

Association Between Health Information Seeking Behaviour and Health Literacy Among People with Type 2 Diabetes: A Cross-sectional Study

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Abstract

This paper investigated the association between health information-seeking behaviour and health literacy among type 2 diabetes patients in Selangor and Negeri Sembilan. This cross-sectional study involved 999 patients with type 2 diabetes who were recruited by nurses at outpatient primary health care clinics in Selangor and Negeri Sembilan with multi-stage random sampling to answer a validated Health Information Seeking Behavior Self-administered Questionnaire (SAQ). Besides descriptive analysis and correlation, one-way ANOVA and independent sample t-tests were conducted using IBM SPSS version 26. The result showed the most preferred sources of health information among the participants were doctors, followed by family members and friends. Most of them were looking for information on diabetes complications (92.1%), balanced diet (91.9%), and prevention of diabetes complications (91.8%). In terms of obstacles in accessing health information related to diabetes, some of them reported poor internet proficiency (48.4%) and difficulty in understanding complex medical terms (25.8%) or foreign language (16.3%). The primary motivations for seeking health information were to ensure proper management and control of their condition (81.4%) and to gain a better understanding of diabetes management (80.7%). Malay and female patients were more active in seeking information. Newly diagnosed patients within 1-5 years were more active in seeking information than those with diabetes for more than ten years. In conclusion, the relationship between health information-seeking behaviour and health literacy is crucial for maintaining and improving overall health, especially among type 2 diabetes patients. Enhancing health information-seeking activities among the target population can elevate the health literacy level of patients.

Keywords: Diabetes Type 2, Health Information-Seeking Behaviour, Health Literacy.

Introduction

Knowledge is the starting point in establishing good self-care management. Besides knowledge, individual attitude also plays a significant role in fostering positive health behaviour. To attain good disease control and management, an individual must possess good knowledge, motivation, and behaviour to complement the clinical treatment prescribed by healthcare professionals (Panting et al., 2020). Patient-centred approach education programmes have been used extensively to encourage self-empowerment and improve self-care management. For instance, Kalantzi et al. (2015) reported that diabetes self-management

education (DSME) and continuous support play a vital role in improving metabolic and psychological outcomes in diabetes management.

In addition, patients' health information-seeking behaviour (HISB) is also an important skill in disease management. The acquisition of information regarding health, illness, health promotion, and health risks is commonly referred to as HISB as outlined by Lambert and Loiselle (2007). The concept of HISB has been utilised in numerous studies to explore patients' information-seeking behaviour regarding their illnesses. Over time, this concept has evolved alongside technological advancements such as increased Internet utilisation as reflected by improvements in these facilities.

Previously, Rees and Bath (2001) referred to HISB as a problem-focused coping mechanism in which individuals focus on potentially harmful circumstances and devote efforts to face them. Coping strategies can also evolve as they are influenced by the specific context of the situation. HISB aims to alter the problematic person-environment dynamic by eliminating the sources of stress through the mediation of individual behaviours (Schoenmakers et al., 2015). In addition, Clark (2005) suggested that information-seeking can also be used to enhance coping skills by helping individuals understand health risks and related challenges. Therefore, HISB should be studied within different contexts, namely coping with a health-threatening situation, participation in medical decision-making, and engaging in preventive behaviour.

Apart from HISB, health literacy (HL) is also closely associated with improving self-care management. Ishikawa (2010) indicates that individuals who want to seek health information should be equipped with sufficient HL. A person is deemed health literate when they possess the ability to access, comprehend, evaluate, and apply health information to make informed decisions regarding healthcare, disease prevention, and health promotion. Health-literate individuals can effectively navigate healthcare services, adopt healthy lifestyles, and address social determinants of health, hence enhancing their overall well-being (Sorensen et al., 2012).

Nevertheless, HL extends beyond the capability to search for information regarding the significance of health. It can serve as a valuable asset that consistently empowers an individual's health status. According to Pourhabibi et al. (2022), limited HL is a prevalent problem among diabetes patients and it can lead to poor awareness and understanding of the condition, subsequently resulting in complications such as retinopathy and poor sugar control. When HL levels are low, it can become a potential risk factor for individuals dealing with illness or disease, further exacerbating their health condition (Lam et al., 2012). A previous study revealed that poor HL often leads to many negative health-related consequences. It has been linked to poor health outcomes, harmful health behaviours, lower patient satisfaction, and in some cases, increased mortality (Goli et al., 2021).

The level of individual HL is essential in determining an individual's ability to seek health information (Abdullah et al., 2019) and make informed health decisions. In Malaysia, the National Health and Morbidity Survey (NHMS) 2019 showed that the prevalence of limited HL among Malaysian adults aged 18 years and above was 35%, a level that is deemed unsatisfactory. Furthermore, studies have shown that the prevalence of limited HL in patients with T2DM was as high as 85.8% in Malaysia (Azreena et al., 2016). Thus, it is crucial to assess the association between HISB and HL among diabetes patients to provide a comprehensive insight into the multiple aspects involved in diabetes self-care management.

Method

This cross-sectional study was conducted at selected government health clinics in Selangor and Negeri Sembilan, Malaysia. Multistage random sampling was applied to recruit type 2 diabetes patients aged 18

years and above, able to read and write in Malay or English. The sample size was calculated based on the number of active diabetes patients in Selangor and Negeri Sembilan (342,645) as reported in the National Diabetes Registry Report (NDRR) 2019. The initial sample size of 384 was calculated at a 5% significance level with a precision of $\pm 0.05\%$. The design effect was assumed to be 2.0 with a response rate of 70%, bringing to the total sample size of 998. Data analysis was performed with IBM SPSS Version 26.

Data collection

Prior to the data collection at clinics, the research team underwent a workshop to familiarise themselves with the questionnaires. During the data collection phase, the team approached individuals diagnosed with type 2 diabetes, irrespective of their attendance for follow-up or clinic appointments. Before enrolment, each participant would be asked to provide written consent for voluntary participation before answering the questionnaire.

Study instrument

The research instrument, Self-Administered Questionnaire (SAQ) was developed in both Malay and English languages. It consisted of 76 items, including demographic profiles and other relevant items adapted from literature reviews. The questionnaire encompassed important aspects of HISB such as frequency in seeking health information, important types of health information searched, preferred sources of information, barriers while seeking information, and the need for diabetes information and HL.

Ethical approval

This study received ethical approval from the Medical Research & Ethics Committee (MREC), Ministry of Health, Malaysia (NMRR-20-2990-57182). All participants were required to provide written consent to acknowledge that they understood their rights and the nature of their involvement in the study before answering the questionnaire.

Data Analysis

The measurement of HISB encompassed two categories: active and passive information behaviours. Active information behaviour entails deliberate physical actions while passive behaviour comprises predominantly psychological, occasionally unintentional processes (Kelly et al., 2014). The subdomain for active information-seeking behaviour in the questionnaire involved the assessment of six intentional items, whereas the evaluation of passive information-seeking behaviour included five intentional and unintentional items (Kelly et al., 2014). All items were originally developed on a 7-point Likert-type scale ranging from strongly disagree to strongly agree. However, in this study, it was changed to a 5-point Likert scale from 5: almost every week, 4: 2-3 times a month, 3: once a month, 2: less than once a month, to 1: never. As for the passive information-seeking behaviour, the number of items was reduced to five in this study. Total scores were calculated by summing all the response scores, ranging from a minimum possible score of 5 to a maximum score of 25. To convert the scores into percentages, the scores would be divided by the highest possible score and then multiplied by 100. Then, the total score will be categorised into passive, active, and very active according to Bloom's cut-off points of low (0.0-0.59%), moderate (0.60-0.79%), and high (0.80-100%) (Abdullahi et al., 2016). A good internal consistency was obtained for all the items with Cronbach-alpha values ranging from .90 to .92.

Meanwhile, the HL assessment was performed using the Health Literacy Survey-Malaysia-Q18 (HLS-M-Q18), a compressed version of HLS-EU-Q47 (NHMS, 2019). The questionnaire contains 18 items on a 5-point Likert-type (very easy, fairly easy, fairly difficult, and very difficult). The final score was based on the responses of all 18 items. The questionnaire was developed based on the conceptual model of HL that measured the four competencies of the ability to access, understand, appraise, and apply health information across three domains, i.e. health care, disease prevention, and health promotion. The general HL Index was computed using the formula: $\text{Index} = (\text{mean} - 1) \times 50/3$ and divided into three levels as presented in

Table 1:

Table 1: Health Literacy level

HL level	Range from	Definition
Limited	0 – 33	Very difficult and fairly difficult to access, understand, appraise, and apply health-related information within the three domains of healthcare, disease prevention, and health promotion.
Sufficient	>33 – 42	Fairly easy to access, understand, appraise, and apply health-related information within the three domains of healthcare, disease prevention, and health promotion.
Excellent	>42 – 50	Very easy to access, understand, appraise, and apply health-related information within the three domains of healthcare, disease prevention, and health promotion.

Results

A total of 999 patients had completed the questionnaires. The group was fairly gender-balanced; male and female. However, it predominantly consisted of Malay (62.2%), 56 years and above (67.1%), married (81.6%), unemployed (49.5%), lower education (58.7%) and household income (below RM4,850). Furthermore, most of them have suffered from T2DM for more than 10 years (40.5%). Moreover, the majority of them (80.1%) had poor DM control (HbA1C more than 6.3%) despite being on different treatment plans.

Frequency of HISB

This study shows that 98.2% of patients passively sought health information regarding diabetes. In other words, they were not actively seeking health information (mean = 4.4, SD = 2.86). Using Bloom's cut-off point, a mean score between 0.0 and 5.9% was classified as passive, while a score between 6.0 and 7.9% was considered active, and a score between 8.0 and 10.0% as highly active.

The frequency of seeking health information was assessed using five items: "asking a doctor about diabetes," "conducting an information search related to diabetes," "discussing with friends or family members about diabetes," "reading the latest news on diabetes," and "watching the latest news on diabetes." The majority of patients (80.2%) claimed that they asked a doctor about diabetes less than once a week, followed by 14.1% who reported asking 2-3 times a week, and none reported asking almost every day. Only very minimal (1.0%) of patients read and watched the latest news on diabetes. Furthermore, another 4.3% mentioned that they never asked a doctor about their disease, even during consultations.

Important types of diabetes information

Table 3 lists the types of information related to diabetes that were sought by the patients based on the perceived levels of importance. The majority of them (92.1%) thought “effects/ complications of diabetes” was the most crucial information. The next most important item was “a balanced diet for diabetic patients” (91.9%), “ways to prevent diabetes complications” (91.8%). Furthermore, “factors or causes of diabetes” were also deemed as important information by 86.4% of participants, “Symptoms of diabetes” were ranked fifth by 86.9% of participants as an important type of diabetes information. Interestingly, those who had DM for a longer period (more than 10 years) claimed that they were satisfied with the knowledge and information they had about the condition and thus not looking for further information.

Table 3: Important types of diabetes information

No.	Statement	Not important	Not Sure	Important
1.	Introduction to diabetes	64 (6.4%)	80 (8.0%)	855 (85.5%)
2.	Symptoms of diabetes	55(5.5%)	81(8.1%)	863 (86.4%)
3.	Factors or causes of diabetes	52 (5.2%)	78 (7.8%)	869 (87.0%)
4.	Effects/complications of diabetes	17 (1.7%)	62 (6.2%)	920 (92.1%)
5.	A balanced diet for diabetic patients	9 (0.9%)	72 (7.2%)	918 (91.9%)
6	The best exercise for diabetic patients	42 (4.2%)	88 (8.8%)	869 (86.9%)
7.	The latest treatment for diabetes	70 (7.0%)	93 (9.3%)	836 (83.7%)
8.	Side effects of diabetes medications	79 (7.9%)	95 (9.5%)	825 (82.6%)
9.	Ways to prevent diabetes complications	18 (1.8%)	64 (6.4%)	917 (91.8%)
10.	Signs of low blood sugar	27 (2.7%)	128 (12.8%)	844 (84.5%)
11.	Signs of high blood sugar	21 (2.1%)	122 (12.2%)	856 (85.7%)

Sources of diabetes information

The source of diabetes-related information is summarised in Table 4. The majority of them (99.3%) relied on their doctors as the main source of information, followed by family members (78%) and friends (63.3%). However, nurses or diabetes educators (48.6%), dietitians (39.4%), and pharmacists (51.8%) ranked lower in importance. Furthermore, the Internet was also considered as a quite important information source as it ranked as the highest non-human source of information.

Table 4: Sources of information used by diabetes patients

No.	Source of information	Frequency	Percentage (%)
1.	Doctor	992	99.3
2.	Nurse or Diabetes Educator	486	48.6
3.	Dietitian	394	39.4
4.	Pharmacist	517	51.8
5.	Television / Radio	442	44.2
6.	Internet (Google / YouTube)	484	48.4
7.	Social media (Facebook, Instagram, TikTok)	400	40.0

8.	Diabetes website (National Diabetes Institute (NADI))	130	13.0
9.	Ministry of Health Malaysia (MOH) Website	158	15.8
10.	Print media (books, newspapers, magazines)	441	44.1
11.	Family members	779	78.0
12.	Friends	632	63.3
13.	Other diabetic patients	617	61.8

Motivation to seek diabetes information

About four in five (81.4%) patients agreed that they were motivated to seek further information to ensure that their diabetic condition is not serious and to gain a better understanding of diabetes management (81.3%). They were also keen to better comprehend diabetes (80.9%), identify the effects or complications of diabetes (80.6%), choose the best option for diabetes treatment (76.1%), make planning to deal with diabetes (76.0%), and to alleviate their fears or worries about diabetes (75.3%) (Table 5).

Table 5: Motivation to seek diabetes information

No.	Statement	Disagree	Not sure	Agree
1.	I find information about diabetes to understand more about diabetes management	94 (9.4%)	93 (9.3%)	812 (81.3%)
2.	I find information about diabetes to fully understand diabetes	92 (9.2%)	99 (9.9%)	808 (80.9%)
3.	I find information about diabetes to identify the effects or complications of diabetes	98 (9.8%)	95 (9.5%)	806 (80.6%)
4.	I find information about diabetes to help me reduce my fear or worry about diabetes	147 (14.7%)	100 (10.0%)	752 (75.3%)
5.	I find information about diabetes to ensure that my diabetic condition is not serious	90 (9.0%)	96 (9.6%)	813 (81.4%)
6.	I find information about diabetes to choose the best option for diabetes treatment	128 (12.8%)	108 (10.8%)	763 (76.4%)
7.	I find information about diabetes to discover what I can do on my own in dealing with diabetes	132 (13.2%)	107 (10.7%)	760 (76.1%)
8.	I find information about diabetes to plan on how to deal with diabetes	131 (13.1%)	109 (10.9%)	759 (76.0%)

Barriers to information-seeking

With regard to the barriers to information seeking, 78.6% of patients identified a "lack of proficiency in using the Internet" as the primary obstacle to seeking diabetes-related information. Apart from this, other barriers included "information containing difficult terms" (25.8%), "information written in a foreign language with difficult terms" (25.4%), "poorly organised information" (16.3%), and "lack of time" (14.1%) (Table 6).

Table 6: The barriers to information-seeking

No.	Statement	Disagree	Not sure	Agree
1.	Lack of time	785 (78.6%)	73 (7.3%)	141 (14.1%)
2.	High expenses	821 (82.2%)	87 (8.7%)	91 (9.1%)
3.	Lack of proficiency in using the Internet	456 (45.6%)	59 (5.9%)	484 (48.4%)
4.	Poorly organised information	482 (48.2%)	354 (35.4%)	163 (16.3%)
5.	Information contains difficult terms	461 (46.1%)	280 (28.0%)	258 (25.8%)
6.	Information is written in a foreign language that is difficult terms	474 (47.4%)	271 (27.1%)	254 (25.4%)
7.	Communication problems between healthcare providers and patients	768 (76.9%)	87 (8.7%)	144 (14.4%)

The level of Health Literacy (HL) and its association with HISB

This study also aimed to identify the HL level among T2DM patients. It reveals that most of the patients (58.5%) reported limited HL, with only 34.0% and 8.0% having sufficient and excellent HL respectively. The score for the categorisation of HL was 0-33 for limited, >33-42 for sufficient, and >42-50 categorised as excellent. Overall, the T2DM patients in this study had limited HL (mean = 31.8, SD = 0.57). There was a significant association between HISB and HL for T2DM patients in Selangor and Negeri Sembilan. It was indicated as weak but positive association between HISB and HL.

Discussion

This research set out to examine the HISB of type 2 diabetes patients in Selangor and Negeri Sembilan. The results showed that most of the patients depended primarily on their doctors for health information as they were considered capable of providing accurate and valuable health information. This was consistent with Xue Zhang et al. (2019) study in which HCPs were seen as the most trustworthy information sources (Kuske et al., 2017; Mingeste et al., 2021). Therefore, effective doctor-patient communication is crucial for collaborative decision-making as it can impact patients' self-management and health-related behaviours.

On a relevant note, the results highlighted the patients' preference in relying on HCPs for diabetes information rather than actively seeking the information themselves. The most common reasons that motivated the patients to seek information included the desire to ensure that their diabetes condition was not severe (81.4%), to gain a deeper understanding of diabetes management (81.3%), and to obtain a comprehensive understanding of diabetes (80.9%). They also expressed a need for diabetes information to recognise potential effects or complications (80.7%) and for them to make informed decisions about the most suitable treatment (76.4%).

Most participants in this study were older at 56 years and above. Therefore, it is not surprising that the most common barrier cited in seeking information was a lack of proficiency in using the Internet (48.4%). This aligns with other studies that have reported similar challenges for older people, specifically poor skills in conducting Internet search (Leelavathi et al., 2018; Jamal et al., 2015). Some of them also expressed troubles in understanding information written in a foreign language (25.4%) or presented in complex terms (25.8%). Additionally, some participants claimed they would be less inclined to engage with information if the education materials were poorly organised (16.3%). Miscommunication with HCPs

(14.4%) would also demotivate patients to enquire further as they felt misunderstood by HCPs and became frustrated with the lack of solutions to their concerns.

The above-mentioned barriers are important to be overcome. Having the right information is essential to ensure informed decision-making so that patients can cope better with their conditions and subsequently reduce stress and anxiety levels. Most study participants pinpointed knowledge about diabetes complications (92.1%) as the most crucial information for them, followed by insights into maintaining a balanced diet (91.9%). The strong interest in dietary nutrition reflects the patients' acknowledgement of its vital role in managing diabetes self-care management. These findings aligned with Robertson et al. (2005) in which a limited availability of information on medication, dietary nutrition, and healthy lifestyle may impede the self-care of diabetic patients. Other topics of interest included how to prevent diabetes complications (91.8%), understanding the causes of diabetes (87%), and identifying the most effective exercises for diabetic patients (86.7%).

In this study, there is a significant difference in the demographic profiles of gender, age group, race, employment, education level, and the duration of diabetes diagnosis. This finding aligns with Gautam et al. (2015) in which females were more likely to report highly satisfactory levels of knowledge and practices. In terms of education, individuals with secondary and tertiary education levels were more active in seeking information compared to those with lower education levels. Additionally, government servants were more active in seeking information than private sector employees, unemployed individuals, and retirees. Furthermore, individuals with shorter diagnosis duration were more active in seeking information than those with diabetes for more than ten years.

On the other hand, the relationship between HISB and HL indicated a positive correlation. The level of diabetes HL among patients has been shown to affect their understanding and management of the disease (Alidosti & Tavassoli, 2019). Individuals with low HL are often associated with poorer health status and outcomes (Abdullah et al., 2020; Jeong & Kim, 2016). One of the reasons would be the difficulty they faced in reading printed instructions and understanding medical advice from HCPs. This group of individuals also tends to have higher medical expenditure (Bains et al., 2011; Haun et al., 2015), poorer medication adherence (Fan et al., 2016), and lower knowledge about their disease. In other words, HL is crucial to empower diabetes patients to apply the information effectively so that they can opt for the best treatment options for their long-term well-being.

In diabetes management, HL is considered a crucial non-clinical factor that determines the disease outcome. Poor HL can also act as a significant therapeutic barrier among certain patients (Mogessie et al., 2022). Our study found that most diabetes patients have limited HL. This finding is consistent with Powell et al. (2007) in which individuals with T2DM often have low HL from 60% to 85%, especially in Asian countries with multi-racial populations (Abdullah et al., 2020). According to Azreena et al. (2016), 85.8% of T2DM patients in Malaysia reported a low HL, much higher than 71.7% in South Korea to 82% in Taiwan (Abdullah et al., 2020). This study also found that HL is the primary factor influencing HISB in diabetes patients. However, most patients were categorised as having limited HL in the literature as highlighted in NHMS 2019, particularly common among older patients as well as those with lower education and low household income levels.

Limited HL is characterised by difficulties in reading, understanding, and acting on medical advice, all of which can negatively impact their health status (Mogessie et al., 2022). Additionally, a study from South Korea reported that about 61% of Koreans have poor HL and face challenges in accessing and using health information (Jeong & Kim, 2016). Therefore, it is vital to develop strategies aimed at improving HL and

reducing barriers for patients in seeking health information, especially with regard to older individuals. In contrast, Bains & Egede (2011) found no link between glycaemic control and HL. Research has shown that diabetes patients who engage in effective self-care practices such as medication adherence, physical activity, healthy diet, blood sugar monitoring, and foot care tend to achieve better clinical outcomes in terms of improved HbA1c levels (Kalantzi et al., 2015). Therefore, diabetes patients should be empowered to continuously seek and effectively manage information about their conditions.

Nevertheless, having sufficient knowledge does not always translate into healthy behaviours or proactive actions (Kalantzi et al., 2015). Thus, it is imperative to gain a comprehensive understanding of patients' perspective of their illness, their approach to managing it, and how they obtain relevant information. Enhancing patient education and encouraging preventive behaviours among patients are necessary steps to improve disease management.

Conclusion

In view of the modest positive correlation between HISB and HL observed in this study, healthcare providers should prioritize enhancing HL among patients. This can be achieved by developing effective health education plans and creating user-friendly educational materials. Additionally, cultivating a supportive hospital environment is essential, beginning with the widespread dissemination of diabetes information to encourage patients to seek credible sources. By adopting this comprehensive approach, we can better support diabetes patients with low HL, empowering them to access valuable resources and make informed medical decisions in the future.

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