

# Knowledge and perception of inborn errors of metabolism (IEMs) among healthcare students at a selected public university in Klang Valley, Malaysia

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**SUMMARY** Healthcare providers play an important role in improving the health of Inborn Error of Metabolism (IEM) patients. However, IEM knowledge level among local healthcare students has yet to be determined. Thus, the aim of this study is to assess the knowledge and perception of IEM among local healthcare students. An online self-administered questionnaire was distributed to 378 students across the Faculty of Health Science, Pharmacy and Dentistry from a selected public university in *Lembah Klang*, Malaysia. For knowledge, a score of 1 is assigned to each correct answer with a maximum total score of 14. Likert scale was used to determine their perception of IEM. The total mean score of IEM knowledge among healthcare students is 5.8. There was no significant difference of mean score of IEM knowledge among the students from the Faculty of Health Science ( $6.1 \pm 2.7$ ), Pharmacy ( $5.5 \pm 2.6$ ) and Dentistry ( $5.8 \pm 2.8$ ). However, the score of knowledge is observed to be significantly different by ethnicity, religion and family history of IEM ( $p < 0.05$ ). Furthermore, students with experience of meeting an IEM patient and attending IEM classes scored higher than those with no experience ( $p < 0.05$ ). Most of the healthcare students (89.5%) perceived their knowledge to be insufficient and very poor. Majority of the students from faculty of pharmacy (70.8%) agreed that the IEM course should be mandatory compared to health sciences and dentistry ( $p < 0.05$ ). This study identified an overall inadequacy of knowledge of IEM among healthcare students. There is a pressing need to improve the IEM-related knowledge and awareness of Malaysian healthcare students. This can be accomplished by incorporating online classes that emphasizes the treatment and management of IEMs in the university curriculum.

**Keywords** knowledge, perception, healthcare, inborn errors metabolism

## 1. Introduction

Inborn errors of metabolism (IEM) denote a large group of rare genetic disorders resulting from an enzyme defect in biochemical and metabolic pathways (1). Although individual IEMs are rare, they are common collectively and have a global prevalence of 50.9 per 100,000 live births (2). Although IEM cases are rare in Malaysia, the true number of IEM patients remains unknown as the country lacks a central IEM patient registry and IEM-related awareness among healthcare providers is low (3,4).

The management of IEMs is divided into two parts: diagnostics and long-term care (5). New-born screening (NBS) is a useful tool with which to detect IEMs in early life (6). Basic laboratory tests; such as blood or

urinalysis; can be used in conjunction with clinical evaluation to obtain a differential diagnosis or confirm a diagnosis (7). Meanwhile, the long-term care and treatment of IEM patients involves collaboration of healthcare professionals from multiple disciplines; such as physicians, nurses, pharmacists, dietitians, laboratory practitioners, speech therapists, occupational therapists, dentists, and social workers (8-14). A multidisciplinary team is essential and crucial to provide IEM patients with better quality health care in terms of treatment, psychological support, and educational resources (15).

Healthcare providers play an important role in recognizing and making referrals for appropriate patient management (16). However, there seems to be difficulty obtaining supportive treatment for IEM patients (17) due to a lack of IEM-related knowledge (3). For instance, a

majority (73.6%) of healthcare professionals in Hong Kong were unaware of the availability of IEM screening (18). Furthermore, because many healthcare students report insufficient IEM-related knowledge, they struggle to distinguish rare IEMs from other common diseases (19,20). A Saudi Arabian study also reported an overall lack of IEM-related knowledge, especially among students in non-medical faculties (21,22).

Healthcare students are also more likely to underrate the epidemiology and burden of IEMs (23). One study reported that healthcare students have little IEM-related knowledge and that the majority of them agreed that healthcare funding should prioritize common diseases over IEMs as the latter only affects a small portion of the population (24). Moreover, the majority of healthcare students are unprepared to care for IEM patients (19,20).

Despite the current circumstances, only a limited number of studies have examined factors that influence IEM-related knowledge among healthcare students. Several studies have concluded that individuals with higher levels of education as well as prior knowledge of genetics had more IEM-related knowledge (25,26). Female participants were also found to have higher levels of IEM-related knowledge. This may be due to their natural ability to produce offspring, which increases concerns (*i.e.*, maternal instincts) of prenatal genetic testing (21,22,27). Other factors; such as a family history of genetic disorders; was also found to contribute to higher levels of IEM-related knowledge (21).

A search of the literature through electronic bibliographic databases, such as PubMed<sup>®</sup>/MEDLINE (National Library of Medicine), ScienceDirect<sup>®</sup> (Elsevier) and google scholar revealed that currently, studies to assess the knowledge of IEM patients were conducted in Saudi Arabia and Poland and there was no study conducted among the Asian population as well as Malaysian healthcare students. Therefore, the purpose of this present study was twofold: *i*) to assess the knowledge and perception of IEMs among healthcare students from the faculties of health sciences, pharmacy, and dentistry, and *ii*) to determine the mean difference in IEM-related knowledge scores according to varying pre-specified sociodemographic factors and other factors among healthcare students.

## 2. Materials and Methods

### 2.1. Study design

This present study conducted a cross-sectional survey using convenience sampling. A sub-sample of 378 healthcare students from three different faculties; namely, the Faculty of Health Sciences, the Faculty of Pharmacy, and the Faculty of Dentistry; were recruited. The inclusion criteria included undergraduate healthcare students from three different faculties who were

able to read and understand either Malay or English. An online survey was distributed via social media, mailing lists, and online discussion groups between August and October 2020. This research was approved by the Research Ethics Committee of the National University of Malaysia (approval number: PPI/111/8/JEP-2020-346). Informed consent was obtained from all participants via online forms. All participants were also informed that participation in the present study was voluntary and that all data would be anonymous and confidential.

### 2.2. Questionnaire

A self-administered questionnaire that consisted of four sections and 47 items was adapted from extant literature (19,22) (Supplemental Table S1, <http://www.irdrjournal.com/action/getSupplementalData.php?ID=111>).

Section I collected the demographic information of the participants, such as gender, age, ethnicity, religion, faculty, year of study, marital status, declaration of a family history of IEMs, and previous encounters with IEM patients, if any. Section II evaluated the IEM-related knowledge of the students. It included 14 single-best answer closed-ended questions on the causes, epidemiology, symptoms, diagnosis, management, and organizational issues of IEMs. A score of one was assigned to each correct answer and zero for each wrong answer, with a maximum total score of 14 for the entire questionnaire. The total score was tabulated by summing up the scores of the 14 questions on IEM-related knowledge. Section III included multiple-answer closed-ended questions that required students to select IEMs from a list of 24 IEMs and non-IEM diseases. This assessed their ability to recognise IEM names among other diseases. Section IV included six questions on self-perceived knowledge and opinions on IEMs.

Prior to data collection, the content validity of the survey instrument was established. The content validity index (CVI) was measured based on the opinions of three experts who have experience teaching IEMs or evaluating IEM-related courses. The content validity form contained four domains and 47 items on IEM-related knowledge and perception. The panel of industry experts were requested to rate the degree of relevance, clarity, simplicity, and ambiguity of each item on a scale of one to four, where a score of one denoted that an item was irrelevant, lacked clarity, lacked simplicity, or was not easily understood and a score of four indicated that the item was highly relevant, very clear, very simple, and easily understood. As the relevance of all 47 items achieved an I-CVI score of 1.00, they were all retained based on the established criteria (28). The CVI score in terms of clarity, simplicity, and ambiguity was 0.98. Item 9 was modified according to the recommendations of a panel member. The questionnaire was then forward translated to Malay. A pilot study was conducted at

the Kuala Lumpur campus of the National University of Malaysia (UKM) with 10 students of different sociodemographic backgrounds. The respondents were asked if they had any questions or if they did not understand any of the words used in the questionnaire. They were also asked to share the rationale behind the answer that they provided based on the instructions given after filling in the form. In the second revision, minor changes were made to the questionnaire based on the feedback received from these 10 students.

### 2.3. Statistical analysis

The collected data was analyzed using Statistical Package for the Social Sciences (SPSS) version 25.0. The categorical variables were described in frequencies and percentages while the continuous variables were described as means and standard deviations. A score of one was assigned to correct answers and zero to incorrect answers or the "I do not know" option of the 14 questions on IEM-related knowledge. The total score on IEM-related knowledge was summed up, with scores ranging between 0 to 14 for each respondent.

Descriptive statistics were then used to describe the sociodemographic characteristics of the respondents. The difference in the mean IEM-related knowledge scores according to pre-specified sociodemographic factors and other factors was tested using the independent-samples *t*-test and the one-way analysis of variance (one-way ANOVA). Pearson's chi-squared test was then used to determine the association between the two variable categories. A *p* value of < 0.05 was deemed statistically significant.

## 3. Results

### 3.1. Sociodemographic characteristics

A total of 378 valid respondents completed the survey. Most of the respondents were from the Faculty of Health Sciences (40.8%) while the others were from the Faculty of Dentistry (31.2%) and the Faculty of Pharmacy (28.0%). Table 1 displays the sociodemographic characteristics of respondents from the faculties of health sciences, pharmacy, and dentistry. The average age was  $22.1 \pm 1.5$  years and

**Table 1. Sociodemographic characteristics across the Faculties of Health Sciences, Pharmacy and Dentistry**

Variables	Faculties, <i>n</i> (%)			Total, <i>n</i> (%) ( <i>n</i> = 378)
	Health Science ( <i>n</i> = 154)	Pharmacy ( <i>n</i> = 106)	Dentistry ( <i>n</i> = 118)	
Age				
18-21	52 (33.8)	36 (34.0)	46 (39.0)	134 (35.4)
22-24	96 (62.3)	68 (64.1)	65 (55.1)	229 (60.6)
> 25	6 (3.9)	2 (1.9)	7 (5.9)	15 (4.0)
Gender				
Male	36 (23.4)	28 (26.4)	36 (30.5)	100 (26.5)
Female	118 (76.6)	78 (73.6)	82 (69.5)	278 (73.5)
Ethnicity				
Malay	58 (37.7)	53 (50.0)	64 (54.2)	175 (46.3)
Chinese	83 (53.9)	30 (28.3)	36 (30.6)	149 (39.4)
India	11 (7.1)	14 (13.2)	11 (9.3)	36 (9.5)
Others	2 (1.3)	9 (8.5)	7 (5.9)	18 (4.8)
Religion				
Islam	60 (39.0)	59 (55.6)	66 (55.9)	185 (48.9)
Buddha	76 (49.4)	29 (27.4)	33 (28.0)	138 (36.5)
Hindu	9 (5.8)	11 (10.4)	11 (9.3)	31 (8.2)
Others	9 (5.8)	7 (6.6)	8 (6.8)	24 (6.4)
Marital Status				
Single	153 (99.4)	106 (100.0)	118 (100.0)	377 (99.7)
Married	1 (0.6)	0 (0.0)	0 (0.0)	1 (0.3)
Year of Study				
1-2	56 (36.4)	44 (41.5)	45 (38.1)	145 (38.4)
≥ 3	98 (63.6)	62 (58.5)	73 (61.9)	233 (61.6)
Have you ever heard the term IEM?				
Yes	71 (46.1)	24 (22.6)	42 (35.6)	137 (36.2)
No	83 (53.9)	82 (77.4)	76 (64.4)	241 (63.8)
Have you ever met an IEM patient?				
Yes	14 (9.1)	6 (5.7)	9 (7.6)	29 (7.7)
No	98 (63.6)	65 (61.3)	73 (61.9)	236 (62.4)
I do not know	42 (27.3)	35 (33.0)	36 (30.5)	113 (29.9)
Is anyone in your family suffering from IEM?				
Yes	0 (0.0)	3 (2.8)	1 (0.9)	4 (1.0)
No	154 (100.0)	103 (97.2)	117 (99.1)	374 (99.0)
Have you had any classes about IEM during your studies?				
Yes	57 (37.0)	15 (14.2)	31 (26.3)	103 (27.3)
No	82 (53.3)	81 (76.4)	65 (55.1)	228 (60.3)
I do not know	15 (9.7)	10 (9.4)	22 (18.6)	47 (12.4)

**Table 2. Students' knowledge about Inborn Error of Metabolism (IEM)**

Item	Correct n (%)	Incorrect n (%)	Don't know n (%)
<b>Causes, Epidemiology, Symptom of IEM</b>			
1. IEM can be caused by infection (yes)	34 (9.0)	173 (45.8)	171 (45.2)
2. IEM can be caused by enzyme deficiency (yes)	273 (72.2)	6 (1.6)	99 (26.2)
3. Symptoms of IEM appear usually at Neonatal/Pediatric/Adult age (Neonatal age)	256 (67.7)	122 (32.3)	-
4. Symptom IEM may include: (Anemia/ Hypoglycemia/ Hepatomegaly/Mental retardation/ Acid/base imbalance/ Coma/ Seizures/ Hearing and visual impairment (all above)	16 (4.2)	362 (95.8)	-
5. Person with positive family history are at higher risk of having IEM (yes)	299 (79.1)	9 (2.4)	70 (18.5)
<b>Diagnosis and treatment of IEM</b>			
6. Some IEM can be diagnosed by using a blood sample only (yes)	99 (26.2)	55 (14.6)	224 (59.2)
7. Diagnosis of some IEM can be done prenatally (yes)	182 (48.1)	31 (8.2)	165 (43.7)
8. Patients diagnosed with IEM should be isolated (no)	276 (73.0)	11 (2.9)	91 (24.1)
9. Some IEM can be controlled by avoidance of some foods (yes)	201 (53.2)	35 (9.2)	142 (37.6)
10. Liver transplantation is an option in management of some IEM (yes)	173 (45.8)	14 (3.7)	191 (50.5)
11. Gene therapy can be a helpful tool for treatment of some IEM (yes)	237 (62.7)	8 (2.1)	133 (35.2)
12. There is no available treatment for most IEM (no)	66 (17.5)	58 (15.3)	254 (67.2)
<b>Organizational Issues of IEM</b>			
13. There is central register for patient IEM in Malaysia (no)	5 (1.3)	102 (27.0)	271 (71.7)
14. There is a national plan for IEM in Malaysia (yes)	80 (21.2)	10 (2.6)	288 (76.2)

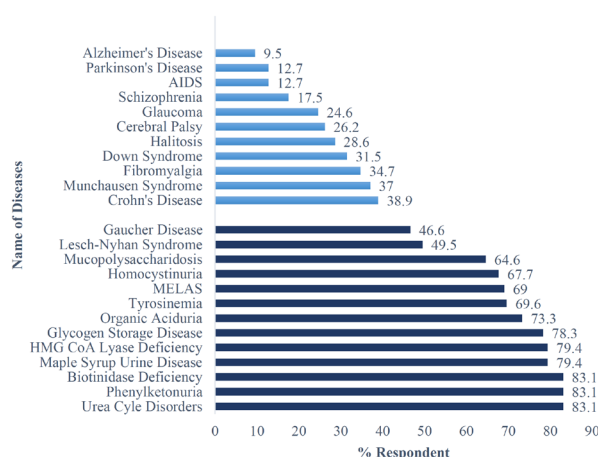
ranged between 18 and 31 years old. More women (73.5%) participated in this present study than men (26.5%). A vast majority of the respondents were single (99.7%). 62.4% of the respondents reported that they had never met an IEM patient while only one percent reported a family history of IEMs. Moreover, most of the respondents (60.3%) reported that they had never attended any classes on IEMs during their studies.

### 3.2. Knowledge of IEM-related topics

The answers seen in Table 2 indicate that a majority of the respondents answered questions on basic IEM-related knowledge correctly (items 2 and 3). However, less than 10% were able to provide correct answers when the questions were more in-depth; such as the specific symptoms of IEMs (item 4) and infections that may cause IEMs (item 1). Furthermore, less than 50% answered items that evaluated their understanding of IEM-related diagnoses, treatments, and organizational issues correctly (items 6, 7, 10, 12, 13, and 14).

As seen in Figure 1, most of the respondents were able to correctly identify IEMs, with the exception of Gaucher disease (46.6%) and Lesch-Nyhan syndrome (49.5%). The most easily recognised IEMs were biotinidase deficiency (83.1%), phenylketonuria (83.1%), and urea cycle disorders (83.1%). Less than 50% of the respondents misidentified non-IEM diseases as IEMs. Of this number, 38.9% of the respondents misidentified Crohn's Disease as an IEM.

A further inferential analysis was conducted to determine if differences existed among the multiple pre-specified sociodemographic variables and other variables in terms of the mean IEM-related knowledge score of the students. As seen in Table 3, ethnicity,



**Figure 1. Proportion of respondents indicating different name of diseases (IEM and non-IEM) as IEM.**

religion, and a family history of IEMs significantly affected IEM-related knowledge scores. Malay students ( $5.4 \pm 2.7$ ) scored significantly lower than Chinese students ( $6.4 \pm 2.6$ ) ( $p < 0.05$ ) while Muslim students ( $5.4 \pm 2.7$ ) scored significantly lower than Buddhist students ( $6.5 \pm 2.5$ ) ( $p < 0.05$ ). Students with a family history of IEMs ( $7.0 \pm 0.8$ ) scored significantly higher than their counterparts without a family history of IEMs ( $5.8 \pm 2.7$ ) ( $p < 0.05$ ). Apart from that, students who had encountered IEM patients or attended IEM classes during their studies scored significantly higher than counterparts without experience or who answered "I do not know" ( $p < 0.05$ ). Overall, the mean IEM-related knowledge score was 5.8 out of 14. Health sciences students scored the highest ( $6.1 \pm 2.7$ ) followed by dentistry ( $5.8 \pm 2.8$ ) and pharmacy ( $5.5 \pm 2.6$ ) students. Interestingly, 46.1% of health sciences students reported

**Table 3. Difference of mean score of IEM knowledge according to sociodemographic and other variables**

Variables	Mean ± SD	<i>p</i> value
<i>Sociodemographic</i>		
Age		0.190
18-21	5.7 ± 2.8	
22-24	5.8 ± 2.7	
> 25	7.1 ± 1.9	
Gender		0.774
Male	6.0 ± 3.1	
Female	6.1 ± 2.7	
Ethnicity		0.020*
Malay	5.4 ± 2.7 <sup>a</sup>	
Chinese	6.4 ± 2.6 <sup>b</sup>	
India	5.5 ± 3.0 <sup>ab</sup>	
Others	5.8 ± 3.1 <sup>ab</sup>	
Religion		0.003**
Islam	5.4 ± 2.7 <sup>a</sup>	
Buddha	6.5 ± 2.5 <sup>b</sup>	
Hindu	5.7 ± 3.0 <sup>ab</sup>	
Others	5.4 ± 3.1 <sup>ab</sup>	
Year of study		0.073
1-2	5.5 ± 2.6	
> 3	6.0 ± 2.8	
Faculty		0.253
Health Science	6.1 ± 2.7	
Pharmacy	5.5 ± 2.6	
Dentistry	5.8 ± 2.8	
<i>Other Variables</i>		
Have you ever met an IEM patient?		< 0.001***
Yes	7.5 ± 2.0 <sup>a</sup>	
No	6.1 ± 2.6 <sup>b</sup>	
I do not know	4.7 ± 2.8 <sup>c</sup>	
Is anyone in your family suffering from IEM?		0.036*
Yes	7.0 ± 0.8	
No	5.8 ± 2.7	
Have you had any classes about IEM during your studies?		< 0.001***
Yes	7.7 ± 1.9 <sup>a</sup>	
No	5.3 ± 2.5 <sup>b</sup>	
I do not know	4.0 ± 3.1 <sup>c</sup>	

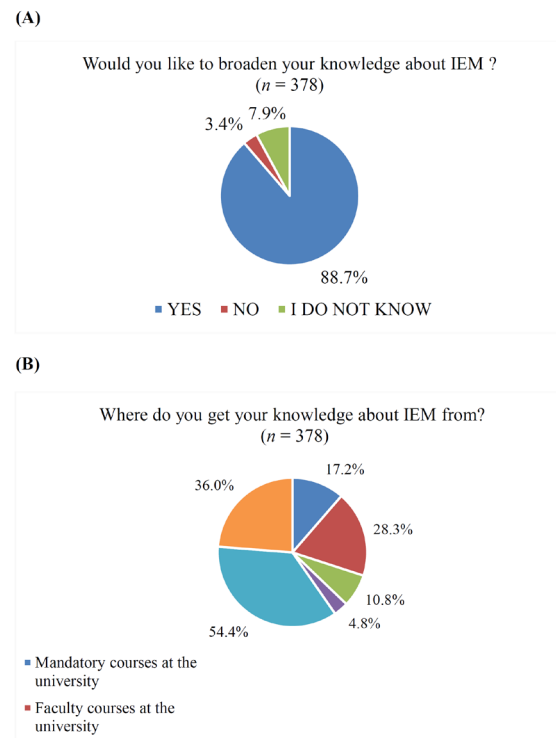
\**p* < 0.05 - significant using Independent t-test for comparison between 2 groups and one-way ANOVA for comparison between three groups. \*\*\**p* < 0.001; \*\**p* < 0.01 - significant using one-way ANOVA. Superscript a,b,c indicate a significant mean difference for groups (*p* < 0.05, Post-Hoc Turkey test).

coming across the term "IEMs" while only 22.6% and 35.6% of pharmacy and dentistry students reported the same, respectively (*p* < 0.05). However, the mean IEM-related knowledge score did not vary significantly between the three faculties.

There was no difference in the mean IEM-related knowledge score in terms of age, gender, or year of study. Marital status was exempted from analysis as a disproportionate number of the respondents were single (99.7%) while only 0.3% were married. This would yield invalid results.

### 3.3. Perception of IEMs

The majority of students (88.7%) expressed an interest in increasing their IEM-related knowledge, with the Internet reported as the most common source (54.4%) (Figure 2). As seen in Table 4, student perception of



**Figure 2. Student perceptions of (A) increasing their knowledge and (B) source of information on IEM.**

IEM-related knowledge was also evaluated. Most of the healthcare students (89.5 %) believed that they had little IEM-related knowledge while 60.3% agreed that IEM courses should be a mandatory part of the school curricula. It is noteworthy that more than half of the pharmacy students (70.8%) and health sciences students (66.2%) agreed that IEM courses should be a mandatory part of the course curricula but only 43.2% of dentistry students agreed. As such, there was a significant difference in opinion between the groups (*p* < 0.001). In terms of preparation to care for an IEM patient, only 42.0% of students were prepared to care for an IEM patient.

## 4. Discussion

As IEMs are becoming more common in Malaysia, its management and treatment has become increasingly important to the Malaysian healthcare system (4). This present study discovered an overall insufficiency of IEM-related knowledge among healthcare students, especially in terms of diagnoses, management, and organisational issues of IEMs. These findings were similar to that of a recent Saudi Arabian study which concluded that both medical and non-medical students lacked the knowledge with which to diagnose and manage IEMs (22). This was also consistent with the findings of several other studies, which reported that the majority of healthcare students also lacked knowledge on the organizational issues of rare disorders,



**Table 4. Students' self-perceived knowledge and opinion regarding Inborn Error of Metabolism (IEM)**

Item	Health Science <i>n</i> = 154 (%)	Pharmacy <i>n</i> = 106 (%)	Dentistry <i>n</i> = 118 (%)	Total <i>n</i> = 378 (%)	<i>p</i> value
16. How would you rate your knowledge about IEM?					0.186
Very good/good	23 (14.9)	6 (5.7)	11 (9.3)	40 (10.6)	
Insufficient	62 (40.3)	50 (47.2)	53 (44.9)	165 (43.7)	
Very poor	69 (44.8)	50 (47.2)	54 (45.8)	173 (45.8)	
17. Do you think that there should be mandatory course on IEM in course curricula?					< 0.001*
Strongly agree/agree	102 (66.2)	75 (70.8)	51 (43.2)	228 (60.3)	
Neutral	46 (29.9)	31 (29.2)	62 (52.5)	139 (36.8)	
Strongly disagree/Disagree	6 (3.9)	0 (0.0)	5 (4.2)	11 (2.9)	
18. Do you feel prepared for caring over a patient with an IEM?					0.784
Strongly agree/agree	70 (45.5)	40 (37.7)	49 (41.5)	53 (14.0)	
Neutral	50 (32.5)	39 (36.8)	43 (36.4)	132 (34.9)	
Strongly disagree/Disagree	34 (22.1)	27 (25.5)	26 (22.0)	31 (8.3)	

\**p* < 0.001 – Significant using Pearson's chi-square's test

including IEMs (19,20). This indicated that students lacked concern or awareness of the launch of the 2019 Malaysian National Medicines Policy regarding palliative care services for IEM patients (29).

Infections are thought to potentially contribute to an accumulation of genetic mutations in mitochondrial DNA, which results in one IEM in particular; mitochondrial encephalomyopathy, lactic acidosis, and stroke-like episodes (MELAS) (30). The findings of this present study were similar to that of extant studies on medical and non-medical faculties which showed that these students were less likely to recognize the modes of IEMs transmission; such as infections (31).

The interfaculty factor did not significantly alter the mean IEM-related knowledge score of the students. This finding was similar to that of a Polish study which reported that although the percentage of students who had encountered rare IEM terms varied significantly between the faculties of medicine (92%), health sciences (82%), and pharmacy (68.8%), the mean IEM-related knowledge scores were similar across the three faculties (23). In terms of year of study and level of education, the findings of this present study were also similar to that of other studies because these factors did not significantly affect the IEM-related knowledge score. One potential explanation for this phenomenon may be that these students acquired IEM-related knowledge out of sheer interest or intellectual curiosity (19).

This present study found that ethnicity, religion, and family history of IEMs affected the IEM-related knowledge score. Furthermore, Muslim students were found to score significantly lower than Buddhist students. This contradicted the findings of Chapman *et al.* (2019) who found no significant correlation between the IEM-related knowledge of Muslim and Buddhist participants (25). This present study also found that students with a family history of IEMs had more IEM-

related knowledge. This finding was similar to that of another study which concluded that a family history of genetic disorders was one of the key determinants of acquiring more knowledge on IEMs (21). This was because most individuals with hereditary diseases have, at the very least, some knowledge of the disease in question (32).

This present study also found that students who had attended IEM classes or interacted with IEM patients had more IEM-related knowledge than those who did not. This was in agreement with an earlier observation that healthcare students with prior IEM-related knowledge and experience or involvement in scientific societies tend to have more IEM-related knowledge (23,31,33).

A majority of the respondents to this present study reported obtaining IEM-related knowledge from the Internet. This finding differed from that of a recent study which concluded that, in descending order, lectures and the Internet were the primary sources of IEM-related knowledge (31). This emphasized the importance of implementing a formal curriculum on IEMs through verified and reliable websites or online classes for healthcare students in the future. Furthermore, a higher proportion of pharmacy and health sciences students believed that IEM classes should be compulsory in the university curricula. The significance difference in perception between the students from the three different faculties may be because pharmacy and health sciences students are more likely to utilize IEM-related knowledge during clinical practice than dentistry students. Furthermore, the treatment of IEMs mainly involves pharmacotherapy treatments, in which a pharmacist plays an important role (11). Apart from that, other allied healthcare professionals; such as dietitians, physiotherapists, and occupational therapists; are a part of the holistic approach of treating and caring for IEM patients (34).

Most of the respondents to this present study expressed a willingness to expand their IEM-related knowledge. This was consistent with that of a previous study (19). However, less than 50% of respondents felt prepared to care for an IEM patient. Therefore, the results of this present study confirmed that healthcare students were unenthusiastic about caring for IEM patients because less than 5% of the respondents were adequately prepared to care for IEM patients. This figure was even lower in extant studies and may be due to a lack of IEM-related knowledge among healthcare students (19,20).

Some of the limitations of this present study included students that were allowed to complete the survey without monitoring or adhering to time restrictions. This meant that respondents could refer to materials or other sources prior to answering the questionnaire. However, the anonymous nature of the questionnaire is believed to have mitigated this issue.

To the best of our knowledge, this present study was the first to assess the knowledge and perception of Malaysian healthcare students on IEMs. It revealed that there is a pressing need to improve IEM-related knowledge and awareness of Malaysian healthcare students. This can be accomplished by incorporating online classes that emphasizes the treatment and management of IEMs in the university curriculum. Future studies should examine the key determinants that influence IEM-related knowledge and perception. It is hoped that this present study serves as a stepping stone to increasing the number of future studies on other healthcare and medical faculties as well as increasing the IEM-related knowledge of future healthcare professionals in the country.

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### References

- Ezgu F. Inborn Errors of Metabolism. In: *Advances in Clinical Chemistry* (Makowski G, ed. Elsevier Inc, Turkey, 2016; pp. 195-250.
- Waters D, Adeloye D, Woolham D, Wastnedge E, Patel S, Rudan I. Global birth prevalence and mortality from inborn errors of metabolism: a systematic analysis of the evidence. *J Glob Health*. 2018; 8:021102.
- Shafie AA, Supian A, Hassali MAA, Ngu LH, Thong MK, Ayob H, Chaikunapruk N. Rare disease in Malaysia: Challenges and solutions. *PLoS One*. 2020; 15:e0230850.
- Yunus ZM, Rahman SA, Choy YS, Keng WT, Ngu LH. Pilot study of newborn screening of inborn error of metabolism using tandem mass spectrometry in Malaysia: outcome and challenges. *J Pediatr Endocrinol Metab*. 2016; 29:1031-1039.
- Vernon HJ. Inborn errors of metabolism: advances in diagnosis and therapy. *JAMA Pediatrics*. 2015; 169:778-782.
- Ombrone D, Giocaliere E, Forni G, Malvagia S, la Marca G. Expanded newborn screening by mass spectrometry: New tests, future perspectives. *Mass Spectrom Reviews*. 2016; 35:71-84.
- Guerrero RB, Salazar D, Tanpaiboon P. Laboratory diagnostic approaches in metabolic disorders. *Ann Transl Med*. 2018; 6:470.
- Ballikaya E, Yildiz Y, Sivri HS, Tokatli A, Dursun A, Olmez S, Coskun T, Uzamis Tekcicek M. Oral health status of children with phenylketonuria. *J Pediatr Endocrinol Metab*. 2020; 33:361-365.
- Scanlan PM. A review of bachelor's degree medical laboratory scientist education and entry level practice in the United States. *EJIFCC*. 2013; 24:5-13.
- Lamoureux MF, Tingley K, Kronick JB, et al. Metabolic clinic atlas: organization of care for children with inherited metabolic disease in Canada. *JIMD Rep*. 2015; 21:15-22.
- Harthan AA. An Introduction to Pharmacotherapy for Inborn Errors of Metabolism. *J Pediatr Pharmacol Ther*. 2018; 23:432-446.
- Echeverri OY, Guevara JM, Espejo-Mojica AJ, Ardila A, Pulido N, Reyes M, Rodriguez-Lopez A, Almciga-Díaz CJ, Barrera LA. Research, diagnosis and education in inborn errors of metabolism in Colombia: 20 years' experience from a reference center. *Orphanet J Rare Dis*. 2018; 13:141.
- Tanpaiboon P. Practical management of lysosomal storage disorders (LSDs). *Transl Sci Rare Dis*. 2019; 4:133-157.
- Yuskiv N, Potter BK, Stockler S, Ueda K, Giezen A, Cheng B, Langley E, Ratko S, Austin V, Chapman M, Chakraborty P, Collet JP, Pender A; Canadian Inherited Metabolic Diseases Research Network (CIMDRN). Nutritional management of phenylalanine hydroxylase (PAH) deficiency in pediatric patients in Canada: a survey of dietitians' current practices. *Orphanet J Rare Dis*. 2019; 14:7.
- De Castro M, Turner C, Kirmse B. Practical recommendations for the transition to adulthood for the adolescent with a genetic diagnosis. Special emphasis on inborn errors of metabolism. *Transl Sci Rare Dis*. 2019; 2019:159-168.
- Agana M, Frueh J, Kamboj M, Patel DR, Kanungo S. Common metabolic disorder (inborn errors of metabolism) concerns in primary care practice. *Ann Transl Med*. 2018; 6:469.
- Tejada-Ortigosa EM, Flores-Rojas K, Moreno-Quintana L, Muñoz-Villanueva MC, Pérez-Navero JL, Gil-Campos M. Necesidades sanitarias y socioeducativas de niños con enfermedades raras de tipo metabólico y sus

- familias: estudio cualitativo en un hospital de tercer nivel [Health and socio-educational needs of the families and children with rare metabolic diseases: Qualitative study in a tertiary hospital]. *An Pediatr (Engl Ed)*. 2019; 90:42-50. (in Spanish)
18. Mak CM, Law EC, Lee HH, *et al*. The first pilot study of expanded newborn screening for inborn errors of metabolism and survey of related knowledge and opinions of health care professionals in Hong Kong. *Hong Kong Med J*. 2018; 24:226-237.
  19. Walkowiak D, Domaradzki J. Needs assessment study of rare diseases education for nurses and nursing students in Poland. *Orphanet J Rare Dis*. 2020; 15:167.
  20. Domaradzki J, Walkowiak D. Medical students' knowledge and opinions about rare diseases: A case study from Poland. *Intractable Rare Dis Res*. 2019; 8:252-259.
  21. Mitra AK, Al-Enezi K. Knowledge, attitude, and satisfaction of university students regarding premarital screening programs in Kuwait. *European Journal of Environment and Public Health*. 2017; 1:1-11.
  22. Alqrache A. Knowledge and awareness of metabolic inborn errors among male and female students at King Abdulaziz University – Rabigh. *The Egyptian Journal of Medical Education*. 2020; 4:1-5.
  23. Jonas K, Waligóra M, Hołda M, Sulicka-Grodzicka J, Strach M, Podolec P, Kopeć G. Knowledge on rare diseases among health care students – the effect of targeted education. *Przegl Epidemiol*. 2017; 71:80-89.
  24. Ramalle-Gomara E, Ruiz E, Quinones C, Andres S, Iruzubieta J, Gil-de-Gomez J. General knowledge and opinion of future health care and non-health care professionals on rare diseases. *J Eval Clin Pract*. 2015; 21:198-201.
  25. Chapman R, Likhanov M, Selita F, Zakharov I, Smith-Woolley E, Kovas Y. New literacy challenge for the twenty-first century: genetic knowledge is poor even among well educated. *J Community Genet*. 2019; 10:73-84.
  26. Schmidlen TJ, Scheinfeldt L, Zhaoyang R, Kasper R, Sweet K, Gordon ES, Keller M, Stack C, Gharani N, Daly MB, Jarvis J, Christman MF. Genetic knowledge among participants in the coriell personalized medicine collaborative. *J Genet Couns*. 2016; 25:385-394.
  27. Olwi D, Merdad L, Ramadan E. Knowledge of genetics and attitudes toward genetic testing among college students in Saudi Arabia. *Public Health Genomics*. 2016; 19:260-268.
  28. Polit DF, Beck CT, Owen SV. Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. *Res Nurs Health*. 2007; 30:459-467.
  29. Ministry of Health Malaysia. Policy and strategic plan 2019-2030: National Palliative Care. 2019. [https://www.moh.gov.my/moh/resources/Polisi/BUKU\\_NATIONAL\\_PALLIATIVE\\_CARE\\_POLICY\\_AND\\_STRATEGY\\_PLAN\\_2019-2030.pdf](https://www.moh.gov.my/moh/resources/Polisi/BUKU_NATIONAL_PALLIATIVE_CARE_POLICY_AND_STRATEGY_PLAN_2019-2030.pdf) (accessed February 7 2022)
  30. Ryzhkova AI, Sazonova MA, Sinyov VV, Galitsyna EV, Chicheva MM, Melnichenko AA, Grechko AV, Postnov AY, Orekhov AN, Shkurat TP. Mitochondrial diseases caused by mtDNA mutations: a mini-review. *Ther Clin Risk Manag*. 2018; 14:1933-1942.
  31. Shareef J, Sridhar SB, Shariff A, Sabah MM, Hameed MY. Inborn errors of metabolism in the United Arab Emirates: Are our future healthcare providers knowing enough about it—A cross-sectional study. *Journal of Applied Pharmaceutical Science*. 2021; 11:093-098.
  32. Claassen L, Henneman L, Janssens AC, Wijdenes-Pijl M, Qureshi N, Walter FM, Yoon PW, Timmermans DR. Using family history information to promote healthy lifestyles and prevent diseases; a discussion of the evidence. *BMC Public Health*. 2010; 10:248.
  33. Ugwu NI. Sickle cell disease: Awareness, knowledge and attitude among undergraduate students of a Nigerian tertiary educational institution. *Asian Journal of Medical Sciences*. 2016; 7:87-92.
  34. Burgard P. A holistic approach to the patients/ Families with inborn errors of metabolism. *J Mother Child*. 2020; 24:65-72.
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