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The "Know Your Lemons" Tools: A strategy to improve breast cancer warning signs recognition in Malaysia

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Abstract:

BACKGROUND: Breast cancer (BC) is the most common cancer in Malaysia, with many diagnosed at late stages. The "Know Your Lemons" (KYL) visual educational tools were developed by KYL Foundation. This study aimed to evaluate participants' confidence levels and perceived knowledge in identifying BC symptoms before and after exposure to KYL tools.

MATERIALS AND METHODS: A cross-sectional study was carried out among 788 participants in three KYL health campaigns from 2017 to 2020. Perceived knowledge (a 5-item Likert scale was used, zero means "very poor" and 4 means "excellent knowledge") and confidence in identifying BC symptoms were studied. A Wilcoxon Matched-Paired Signed-Rank Test was performed to assess the perceived knowledge.

RESULTS: There was a significant improvement in the perceived knowledge Mean (±SD) score (2.84 \pm 1.02) versus (4.31 \pm 0.66) before and after the campaign (P < 0.01). About 95.6% agreed that the language used in KYL materials was clear and understandable, 89.8% agreed it is acceptable in Malaysian culture, and 80% felt more confident in identifying BC symptoms. Therefore, 90.8% had the intention of breast self-examination and 90.8% would consult a doctor if symptomatic. The majority (92.7%) agreed that the KYL tools clarified the BC tests needed.

CONCLUSION: The KYL tools enhanced perceived BC symptom recognition knowledge and confidence levels.

Keywords:

Breast cancer, confidence, health literacy, knowledge, perceived

Introduction

reast Cancer (BC) is the most common igcup cancer in Malaysia (19%), and the latest National Cancer Registry has reported an increase from 43.2% (2007-2011) to 47.9% (2012-2016) of advanced BC.[1] The 5 years relative survival for BC in Malaysia is 66.8% in comparison to Singapore's 80.3% and Japan's 88.9%.[2] More than 50% of women diagnosed with BC are below the age of 50 years.[3] Stage is an independent predictor for survival.[4-6] Reasons for delayed presentation are complex, but breast health literacy is a major component. [7-9]

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There is limited access to health education in middle- and low-resource settings on the effectiveness of BC education.[10] In addition to BC symptom recognition, literacy on the disease and treatment outcomes were also identified as reasons for delayed presentation.[8] Furthermore, most of the Malaysian women were unaware of the significance of screening and knowledge of risk factors.[11,12]

A wide gap between knowledge and actual practice of BC screening revealed poor acceptability of practices in the community.[12] Ministry of Health (MOH) Malaysia reported that 75% of women

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above the age of 40 years have never had a mammogram in their lifetime and more than 50% of women aged 18 years and above did not practice breast self-examination (BSE). [13]

Know Your Lemons (KYL) educational materials were developed by designer and author Corrine Ellsworth-Beaumont to improve BC awareness initially in 2003, with further interations since then. BC is not a common topic discussed in public, as many regard breast images and the topic of cancer are taboo due to their respective connotations with sex (breasts) and death (cancer). With regard to these issues, a visual metaphor was designed as a communication tool to educate the public regardless of their ethnicity, age, or literacy level. These KYL materials contain information on the 12 signs and symptoms of BC [Figure 1], information on BSE [Figure 2], and screening and the process of diagnosis [Figure 3]. KYL materials were designed to overcome communication barriers of fear, taboo, and low literacy. The material was developed through a "design thinking" approach to visual metaphor using lemons to visually represent breasts to remove the taboo of displaying breast health information and use universal design methods that are culturally acceptable for a variety of global audiences.

KYL educational materials and Know Your Lemons app have been introduced and promoted worldwide to raise awareness of BC, reaching over 1.5 billion people online alone, now in 34 languages.^[14] However, there were inadequate studies that evaluated the efficacy of

KYL materials in improving BC awareness in Asia. In a middle resource setting country like Malaysia, there is limited access to breast health education. KYL materials were designed as a communication tool to educate the public regardless of their culture or literacy level. These KYL materials, which we used in our BC campaign, contain information on the 12 signs and symptoms of BC, BSE, screening, and the process of diagnosis in layman language to overcome communication barriers of fear, taboo, and low literacy. No studies had yet been undertaken in Asia to evaluate the effectiveness of KYL material on gaining perceived knowledge and confidence level in identifying symptoms of BC.

Hence, the study aimed to determine the effectiveness of the KYL materials and the confidence level of women in recognizing signs and symptoms of BC before and after exposure to KYL materials during health campaigns in Malaysia.

Materials and Methods

Study design and setting

This study was a cross-sectional pragmatic research design conducted in Malaysia across three urban settings from July 2017 to January 2020. These locations were the University of Malaya (UM) campus in Kuala Lumpur targeting students, visitors, and university faculty staff (2017); and two community outreach centers in Puchong (2019) and Klang (2020). In total, 788 participants were recruited across these three sites, details are described in Table 1.



Figure 1: Illustrating the 12 symptoms of BC visualized through the lemon metaphor (courtesy knowyourlemons.com)

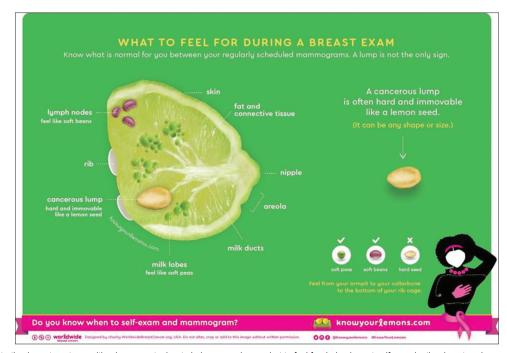


Figure 2: Illustrating breast anatomy with a lemon metaphor to help women know what to feel for during breast self-examination (courtesy knowyourlemons.com)

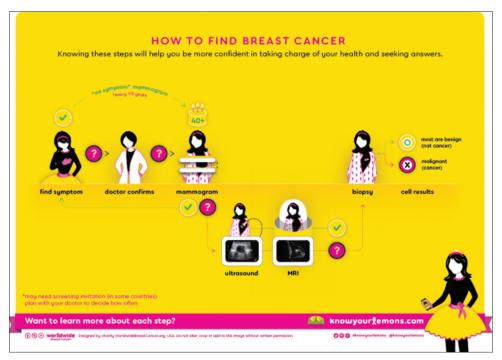


Figure 3: Illustrating screening and diagnostic pathways for BC (courtesy knowyourlemons.com)

Instruments

The KYL materials were developed in English and were translated by two native bilingual individuals according to MAPI protocol. A simple survey questionnaire was developed and used to assess the effectiveness of the educational material. The educational intervention sessions were provided in the form of KYL materials (leaflets, posters, and banners) and displayed in

awareness booths in both English and Malay languages. The pre- and post-campaign questionnaire were distributed to all respondents.

The second set of additional questionnaires was given to the community members in Puchong and Klang (n = 109) which asked about the impact of the KYL campaign and known barriers in seeking medical treatment for breast symptoms.

Table 1: Health campaign site and social demographic characteristics (*n*=788)

Demographic characteristics	Frequency (n)	Percentage (%
Venue		
University of Malaya (UM) 2017	679	86.2
Puchong 2019	46	5.8
Klang 2020	63	8.0
Age		
<30 years	428	54.3
30-49 years	207	26.3
50 and above	153	19.4
Gender		
Male	40	5.1
Female	748	94.9
Ethnicity		
Malay	532	67.5
Chinese	169	21.4
Indian and others	87	11.0
Education level		
No formal education	2	0.3
Primary education	28	3.6
Secondary education	123	15.6
College/university	635	80.6
Marital status		
Single	442	56.1
Married	296	37.6
Widow/Separate/Divorce	50	6.3
Occupation		
Homemaker	52	6.6
Student	366	46.4
Working	307	39.0
Retired	51	6.5
Unknown	12	1.5

Categorical data are expressed as percentage

Data collection

The pre- and post-surveys in the form of a questionnaire (socio-demographic and KYL-related) were carried out via face-to-face interviews by the health care providers and trained medical students. Both the survey and KYL brochures were provided in English and Bahasa Malaysia languages. Participants could choose their preferred language. Basic information about BC, 12 common symptoms of BC, what to feel for during BSE, screening and diagnostic (detection) pathways, and screening tools available were described using KYL leaflets.

Statistical analysis

Statistical analysis was performed using Social Package of Social Sciences (SPSS Inc, Chica go, IL) software, version 21. Socio-demographics, participant feedback, perception of KYL materials, and perceived knowledge before and after the campaign were tabulated to provide the number and percentage for categorical variables and the mean, standard deviation, and range for continuous variables. A Likert scale response using a 5-number scale

was used for the perceived knowledge, (0 means "very poor" and 4 means "excellent"). The scoring was done before and after the KYL campaign program. Wilcoxon signed-rank test was chosen to analyze the significant difference in knowledge of BC awareness before and after the campaign. The *P* value < 0.05 was used for statistical significance.

Ethics consideration

Ethical approval was obtained from the UMMC Ethics Committee (Ref No. 2018524-6317). Verbal informed consent was obtained from all the participants.

Results

Study venues and social demographic characteristics

The study was conducted in three different settings during three different health campaigns, UM 2017 (n = 679), Puchong 2019 (n = 46), and Klang 2020 (n = 63) between 2017 and 2020 [Table 1]. More than half of the respondents aged were less than 30 years (54.3%) and the majority of them were female participants, 94.9% (n = 748). Most were Malay ethnicity (67.5%), followed by Chinese (21.4%) and Indian or other (11.0%). Most of the participants obtained a college or university education level (80.6%). Around half of the participants were single (56.1%) and 39.0% of them were employed, with half of them being students (46.4%).

Sources of KYL materials and knowledge of BC

Table 2 shows that before the awareness campaign, out of 788 respondents, 570 (72.3.7%) had seen the KYL materials mainly from the poster (campaign site) which accounts for 43%. Some of them were exposed to KYL materials via social media (5.8%) and websites (3.3%). A minority of them knew the materials via other sources.

The participants' language preference was as follows: 54.7% chose Malay, 39.0% chose English, and only 0.3% chose Chinese language. During the campaign, only Malay and English leaflets were distributed according to language preference. About 58.1% (n = 458) of the respondents used Malay leaflets. Out of the 788, 80.0% felt more confident in recognizing BC signs and symptoms after seeing the KYL materials. The majority (95.6%) agreed that the language used was clear and understandable. So, 94.8% found that the KYL material was attractive and able to draw attention to the contents. And 89.8% agreed that KYL materials can be accepted in the Malaysian context. The majority (95.7%) of the participants also stated that the campaign helped them to improve their knowledge of the process of detecting BC.

There was a significant improvement in perceived knowledge regarding BC detection before and after the

Table 2: Participant feedback on KYL materials and campaign (n=788)

Items	Responses	Number of participants (%)
Prior to receiving this questionnaire, have you already	Yes	570 (72.3%)
seen Know Your Lemons materials?	No	195 (24.7%)
	Don't Know	23 (2.9%)
Which language did you use to see the materials?	Malay	458 (58.1%)
	English	299 (37.9%)
	Malay and English	29 (3.7%)
	Unknown	2 (0.3%)
Which language do you prefer to read the materials?	Malay	431 (54.7%)
	English	307 (39.0%)
	Mandarin	2 (0.3%)
	Malay and English	44 (5.6%)
	Unknown	4 (0.5%)
Was the language used in the "Know Your Lemons"	Yes	756 (95.6%)
poster or leaflet clear and understandable?	No	9 (1.1%)
	Don't know	23 (2.9%)
Are the "Know Your Lemons" materials attractive and	Yes	747 (94.8%)
able to draw your attention?	No	9 (1.1%)
	Don't Know	32 (4.1)
Having seen the 12 signs of breast cancer in the	Strongly disagree	119 (15.1%)
'Know Your Lemons" materials, do you now feel more	Disagree	18 (2.3%)
confident in being able to recognize the signs and symptoms yourself?	Agree	382 (48.5%)
	Strongly agree	248 (31.5%)
	Unknown	21 (2.7%)
Are the "Know Your Lemon" materials acceptable in	Yes	708 (89.8%)
Malaysian culture?	No	15 (1.95)
	Don't know	65 (8.2%)
Did the campaign help to improve your knowledge on	Yes	754 (95.7%)
the process of detecting breast cancer	No	7 (0.9%)
	Don't Know	27 (3.4%)

Categorical data are expressed as percentage

Table 3: Participants' perceived knowledge before and after the campaign (*n*=788)

Perceived	Before Campaign	After Campaign	P
Knowledge Level	(<i>n</i> =788)	(<i>n</i> =788)	
on Breast Cancer Detection	n (%)	n (%)	
Mean (SD)	2.84 (±1.02)	4.31 (±0.66)	<0.001
Very Poor	80 (10.3)	1 (0.1)	
Poor	194 (25.0)	3 (0.4)	
Good	313 (40.4)	72 (9.3)	
Very Good	146 (18.8)	376 (48.5)	
Excellent	42 (5.4)	323 (41.7)	

Abbreviations: SD, Standard deviation. Categorical data are expressed as percentage. Wilcoxon signed-rank test was done to assess the perceived knowledge before and after the campaign. Significantly different at *P <0.05. and $^{**}P$ <0.001

campaign. The average Mean (SD) scores before and after the campaign were 2.84 (± 1.02) and 4.31 (± 0.66), respectively (P < 0.001) [Table 3].

Impact of KYL campaign and help-seeking intentions (n = 106)

In general, the KYL materials were successful in knowledge transfer and promoting positive health-seeking intentions [Table 4]. With a breast lump being the most

common sign of BC, understanding the palpability of a cancerous lump is important for recognition and reporting. When we surveyed the participants, after being given the KYL leaflet, most correctly understood that a cancerous lump usually feels hard and immovable (67.0%, n=73), with hard and movable being partly correct (14.7%), and only a few choosing the incorrect answer of "soft and squishy" (2.8%). The remainder of respondents chose the "unsure" answer (15.6%), which indicated that they understood they still had a knowledge gap.

When it came to breast health-seeking intentions, over half (54.1%) had performed BSE before taking the survey. Encouragingly, nearly all (90.8%) agreed that they were planning to check their breasts after learning about the 12 symptoms displayed in KYL materials. After seeing the KYL materials, 97 (89.0%) agreed that they would like to have a clinical breast examination (CBE). Majority (90.8%) said that they would see a doctor if they noticed breast changes that lasted longer than a month. And 72.5% of participants stated that nothing would keep them from reporting a symptom to their doctor; Finally, 14.7% of respondents did have some reservations about reporting symptoms, stating they

Table 4: Impact of KYL campaign and help-seeking intentions (n=109)

Items	Responses	Number of Participants (%
What does a cancerous lump feel like?	Soft and squishy	3 (2.8%)
	Hard and immovable	73 (67.0%)
	Hard and movable	16 (14.7%)
	Any of the above	17 (15.6)
Have you ever checked your breasts for changes or felt	Yes	59 (54.1%)
or a lump before today?	No	50 (45.9%)
After learning about the 12 symptoms, are you planning to	Yes	99 (90.8%)
check your breasts in the future to look for changes or feel or a lump?	No	2 (1.8%)
	Unsure	8 (7.3%)
f you were told you had breast cancer, what things would nold you back from getting treated?	I don't think the treatment would work	8 (7.3%)
	I don't want to lose my breast, or I don't want to look different because of cancer treatment	11 (10.1)
	I couldn't afford the cost of breast cancer treatment	6 (5.5%)
	If I had breast cancer, my spouse might leave me or my family might treat me differently	1 (0.9%)
	If I am sick, who will take care of my family? They come first before my health	2 (1.8%)
	Nothing of these. I would get treatment.	77 (70.6%)
	Others	4 (3.7%)
Vould you like to have a clinical breast examination?	Yes	97 (89%)
	No	12 (11%)
Did the lemon campaign help you to better understand the	Yes	101 (92.7%)
options for breast cancer tests when you have symptoms?	No change	6 (5.5%)
	Don't know	2 (1.8%)
Did the lemon campaign help you to better understand the	Yes	103 (95.4%)
options for breast cancer screening when you don't have	No change	4 (3.7%)
any problem?	Don't know	1 (0.9%)
How likely are you to share the lemon image with family	Definitely	98 (89.9%)
and friends?	Possibly	9 (8.3%)
	Not likely	2 (1.8%)
f you found a change on your breast, what would keep	I don't want anyone else to see my breasts	4 (3.7%)
you from telling a doctor quickly?	I would be worried to find out the answer	16 (14.7%)
	If I get a serious disease, It's God's will and I cannot do anything to change it	2 (1.8%)
	I'm worried about the cost of seeing a doctor	3 (2.8%)
	I don't know a doctor that could help me with a breast change problem	3 (2.8%)
	Nothing would keep me from seeing a doctor	79 (72.5%)
	Others	2 (1.8%)
f you notice a change on your breast that lasts for longer	Go to the doctor	99 (90.8%)
han a month, what will you do?	Tell a friend and family member and ask for their advice	6 (5.5.%)
	Wait for few months more	3 (2.8%)
	I will be too afraid to go to the doctor	1 (0.9%)

Categorical data are expressed as percentage

would be worried to find out the answer to their breast changes.

To understand patient beliefs or hold back toward getting treated if diagnosed with BC, participants were asked about potential behavior if a future diagnosis of BC should occur. Most said they would participate in treatment (70.6%), with a minority stating that losing their

breast or looking different because of treatment therapy would keep them from seeking treatment (10.1%). Very few believed that treatment would not work (7.3%).

A significant percentage of respondents agreed that the KYL materials helped them to better understand the options available for BC tests when there will be symptoms. Ninety two percent (92.7%) also understand the options for BC screening when there is no problem or symptoms, 95.4%. Ninety-one percent stated that they would share the KYL images with their families and friends.

Discussion

KYL material was successful in enhancing perceived knowledge of BC (P < 0.001). A large proportion (95.7%) of respondents agreed that the KYL campaign helped them to better understand the options available for BC detection. Notably, most of our participants (80.0%) strongly agreed or agreed on the increase of perceived knowledge on BC detection and were confident in the recognition of BC signs or symptoms after the campaign. We found that the visuals in the materials were easy to understand, clear, and attracted their attention. Almost all respondents (89.8%) agreed that KYL material was acceptable in their context.

A similar study^[15] researching the KYL Materials was conducted by KYL and Race for a Cure Africa in Nigeria (n = 1061). Results in Malaysia found remarkably similar findings with the KYL materials in Nigeria: Accurate knowledge of lump palpability in Nigeria was at 70% (compared to 67%); willingness to share the image with family and friends at 92% (compared to 90%); and the response that nothing would keep the patient from seeing a doctor if they noticed a change at 72% (compared to 72.5%). Despite the difference in culture and geography, our findings show similar results for the KYL materials across both cultures. Visually, the only significant adjustment for the KYL materials in Nigeria was showing the lemons in green, as lemons are typically green in Africa. The most contrasting results were whether patients would seek treatment, with Nigerian respondents at 55% (compared to 70.6% in Malaysia). For this, finances may have been a factor as cost of treatment was seen as a barrier at 25%, compared to 5.5% in Malaysian respondents.

People need to know how to conduct a BSE to recognise breast cancer symptoms. In developing country like Malaysia, with a high proportion of symptomatic advanced cancer, BSE may play a major role in downstaging cancer. However, we found the practice of BSE was similar (54.1%), compared to the 50% national average reported by the National Institutes of Health, 2019. A recent study from Eastern Uganda (42%) had never practiced BSE. Several studies from Malaysia highlighted several reasons for respondents not practicing BSE, including not knowing the technique of BSE, belief that lack of symptoms meant BSE was unnecessary, being afraid of a diagnosis, and being unaware of the need to perform BSE. In our study, after seeing the KYL materials, 90.8% had a high

intention to practice BSE and 89% wanted to receive a CBE, indicating a likelihood to engage in positive health behavior linked to earlier detection.

Without a population screening program, BC symptom awareness is an important key to early detection. Social stigma and cultural perceptions are barriers toward the early detection of BC.^[19] Majority (95.6%) of our participants agreed that the language used was clear and understandable. Therefore, 94.8% found that the KYL material was attractive and able to draw attention to the contents. And 89.8% agreed that KYL materials can be accepted in the Malaysian context.

Limitations and recommendations

Several methodological strengths and limitations of this pragmatic study warrant mention. Although a majority of our participants were young and educated, we tried to capture opinions from different people from the community having a different background. During UM 2017 campaign, we received feedback not only from students (different faculty) but also from the UM staff and people who were visiting the University Malaya Medical Center (UMMC) hospitals. We also got views from the Puchong and Klang community people. Another strength of our study is that we present BC information on the signs, symptoms, BSE, screening, and the process of diagnosis using innovative visual metaphors which can promote awareness and empower the community to actively battle cancer through early presentation and initiation of treatment. For our study, we used the universal design methods which were one of our limitations. Although this design is culturally acceptable for a variety of global audiences, there could be selection bias as the study participants who attend community health campaigns are those who already possess positive health-seeking behavior. A better design is to incorporate health campaigns with other non-health activities to sample a more representative population from the rural and low-income group.

Conclusion

The study results provided participants' confidence level and perceived knowledge in identifying BC symptoms before and after exposure to KYL tools. The KYL materials were effective in improving perceived knowledge and confidence in BC detection among participants and showed similar findings with other women outside of Malaysia, validating our findings and highlighting areas of divergence. The language in the materials was clear, acceptable, and culturally appropriate. Future studies need to explore community-based KYL program in low-income urban observatory and rural areas. Overall, health education using KYL materials improves breast health literacy. Innovative ways should be implemented

to introduce this effective breast literacy KYL tool into existing programs within NGOs and MOH.

Authors' contributions

The study was conceived and designed by Nur Aishah Taib, Tania Islam, Corrine Ellsworth-Beaumont, and Mary Chan Mei Yen. Data collection was performed by Tania Islam, Sarinder Kaur Dhillon, Mogana Darshini Ganggayah, and Nur Aishah Taib. Analysis was performed by Tania islam and Mary Chan Mei Yen. Funding was obtained by Nur Aishah Taib and Corrine Ellsworth-Beaumont. All the authors have revised the manuscript critically for important intellectual content, and agreed on all aspects of the work of the manuscript.

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List of Abbreviations

BC Breast cancer

BSE Breast self-examination
CBE Clinical breast examination

KYL Know Your Lemons MOH Ministry of Health

UMMC University Malaya Medical Centre

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Conflicts of interest

There are no conflicts of interest.

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