CORRESPONDENCE



Exploring the health information-seeking practices of breast cancer patients in a middle-income country with a diverse ethnic population: a cross-sectional investigation

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Abstract

Seeking health information is an important step for cancer patients to understand their condition and facilitate treatment. It also helps them deal with the unknown and aid in recovery. Therefore, it is vital to understand the factors that drive health information-seeking behavior. This study aims to achieve that objective in a localized context by surveying 421 breast cancer patients in an urban teaching hospital. The patients were presented with a 5-point questionnaire that explored their demography, health status, information-seeking behavior, and literacy level. The prevalence of health information-seeking initiatives reported was 60%. Patients with higher education (OR 3.31; 95% CI (1.39–7.87), p = 0.01), having their own business or were self-employed (OR 4.68; 95% CI (1.03–21.24), p = 0.046), and in a Medium 40 (M40) income level (OR 2.31; 95% CI (1.09–4.88), p = 0.03) and Top 20 (T20) level were more likely to seek health information. The mean e-Health Literacy Score (eHEALS) was 28.01 ± 5.0 , with healthcare professionals having the highest level of trust (mean 4.22 \pm 0.79) and most useful resource score (mean 4.21 \pm 0.78). Even though Google was the most popular online search tool used by respondents, most of them seldom (23.77%) or had never (34.34%) discussed the online information they found with healthcare professionals. In conclusion, it is still best for patients to appraise the sought-after information with experts to avoid misinformation and treatment delay.

Keywords Health information-seeking behavior \cdot Breast cancer \cdot Predictors \cdot Sources of online health information \cdot Malaysia

Introduction

Breast cancer is the most common malignancy worldwide, followed by lung, colorectal, prostate, and skin cancers. It contributed to 19% of all new cancers diagnosed from 2012

to 2016 as compared with 17.7% from 2007 to 2011. Of all the cases, 52.1% were diagnosed at early stage (Stage I, II), whereas 34.5% were detected in advanced Stage III. Surprisingly, breast cancer had seen an increasing percentage of late diagnosis in Malaysia from 43.2 to 47.9% over the past

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10 years, despite advancements in information technology and modern treatment modalities [1, 2]. A systematic review found that Malaysian women had good awareness of breast cancer and its screening tools, such as self-examination, mammography access, and availability of treatment, but their level of knowledge was superficial only [3]. Multiple studies on the factors associated with late presentation of breast cancer among patient shared common findings, which are poor accessibility to quality health information and limited knowledge, hence leading to misinterpretation of risk factors and symptoms of the disease. The review highlights the little information we have on detailed sources of information that Malaysian breast cancer patients seek after despite the abundance of research [3]. Furthermore, the reason for the discrepancy among ethnic groups in the country in early presentation of the disease is also not well established [4, 5]. The strong belief in traditional medicine, sociocultural practices, and religious faith also played a role in the observed trend [3]. A study has shown that misleading online health information is associated with poor patient outcome [6].

To date, little is known about the health information-seeking behavior among breast cancer patients in Malaysia. The Internet today is flooded with tons of information; hence, the patients' ability to appraise and discern the right information about the disease is yet to be discovered [5]. The aim of this study is to determine the socio-demographic distribution of health information-seeking behavior in breast cancer patients in Malaysia, besides identifying the sources and contents of the health information sought.

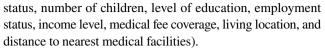
Methodology

This is a cross-sectional study carried out in the surgical clinic of University of Malaya Medical Center (UMMC), Kuala Lumpur, Malaysia, from November 2021 to March 2022. Ethics approval was obtained from the Universiti Malaya Medical-Center Research Ethics Committee (MREC ID: 2021106-10654).

Patients aged 18 and above who were diagnosed with breast cancer and referred to the surgical clinic from November 2021 to March 2022 were recruited through the purposive sampling method. The eligible patients were identified and recruited at the registration counter. They were briefed on the details of the study before written informed consent was obtained. Patients aged below 18, those who were illiterate, and those who could not provide their own consent were excluded.

Questionnaire development

The questionnaire was adapted from Lim et al. (2021) [7] with four sections. The first section included the participants' demographic background (age, gender, ethnicity, marital



The second section inquired about their medical background, which included the timing of cancer diagnosis, duration of presentation, staging, treatments, awareness of cancer support groups, and other illnesses. The third section explored their health information-seeking behavior, such as the reasons for seeking information, the sources they used, their trust level, and the usefulness of each resource. Patients were told to rate the items in the section using a 5-point Likert scale (1 = strongly disagree, 5 = totally agree).

The last section focused on e-Health using the eHealth Literacy Scale (eHEALS), which was an eight-item scale to assess perceived skills, ability, and confidence in applying and appraising online health information [8]. The scale was used across different studies and had been proven well on its validity and reliability [7, 9, 10].

Data analysis

The data analysis was performed using the IBM SPSS software version 21.0. All continuous data was tested for normality by determining their skewness and kurtosis using the Shapiro-Wilk test and histogram. Those with a normal distribution were described with means and standard deviations, while those that were skewed were described with medians and inter-quartile ranges. Proportions and percentages were used to describe categorical data.

The independent variables associated with dependent variables, such as taking the initiative to seek health information during or after cancer diagnosis (yes or no), were predicted. A chi-square test was used to analyze the categorical data, and the independent t-test was used to compare the means between two groups of data with a normal distribution. Univariate analysis was carried out to determine a factor's contribution to health information-seeking behavior. Those with a p value of <0.05 were considered clinically important and included in the multivariate binary logistics regression model. Other independent variables included age, ethnicity, marital status, number of children, level of education, employment status, level of income, medical fee coverage, distance between place of residence to the nearest medical facility, breast cancer presentation, cancer stage, medical history, awareness of breast cancer support group, and treatments undertaken.

Results

Sociodemographic distribution

A total of 493 breast cancer patients were recruited, and 421 of them managed to submit their completed



such information (21.1%).

questionnaires (response rate of 85%). The sociodemographic distribution is recorded in Table 1. The prevalence of health information-seeking initiatives reported was 60%. The mean age of those who sought health information was 57.96 ± 11.32 , whereas for those who did not, it was 64.13 ± 10.65 . Most subjects were Chinese (62.8%), followed by Malays (20.6%), Indians (15%), and others (1.7%). Most were also married (65.8%) and had fewer than four children in a household (79.8%). The respondents who sought health information mostly had higher education (36.8%) while on the contrary, a

majority of those with secondary education did not seek

Most of our patients came from a low-income background, known as the Bottom 40 (B40) group (median income range: RM1929–RM4387). The majority did not have any medical fee coverage (73.1%) and were living within 10 km from the nearest medical facility (57%). A total of 45.1% of our respondents detected their own symptoms via self-examination, and the majority were diagnosed with Stage II disease (38.5%). A total of 30.6% of info-seekers were aware of the existence of breast cancer support groups compared with 10.5% only among the non-info-seekers. Surgery was the most common treatment, especially mastectomy (51.5%). The mean e-Health Literacy Score (eHEALS) was 28.01 ± 5.0 .

Predictors of health information-seeking behavior

Table 1 depicts the multivariate binary logistics regression exploring the predictors that drive health informationseeking behavior among breast cancer patients. Educational level, employment status, level of income, medical fee coverage, awareness of cancer support groups, and treatment were found to be significantly associated with health information-seeking behavior. Patients with higher education (OR 3.31; 95% CI (1.39–7.87), p =0.01), having their own business or were self-employed (OR 4.68; 95% CI (1.03–21.24), p = 0.046), and in the Medium 40 (M40) (OR 2.31; 95% CI (1.09–4.88), p =0.03) and Top 20 (T20) (OR 5.59; 95% CI (1.15–27.21), p = 0.03) income groups were more likely to seek health information. The patients who were aware of breast cancer support groups were also positively associated with seeking health information (OR 2.01; 95% CI (1.19–3.40), p = 0.01). Those with retirement funds (OR 3.13, 95% CI (1.08–9.05), p = 0.04) and insurance coverage (OR 2.45, CI (1.16–5.14), p = 0.02) tend to seek for heath information. Patients who had undergone surgery (OR 4.39; 95% CI (1.09–17.67), p = 0.04) and targeted therapy (OR 4.0, 95% CI (1.04–15.32), p = 0.04) were more likely to seek health information as well.

Sources of online health information and their trustworthiness

Figures 1 and 2 show the sources of online health information and how the patients decided that it was trustworthy. The mobile phone was the most popular device for searching online health information (66.04%). The commonly used sources of online information was Google (97.3%), followed by WhatsApp (60.1%), Facebook (59.3%), You-Tube (56.3%), and Wikipedia (42.6%). The healthcare professionals had the highest trust level and most useful resource with mean scores of 4.22 ± 0.79 and 4.21 ± 0.78 , respectively. Most participants decided the trustworthiness of an online health information based on "Where the health information comes from" (87.3%), followed by other reasons, such as "What are the references for the health information" (77.5%), "Whether the language used is simply and easy to understand" (68.9%), and "Who wrote the health information" (66.0%). However, most participants never shared or discussed the online health information that they found with their doctors (34.34%) (Tables 2 and 3).

Patient-doctor relationship regarding online health information

Figure 3 demonstrates the frequency of our patients discussing the online health information with their doctors. Most of the respondents seldom (23.77%) or had never (34.34%) discussed the online information they found.

Discussion

To date, there have been limited studies that explored the health information-seeking pattern of breast cancer patients in the local context. Our study found a prevalence of 60% of health information-seeking initiative among the patients in UMMC. An American cross-sectional study reported an almost similar prevalence of 66.7% [11]. In the local context, Lim et al. (2021) observed a lower prevalence of 54.7% for online health information-seeking at a primary care setting in Kuala Lumpur, Malaysia [7], whereas a survey by Mohd-Nor et al. (2013) conducted at a rural district in Sarawak, Malaysia, had found a prevalence of 46% [12]. The lower prevalence was expected in Malaysia as compared with the USA as the latter was a high-income country, whereas the former was an upper middle-income country [13]. However, the higher prevalence in our study compared with Lim et al. (2021) could be explained by the gender discrepancy. All participants were female in our study whereas Lim et al. (2021) had 62.7% female. The female patients were found to be more health conscious and inclined to seek information



Table 1 Sociodemographic data of respondents and comparison between those who did and did not seek health information

Variable	Groups	Total respondents	<i>p</i> -value		
		Sought health information (<i>n</i> =253)	Did not seek health information (<i>n</i> =168)		
Age	Years (mean ± SD)	57.96 ± 11.32	64.13 ± 10.65	< 0.05	
Age group	<50	62 (14.7%)	18 (4.3%)	< 0.05	
	50–59	78 (18.5%)	38 (9.0%)		
	60–79	107 (25.4%)	102 (24.2%)		
	80 or above	6 (1.4%)	10 (2.4%)		
Ethnicity	Malay	62 (14.7%)	25 (5.9%)	0.092	
	Chinese	148 (35.2%)	116 (27.6%)		
	Indian	39 (9.3%)	24 (5.7%)		
	Other	4 (1.0%)	3 (0.7%)		
Marital status	Single	52 (12.4%)	20 (4.8%)	0.125	
	Married	159 (37.8%)	118 (28%)		
	Divorced/separated	17 (4.0%)	10 (2.4%)		
	Widowed	25 (5.9%)	20 (4.8%)		
Number of children	<4	202 (48%)	134 (31.8%)	0.468	
	4–6	51 (12.1%)	33 (7.8%)		
	>6	0	1 (0.2%)		
Level of education	Primary school or no education	21 (5.0%)	41 (9.7%)	< 0.05	
20,01,01,04,04,04	Secondary school	77 (18.3%)	89 (21.1%)	10.02	
	Higher education	155 (36.8%)	38 (9.0%)		
Employment status	Business or self-employed	18 (4.3%)	4 (1.0%)	0.07	
Employment status	Full or part-time employment	79 (18.9%)	32 (7.7%)	0.07	
	Unemployed	26 (6.2%)	16 (3.8%)		
	Student, military, or community service	0	1 (0.2%)		
	Retired	79 (18.9%)			
		` ′	63 (15.1%)		
I1 - 6 '	Homemaker	51 (12.2%)	48 (11.5%)	10.05	
Level of income	B40	158 (37.5%)	150 (35.6%)	< 0.05	
	M40	72 (17.1%)	16 (3.8%)		
	T20	23 (5.5%)	2 (0.5%)	0.05	
Medical fee coverage	None	105 (25.0%)	105 (25.0%)	< 0.05	
	Pension	61 (14.5%)	39 (9.3%)		
	Retirement fund	27 (6.4%)	7 (1.7%)		
	Insurance	59 (14.0%)	17 (4%)		
Distance between residence and nearest	<10 km	148 (35.4%) 91 (21.6%)		0.226	
medical facility	10–25 km	70 (16.7%)	57 (13.6%)		
	>25 km	34 (8.1%)	20 (4.8%)		
Breast cancer presentation	Detected during routine check-up	44 (10.5%)	30 (7.1%)	0.206	
	Coincidental discovery with other test(s)	23 (5.5%)	26 (6.2%)		
	Breast self-examination	121 (28.7%)	69 (16.4%)		
	Presented with symptoms	65 (15.4%)	43 (10.2%)		
Stage	Unsure	10 (2.4%)	9 (2.1%)	0.627	
	Stage 0	28 (6.7%)	22 (5.2%)		
	Stage 1	65 (15.4%)	46 (10.9%)		
	Stage 2	98 (23.3%)	64 (15.2%)		
	Stage 3	50 (11.9%)	24 (5.7%)		
	Stage 4	2 (0.5%)	3 (0.7%)		
Past medical history	Yes	147 (34.9%)	106 (25.2%)	0.012	
-	No	118 (28.0%)	50 (11.9%)		



Table 1 (continued)

Variable	Groups	Total respondents		
		Sought health information (n=253) Did not seek h information (n		
Medication history	On medication	125 (29.7%)	104 (24.7%)	0.012
	Not on any medication	128 (30.4%)	64 (15.2%)	
Breast cancer support group awareness	Aware	129 (30.6%)	44 (10.5%)	< 0.05
	Not aware	124 (29.5%)	124 (29.5%)	
Treatment	Surgery	244 (58.0%)	151 (35.9%)	0.006
	Radiotherapy	145 (34.4%)	88 (20.9%)	0.319
	Hormonal therapy	81 (19.2%)	38 (9%)	0.036
	Targeted therapy	22 (5.2%)	4 (1%)	0.008
	Chemotherapy	155 (36.8%)	91 (21.6%)	0.148
	Traditional and complementary medicine	5 (1.2%)	1 (0.2%)	0.242
Type of surgery	Breast-conserving surgery	87 (20.7%)	59 (14%)	0.877
	Mastectomy only	126 (29.9%)	91 (21.6%)	0.38
	Mastectomy with reconstruction	35 (8.3%)	9 (2.1%)	0.005
eHEALS score	Mean \pm SD	28.01 ± 5.0		

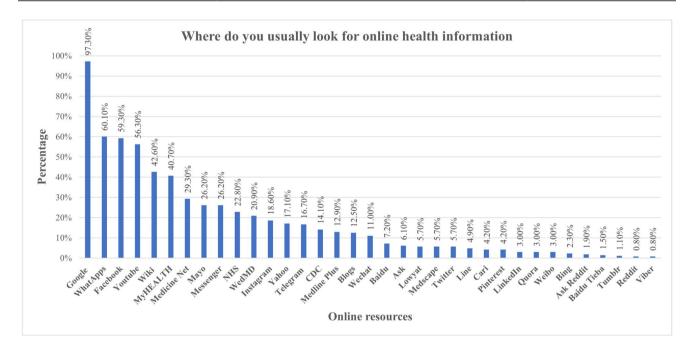


Fig. 1 The sources of online health information

proactively than males [14]. An Iranian study had a prevalence of 45%. Iran is a Middle Eastern country and has a lower middle income, and health-related TV channel was the second popular source of health information following the healthcare profession. The Internet was less frequently utilized as compared to other regions' studies. It may be explained by the lower education level of the cancer population as 65.5% of the participants of that study reported had less than high school education level [15]. Another health

information-seeking behavior study on the cancer patients in Mexico, an upper-middle country from Latin America and the Caribbean region, showed a similar prevalence of 59.5% [16]. Most findings were consistent with our study; however, the younger age and lesser comorbidities were found significantly associated with health information seeking in that study. Our study found that age did not reflect the health information-seeking tendency. This could be explained by the difference in the cancer population in both studies. Only



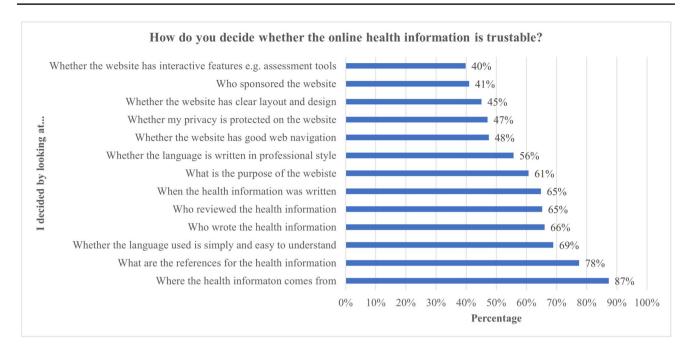


Fig. 2 How the patients decided that the online health information is trustable

Table 2 Logistic regression on the factors associated with health information-seeking behaviors

Predictors	Level	OR	CI	<i>p</i> -value
Level of education	Primary school or no education	1		0.001
	Secondary school education	1.09	0.52-2.28	0.83
	Higher education	3.31	1.39-7.87	0.01
Employment status	Homemaker	1		0.05
	Business or self-employed	4.68	1.03-21.24	0.046
	Full or part-time employment	0.56	0.25-1.26	0.56
	Unemployed	1.50	0.60 - 3.76	0.39
	In retirement	0.601	0.30 - 1.22	0.60
Level of income	B40 (<rm 4850)<="" td=""><td>1</td><td></td><td>0.02</td></rm>	1		0.02
	M40 (RM 4850–RM 10,959)	2.31	1.09-4.88	0.03
	T20 (>RM 10,959)	5.59	1.15-27.21	0.03
Medical fee coverage	None	1		0.03
	Pension	1.47	0.76-2.85	0.25
	Retirement funds	3.13	1.08-9.05	0.04
	Insurance	2.45	1.16-5.14	0.02
Awareness of breast cancer support groups		2.01	1.19–3.4	0.01
Treatment	Surgery	4.39	1.09-17.67	0.04
	Radiotherapy	0.82	0.45-1.50	0.52
	Hormonal therapy	1.05	0.58-1.89	0.88
	Targeted therapy	4.0	1.04-15.32	0.04
	Chemotherapy	0.88	0.50-1.55	0.66
	Traditional medicine	5.40	0.48–60.65	0.17

breast cancer patients were investigated in our study whereas all types of cancer patients with both genders were included in the forementioned Mexican study. Our study suggests that the level of education, employment status, income level, medical fee coverage, knowing any cancer support group, and treatment options were



Table 3 The level of trust and usefulness of resources on breast cancer

Items	Frequency, n (%)					Mean (SD)	
Level of trust on resources	Not trusted at all	Not trusted at all Mostly not trusted		Mostly trusted	Completely trusted		
Books, newspapers, magazines	4 (1.6)	5 (2.0)	145 (57.3)	84 (33.2)	15 (5.9)	3.4 ± 0.7	
Leaflets, posters	7 (2.8)	29 (11.5)	153 (60.5)	55 (21.7)	9 (3.6)	3.12 ± 0.76	
TV/radio	3 (1.2)	11 (4.3)	147 (58.1)	77 (30.4)	15 (5.9)	3.36 ± 0.71	
Internet: search engine	3 (1.2)	7 (2.8)	152 (60.1)	79 (31.2)	12 (4.7)	3.36 ± 0.67	
Internet: referring to certain websites	2 (0.8)	7 (2.8)	133 (52.6)	95 (37.5)	16 (6.3)	3.46 ± 0.69	
Internet: social media	11 (4.3)	31 (12.3)	163 (64.4)	45 (17.8)	3 (1.2)	2.99 ± 0.72	
Healthcare professionals: doctors, pharmacists, nurses	3 (1.2)	1 (0.4)	35 (13.8)	112 (44.3)	102 (40.3)	4.22 ± 0.79	
Health seminars/talks	4 (1.6)	4 (1.6)	101 (39.9)	109 (43.1)	35 (13.8)	3.66 ± 0.79	
Family, relatives, friends	1 (0.4)	4 (1.6)	167 (66)	64 (25.3)	17 (6.7)	3.36 ± 0.87	
Usefulness of the resources	Not useful at all	Least useful	Neutral	Useful	Very useful		
Books, newspapers, magazines	4 (1.6)	13 (5.1)	122 (48.2)	101 (39.9)	13 (5.1)	3.42 ± 0.74	
Leaflets, posters	7 (2.8)	22 (8.7)	151 (59.7)	64 (25.3)	9 (3.6)	3.18 ± 0.75	
TV/radio	4 (1.6)	16 (6.3)	136 (53.8)	89 (35.2)	8 (3.2)	3.32 ± 0.71	
Internet: search engine	4 (1.6)	4 (1.6)	131 (51.8)	97 (38.3)	17 (6.7)	3.47 ± 0.72	
Internet: referring to certain websites	2 (0.8)	3 (1.2)	111 (43.9)	108 (42.7)	29 (11.5)	3.63 ± 0.73	
Internet: social media	11 (4.3)	17 (6.7)	152 (60.1)	58 (22.9)	15 (5.9)	3.19 ± 0.82	
Healthcare professionals: doctors, pharmacists, nurses	1 (0.4)	2 (0.8)	43 (17)	105 (41.5)	102 (40.3)	4.21 ± 0.78	
Health seminars/talks	3 (1.2)	2 (0.8)	96 (37.9)	111 (43.9)	41 (16.2)	3.73 ± 0.78	
Family, relatives, friends	0	5 (2.0)	126 (49.8)	91 (36)	31 (12.3)	3.58 ± 0.73	

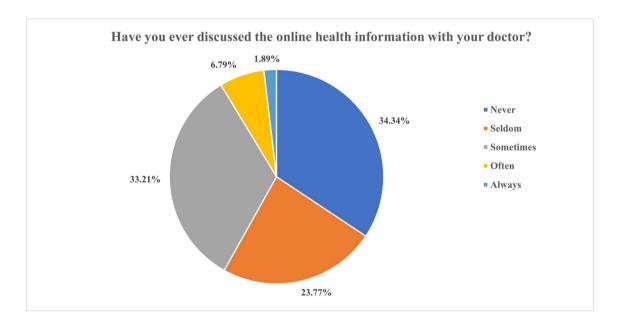


Fig. 3 The frequency of the patients discusses online health information with the doctors

associated with health information-seeking behavior. Patients who had higher education, were self-employed or owned a business, and had higher income level were positively associated with the initiative to seek health

information [7, 17, 18]. Interestingly, age was not one of the predictors for the behavior as suggested in our study. Nonetheless, we did observe that the info-seeker group tended to be younger compared with non-info-seekers, which was



consistent with another study [11]. This could probably be attributed to the lower education level observed among the non-info-seeker group and, hence, their low health literacy.

Similarly, age did not reflect health literacy as suggested by other studies, which reported that the elderly would actively seek health knowledge with the advent modern technology [11].

Patients who were aware about the availability of breast cancer support would more likely seek health information. Cancer support groups are often the source of reliable information, besides providing emotional support. Poor health literacy and fatalistic attitude colored by emotional distress were often the reasons of delayed disease presentation [19]. There was a fine line between health information-seeking and being overwhelmed by a flood of information. A study showed that patients often got more benefits from face-toface encounters with healthcare professionals who discussed health materials with them [20]. Ironically, our findings surprisingly demonstrated that 34.4% of the participants never discussed or shared the health information they found with their doctors. This indicated a poor patient-doctor relationship likely because of high patient load, limited duration of consultation, and lack of response from doctors, all of which would contribute to the patients' dissatisfaction [21]. These barriers consequentially kept the patients away from accessing proper healthcare information and encouraged misinformation. Our study highlighted the potential benefits of other reliable information resources, such as the cancer support groups, medical books and leaflets, and hospital-produced education videos for disease management, which may help patients to navigate across the sea of information and reduce the risk of misinformation [20]. A study showed that reading brief information booklets could improve the patients' knowledge, and specific gaps were identified in the provision of cancer education and information, which were often missed during consultations [22].

Mobile phones were the most used gadgets for seeking health information as they provided the most convenient access to the Internet [23]. Malaysian's mobile phone usage showed a 0.5% increase from 98.2% in 2020 to 98.7% in 2021 [24]. A cross-sectional survey found 59.2% of a local population owning mobile phones and 91.7% of the owners routinely used them. A total of 87.1% of handphone owners said they were ready and willing to receive health messages through their devices. The impact of massive mobile phone usage has significantly changed the healthcare delivery system. An American health information-seeking behavior study on the colorectal cancer patients revealed that higher proportion of younger patients were using digital technologies for healthcare-related activities such as making appointment and looking up medical result. Furthermore, 58.9% of them reported having at least a wellness application on their mobile phone to track their health status. The patients'

dependency on mobile gadgets for health information could be seen increasing over the time [25].

However, citizens who had access to a plethora of online information but without access to trained healthcare workers might be vulnerable to ineffective or even harmful mistreatment or delay in obtaining proper healthcare [26]. Ironically, 34.3% of our participants never discussed the online health information they found with their doctors, despite 60% of them having actively sought health information. Google was the most popular online resource for health information-seeking, followed by YouTube. A DISCERN analysis showed that health information websites had a wide range of quality scores. A lower score was generally attributed to a deficiency in writing, editing, and updating the information. The lack of transparency with authorship and references was commonly observed [27]. These findings warranted the need to guide patients in seeking proper health information, since the aforementioned resources often lacked validity and were not evidence-based.

Study strength and limitations

The sample size of this study could be considered large, and it is one of the few health information-seeking behavior studies on cancer patients in Malaysia, which shed light on their health behavior and resource preference. Since the self-administered questionnaire was utilized, the results might be subjected to self-reporting bias. The results generated were indicative of a single center only at an urban setting and not the representation of a nationwide trend.

Conclusion

Health information-seeking was a common behavior among female breast cancer patients. Nonetheless, information appraisal and misinformation management should be evaluated with healthcare professionals. The availability of other reliable resources, such as cancer support groups and printed materials by health organizations, might potentially augment the potential of information delivery.

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Author contribution All authors contributed to the study conception and design.

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Data availability The datasets generated during and/or analyzed during the current study are available from the corresponding author at reasonable request.



Declarations

Ethics approval This study was not funded by any organization or entity. Ethics approval was granted by the Medical Research Ethics Committee (MREC) of the University of Malaya Medical Center (MREC ID: 2021106-10654).

Conflict of interest The authors declare no competing interests.

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