.0%)	
Total	51	140		

3.4 Association between Years of Study with Awareness Level of Thalassemia

Table 4 presents the association between the year of study and the level of awareness of thalassemia among undergraduate nursing students at IIUM. The table outlines the distribution of students categorised by poor and good awareness across different academic years, accompanied by the corresponding p-value to determine statistical significance.

The data reveal that in Year 2, 2 respondents (3.4%) exhibited poor awareness, while 57 respondents (96.6%) demonstrated good awareness. In contrast, all respondents in Year 3 (n = 54) and Year 4 (n = 78) displayed good awareness, with no cases of poor awareness recorded in these cohorts. Collectively, only 2 students exhibited poor awareness across all academic years, compared to 189 students with good awareness.

Statistical analysis yielded a p-value of 0.104, indicating that the association between the year of study and the awareness level of thalassemia was not statistically significant. These findings suggest that the level of awareness remained consistently high across the different years of study, with no substantial variation attributable to academic progression.

Table 4
Association between years of study with awareness level of thalassemia (n=191)

Year of study	Poor (%)	Good (%)	Total (%)	p-value
Year 2	2 (3.4%)	57 (96.6%)	59 (100.0%)	0.104
Year 3	0 (0%)	54 (100.0%)	54 (100.0%)	
Year 4	0 (0%)	78 (100.0%)	78 (100.0%)	
Total	2	189		

3.5 Association between Years of Study with Attitudes toward Thalassemia Screening

Table 5 presents the association between the year of study and attitudes towards thalassemia screening among undergraduate nursing students at the International Islamic University Malaysia (IIUM). This analysis provides critical insights into how academic progression influences students' perspectives on the importance of thalassemia screening.

The findings reveal a significant variation in attitudes across academic years. Among Year 2 students, 13 respondents (22.0%) exhibited negative attitudes towards thalassemia screening, while the majority, 46 respondents (78.0%), demonstrated positive attitudes. Although most second-year

students recognised the importance of screening, a noteworthy minority maintained negative views, suggesting an opportunity for further educational intervention.

In contrast, attitudes among Year 3 students showed a marked improvement. Only 3 respondents (5.6%) exhibited negative attitudes, whereas 51 respondents (94.4%) displayed positive attitudes towards thalassemia screening. This significant shift suggests that academic progression may enhance students' awareness and understanding of the importance of genetic screening.

Similarly, Year 4 students reflected predominantly positive attitudes, with 9 respondents (11.5%) holding negative views and 69 respondents (88.5%) demonstrating positive attitudes. Although the proportion of negative attitudes was slightly higher than in Year 3, the overall trend remained overwhelmingly positive, indicating sustained recognition of the value of thalassemia screening among senior students.

Overall, 25 respondents (13.1%) expressed negative attitudes, while 166 respondents (86.9%) demonstrated positive attitudes. The association between the year of study and attitudes towards thalassemia screening was statistically significant ($p = 0.03$). This finding underscores the importance of academic progression in shaping more favourable attitudes, likely due to increased exposure to relevant knowledge and clinical experiences regarding thalassemia and its screening.

Table 5
Association between years of study with attitudes toward thalassemia screening (n=191)

Year of study	Negative (%)	Positive (%)	Total (%)	p-value
Year 2	13 (22.0%)	46 (78.0%)	59 (100.0%)	0.03
Year 3	3 (5.6%)	51 (94.4%)	54 (100.0%)	
Year 4	9 (11.5%)	69 (88.5%)	78 (100.0%)	
Total	25	166		

4. Discussion

4.1 Knowledge of Thalassemia among Nursing Students

This study assessed the level of thalassemia knowledge among 191 undergraduate nursing students at the International Islamic University Malaysia (IIUM), revealing that 73.3% demonstrated good knowledge. These findings are consistent with prior studies, underscoring the vital role that nursing education plays in fostering genetic literacy.

Research at the Royal College of Medicine Perak, for example, similarly highlighted that nursing students possessed significantly higher levels of knowledge about thalassemia than peers in other medical fields, reinforcing the impact of nursing curricula on understanding genetic condition [4]. Another study found that across various Malaysian universities, nursing students outperformed pharmacy and medical students in thalassemia knowledge, a trend attributed to nursing students' enhanced exposure to clinical and community health education [5].

Despite these positive outcomes, disparities in broader awareness remain. A Bangladeshi study revealed gaps in understanding the socio-cultural implications of thalassemia, such as the importance of prenatal screening, suggesting that even high levels of clinical knowledge may not fully translate into public health literacy [6]. This indicates a need for educational initiatives that address both the biological aspects and the preventative, societal dimensions of thalassemia.

The statistically significant association found between the year of study and knowledge levels ($p < 0.05$) further highlights the impact of academic progression on thalassemia awareness. As students advance in their nursing education, their understanding deepens, likely due to increased exposure to

genetics and public health issues. These findings align with international research demonstrating a positive correlation between the level of education and disease-specific knowledge [7].

In conclusion, while the results affirm that nursing students have a solid foundation of thalassemia knowledge, there remains a pressing need to integrate genetic counselling and public health strategies into the curriculum. This will ensure that future healthcare providers are equipped to deliver comprehensive patient education and play an active role in reducing thalassemia incidence through informed advocacy.

4.2 Awareness Level towards Thalassemia

This study found an exceptionally high level of awareness about thalassemia among undergraduate nursing students at IIUM, with 99.0% of respondents demonstrating good awareness. Only 1.0% exhibited poor awareness, suggesting that IIUM nursing students are well-informed about the disease. Several factors may contribute to this heightened awareness, including access to educational resources such as seminars, workshops, and relevant literature.

Comparing these results to previous studies underscores the distinctiveness of IIUM's educational impact. For instance, a study conducted among undergraduate students in Bangladesh reported that only 1.3% of participants had a good awareness of thalassemia [8]. This stark contrast highlights the effectiveness of IIUM's curriculum and public health initiatives in raising awareness. The high awareness level at IIUM suggests that institutional efforts in promoting genetic literacy may play a crucial role in equipping future healthcare providers with essential knowledge, which can be pivotal for improving patient outcomes.

4.3 Attitude towards Thalassemia Screening

In addition to awareness, this study assessed attitudes towards thalassemia screening among nursing students. An overwhelming majority, 86.9% of the participants, expressed positive attitudes towards screening, indicating a strong readiness among these future healthcare providers to support and participate in screening programmes. Such positive attitudes are critical for the early detection and management of thalassemia, which remains a key component of effective public health interventions.

These findings are consistent with previous research. For example, a study among Indonesian youth found that 83.3% of respondents viewed thalassemia screening positively, particularly as a necessary consideration before marriage [9]. This parallel reinforces the importance of integrating genetic screening education into nursing and healthcare curricula, as it promotes proactive public health engagement and underscores the perceived value of genetic screening in preventing disease transmission.

4.4 Relationship between Years of Study and Knowledge Level

Interestingly, this study found no significant relationship between the year of study and the level of thalassemia knowledge among nursing students ($p = 0.157$). This suggests that knowledge levels remain consistently high across all academic years, indicating that thalassemia education is likely introduced early and reinforced consistently throughout the curriculum. The uniform access to educational materials across academic levels may also contribute to this consistency.

These findings align with similar studies, such as one conducted among first- and second-year medical students in Delhi, which reported no significant relationship between students' knowledge

of thalassemia and their year of study [8]. However, this contrasts with findings from a study among junior doctors in Babylon Province, where a significant association was observed between knowledge and years of practice, indicating that experience can enhance understanding [10]. The consistency of knowledge across academic years at IIUM highlights the strength of its nursing curriculum in delivering comprehensive and early education on thalassemia.

4.5 Relationship between Years of Study and Awareness of Thalassemia

This study found no statistically significant relationship between the years of study and the awareness level of thalassemia among undergraduate nursing students ($p = 0.104$). Regardless of whether students were in their first or final years, awareness remained consistent. This finding aligns with previous research suggesting that static awareness levels may result from well-structured curricula that evenly distribute content across academic years, ensuring uniform exposure to essential knowledge throughout the program. Levine *et a*l., (2023) emphasized that health literacy, particularly in rare diseases like thalassemia, is often influenced by structured educational interventions, rather than the duration of study alone [11]. Furthermore, consistent reinforcement through integrated coursework and clinical case studies likely plays a crucial role in maintaining uniform awareness levels [12].

The lack of variation in awareness may also be attributed to the students' limited opportunity to engage in patient advocacy or outreach activities early in their academic journey, as suggested by studies emphasizing the importance of experiential learning in enhancing disease literacy [13].

4.6 Relationship between Years of Study and Attitude towards Thalassemia Screening

In contrast, a significant association between the years of study and attitudes toward thalassemia screening was observed ($p = 0.03$). The proportion of students with positive attitudes increased from 78% in Year 2 to 94.4% in Year 3, reflecting a marked shift as students advanced academically. This finding resonates with research indicating that attitudes toward health behaviours improve with increased clinical exposure and theoretical understanding [14]. Specifically, the Cleveland Clinic highlights that enhanced understanding of the complexities and management strategies of thalassemia, including genetic counselling and early detection, likely contributes to improved attitudes [15].

Clinical placements play a pivotal role in shaping positive attitudes, as they expose students to real-world implications of early detection and management, thereby fostering empathy and advocacy for screening. These insights support the notion that nursing education, particularly the IIUM program, effectively integrates theoretical knowledge with practical experiences to cultivate a proactive attitude toward thalassemia screening [11].

Moreover, previous studies among health science students in Bangladesh also demonstrate the critical role of academic progression in shaping attitudes, where 88.8% of participants supported premarital screening for thalassemia [16]. This suggests that academic maturity, coupled with exposure to the societal impact of genetic disorders, significantly influences the students' stance on public health interventions.

5. Limitations

This study has several notable limitations, primarily stemming from its cross-sectional design, which restricts its ability to establish causal relationships between years of study and levels of

knowledge, awareness, and attitudes toward thalassemia screening. Cross-sectional studies, while valuable for providing snapshots of variables at a single point in time, are inherently limited in identifying temporal dynamics and causal inferences [17]. Future research employing longitudinal designs would better capture changes over time, offering insights into how students' educational experiences influence their evolving knowledge and attitudes.

Although the study achieved a commendable 100% response rate, response bias remains a potential concern. Participants who chose to engage in the study may have had pre-existing interest or knowledge in thalassemia, potentially skewing the results. This aligns with findings from previous research indicating that self-selection can introduce biases in educational and health-related studies [18]. To mitigate this, future studies should employ strategies such as random sampling or incentivising participation to ensure a more representative sample.

Another limitation is the exclusive focus on nursing students from IIUM's Kuantan campus, which limits the generalisability of the findings. Similar studies have highlighted the need for diverse, multi-institutional samples to ensure broader applicability across different educational and cultural contexts. Including nursing students from various universities and regions in future research would enhance the robustness and external validity of the findings.

Additionally, the reliance on self-reported data introduces the risk of social desirability bias, where participants may provide responses that they perceive as socially acceptable rather than their genuine beliefs. Previous studies have demonstrated the susceptibility of self-reported data to such biases, which can affect the accuracy of research outcomes [19]. Employing mixed-method approaches, such as incorporating qualitative data through interviews or focus groups, could provide deeper insights and help triangulate findings, offering a more nuanced understanding of students' attitudes and awareness [20].

Lastly, the study could be strengthened by a clearer identification of the research gap in the introduction. Explicitly articulating how this study addresses a specific gap in the existing literature would further justify its significance and contribution to the field. Identifying such gaps is critical, as it situates the study within the broader academic discourse and underscores its relevance [21].

6. Conclusions

In conclusion, IIUM nursing students have high level of knowledge and awareness and exhibiting good awareness and positive attitudes. These results highlight the significant role of a structured nursing curriculum in fostering comprehensive knowledge and promoting positive attitudes toward genetic screening programs. However, despite the high levels of awareness and positive attitudes, it remains crucial to sustain and enhance educational initiatives aimed at reinforcing the importance of early screening and management. Overall, the findings suggest that educational interventions focusing on thalassemia awareness are effective in shaping students' attitudes. This study contributes to the growing body of evidence supporting the critical role of health education in promoting proactive health behaviours and fostering a culture of early detection and prevention.

Acknowledgement

This research was not funded by any grant.

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